

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. The examination of diseased tissues by a trained pathologist remains the gold standard for 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 Sue Hagen at (763/231-2742), Susan@ataxia.org or Mary Ann Peterson (763/231-2750), Mary_Peterson@ataxia.org if you have any questions.

How do I donate my brain?

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), funeral director, your attorney and NAF of your desire to donate your brain upon your death. At least one person should be designated to contact NAF at 763/553-0020 or naf@ataxia.org as soon as death is imminent or has occurred. NAF will work with your family members, funeral director, hospital or nursing home staff to arrange for the transfer of the body, if applicable, and the tissue recovery at an appropriate location.

Does the donor family incur any expense for the donation?

The donor family is responsible for regular funeral/mortuary or cremation expenses, or an official autopsy if requested to determine cause of death. There will not be any financial cost to the family for the brain donation.

How much time does the contact have to notify NAF?

Timely recovery is a very important issue. An arrangement will be made with a pathologist to facilitate the recovery ideally within 6 hours of death. If the time interval exceeds 6 hours, the recovery might still be performed, but no longer than 24 hours after death. The entire process should be approximately 1-2 days and then the body will be available to the family for funeral services.

Is the body transported to the National Ataxia Foundation office?

No. Recovery of tissues is performed at your local hospital, funeral home, or other designated institute. The brain tissue is then shipped to one of the labs in the NAF brain donation consortium.

Who will dispose of the remains of the body after the donation is made?

The family is responsible for these arrangements and expenses.

What happens to the tissues I donate?

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

Thank you for your generosity and dedication to serving ataxia research. If you are interested in becoming a donor for research and have further questions or if you would like to make a financial contribution to support important medical research, please contact NAF at 763-553-0020