

BRAIN DONATION PROGRAM

FREQUENTLY ASKED QUESTIONS

Why is brain donation important for Alzheimer's disease research?

One brain can provide information for hundreds of research studies and impact millions of people. This work is leading researchers toward a greater understanding of Alzheimer's disease processes and to the discovery of potential effective treatments. Brain donation is a generous gift for future generations.

Why is brain donation important to surviving family members?

The only definitive way to diagnose Alzheimer's disease and related dementias is by direct examination of brain tissue. Since dementia can run in families, this can help family to seek help and make plans for the future.

Is brain tissue donation of value from individuals without memory impairment?

Yes. It is extremely important to study the brains of those individuals who do not have Alzheimer's disease or other dementias. Brain donation from older adults without cognitive impairment allows researchers to determine the exact changes that are related to Alzheimer's disease and other disorders and which changes are related to normal aging.

Who is next-of-kin and should I inform them of my decision to become a donor?

A donor's next-of-kin is their surviving spouse or domestic partner, children, siblings, or close friend or relative who would be familiar with the decedent's wishes. You should inform them, as they are directly involved in the final consent process. We encourage you to discuss your interest in this program with them and urge them to call 212-263-6262 (9am-5pm, Monday-Friday) to discuss any questions or concerns.

What will my next-of-kin be responsible for helping with?

Before death, to help avoid possible problems or questions that may be encountered at such an emotional time, it is recommended that preliminary arrangements be made in advance whenever possible. We advise you to speak with your next-of-kin about your interest in this program, request additional information from us for them if they require it, and ask them to call **212-263-6262** (9am-5pm, Monday-Friday) to discuss any questions or concerns.

At the time of death, we must be contacted. During regular business hours (9am-5pm, Monday-Friday), the phone number is **212-263-6262**. Outside of regular business hours the number is: **347-949-1424**. If your family does not get a response within 30 minutes, they will call our transportation service, Metropolitan Funeral Home: **1-800-332-1880** or **212-674-3630**. If we do not have your consent form on file at the time of death, we will request it from your health care proxy. This allows us to initiate transportation to NYU. Additionally, we ask your health care proxy to fill out and sign the [NYU Autopsy Consent](#), which allows us to initiate the autopsy. Forms can be emailed to NYULHBrainDonation@nyulangone.org or faxed to **212-263-6991**.

These instructions may be slightly different for those who live outside of the New York City area.

Why is participation of diverse individuals in brain donation research important?

The participation of diverse individuals can help researchers understand how dementia affects certain groups and why some communities are disproportionately affected by certain diseases. For example, research suggests that African Americans and Latinos have higher rates of dementia than whites or Asians. Yet, because these groups are underrepresented and understudied in research, there is little information about why this might be and how these diseases affect their communities.

How does transportation work?

NYU contracts with Metropolitan Funeral Services and we arrange with them for transportation at time of death. After the autopsy, we will contact your elected funeral home for transport to the funeral home. This may differ if you live outside of the New York City area.

Will funeral arrangements need to be altered?

No. Brain donation does not interfere with traditional or religious funeral arrangements. The procedure takes approximately 2 hours to complete and does not cause disfigurement that would prevent an open casket funeral.

Does NYU help with funeral home arrangements?

No, you and your family will pick a funeral home and coordinate with them. We should be consulted about which funeral home you have chosen.

What are the religious implications of this decision?

Most major religions do not prohibit brain donation for autopsy.

Will the results of the examination be available?

Yes, your family is given with a copy of the final neuropathology report (provided about 3-6 months after procedure is performed) and are invited to speak with our neuropathologist to address any questions and concerns generated from the information provided.

Will there be any cost?

There is no cost for transportation to NYU or for the brain autopsy and no cost for the autopsy.

Can I still participate even if I move out of New York?

Participation in this program does not have to change if you move from or live out of the New York area but remain in the United States. Arrangements can be made to have the brain donation procedure done in a hospital or facility close to where you have relocated and can be done if there is a qualified facility near you who can do the procedure.

Can I still donate my brain if I'm an organ donor?

Yes, at time of death the organ donation center will be called first and be notified that brain donation is being done at NYU after.

What if I have never been evaluated at the NYU Alzheimer's Disease Research Center (ADRC)?

Potential participants that have not been evaluated at our Center are welcome to inquire about our Brain Donation Program and will be evaluated on a case-by-case basis. We will ask questions to understand medical history, including medications, dates of significant medical events and diagnoses/history pertaining to memory loss.

What if I change my mind and no longer wish to donate?

If you change your mind about participation in our Brain Donation Program, simply let us know by calling **212-263-6262** (9am-5pm, Monday-Friday) and your name will be removed from the database.