



To foster cutting-edge Huntington's disease drug discovery research, this collaborative initiative between CHDI and HDSA will support brain and other organ donations from HD families. A brain donation is a gift of knowledge, and it is essential to enhance our understanding of HD.

This program encourages brain and organ donations from HD gene-expansion carriers, at-risk individuals regardless of whether they know their gene status, and healthy controls.

TO REGISTER AS A BRAIN OR ORGAN DONOR:

- Visit the Harvard Brain Tissue Resource Center (HBTRC) website at www.mcleanhospital.org/brain-bank to learn more or call 1-800-272-4622.
- Registration to become a donor is non-binding. You can change your decision at any time.
- Registering ahead of time helps family members prepare so that, when a loved one passes, they can make a contribution that could benefit the lives of others without having to make a difficult decision during a very trying time.

HOW DOES BRAIN DONATION WORK?

- STEP 1:** Have a family discussion about brain donation. Don't forget to inform healthcare providers and funeral professionals. Register with HBTRC.
- STEP 2:** At the time of impending death, or immediately after death, family members or caretakers should call 1-800-BRAIN BANK (1-800-272-4622). HBTRC Donation Coordinators can be reached by phone 24/7 to guide the legal next-of-kin through the process of brain donation and carry out a screening process.
- The brain donation *must be completed within 24 hours* (from the time of death to the time the tissue samples are stored at the HBTRC). It is very important to contact the HBTRC as soon as possible.
- STEP 3:** Once HBTRC staff members confirm that the HBTRC can accept the brain donation, they will guide the legal next-of-kin/legal representative through the consent process.
- STEP 4:** HBTRC staff will coordinate with qualified professionals in the area who will harvest the brain tissue locally and take care of all transport logistics. Brain recovery often takes place in a funeral home or hospital and must happen within hours following the death of the donor.
- STEP 5:** A few days after the brain donation, HBTRC will send the legal next-of-kin instructions and forms to guide them through the process of releasing the donor's medical records and complete a questionnaire about the donor.

FAQ

What should I consider when deciding to donate? This is an extremely personal decision, and it is vitally important to have a family discussion about your wishes regarding brain donation. It may also be helpful to speak with trusted healthcare professionals about the value that organ donation can bring to HD research. You may also want to discuss any cultural or religious implications with funeral professionals or spiritual counsels.

Will there be a financial cost to the family? No. There is no financial cost associated with any step in the brain donation process, including registration, donation, or transport.

Will brain donation interfere with funeral arrangements? No. The HBTRC will work closely with families and funeral homes to ensure that this will not delay or interfere with plans for a funeral, cremation, or burial.

Can the donor still have an open casket? Yes. Brain removal can be carried out in a way that is compatible with an open-casket funeral.

Will brain donation conflict with religious practices? Many religious groups, including Protestant, Catholic, Jewish, and others, support tissue donation for research as an altruistic, humanitarian gift to the living consistent with the basic tenets of these faiths.

What will happen to my/my loved one's brain? It will be carefully examined by a neuropathologist and then stored. Small tissue samples will be sent to qualified researchers within the US and across the world – the donation will be essential to investigations into how HD affects the human brain. Each donated brain will provide hundreds of samples to researchers conducting HD research for many years.

Are there any medical or logistical restrictions on brain donation? Some medical circumstances may prevent a brain from being viable for donation. For example, HBTRC may not be able to accept brain donations from people who died because of a stroke or head injury because there may be too much damage to the brain for it to be used for research.

Other factors may hinder the ability to donate, such as unforeseen logistical challenges, difficulty obtaining medical information, or family disagreements around donation.

I am identified as an organ donor on my driver's license. Is this sufficient to ensure that my brain will be donated for research? No. Organ donation preference status on an ID card is about donating organs for transplant, not for medical research.

Will any of my/my loved one's personally-identifying information be shared? No. All identifying information is strictly confidential and will not be disclosed to third parties. Brain samples are coded at HBTRC to ensure that the donor and their family remain anonymous.