



A BRAIN DONATION IS A GIFT OF KNOWLEDGE

Harvard Brain Tissue Resource Center
at McLean Hospital



McLean



HARVARD MEDICAL SCHOOL
AFFILIATE

THE HARVARD BRAIN TISSUE RESOURCE CENTER

The Harvard Brain Tissue Resource Center (HBTRC), established at McLean Hospital in 1978, is a centralized resource for the collection and distribution of human brain specimens for brain research. The HBTRC collects brain and tissue samples from across the United States and distributes them to investigators all over the world.

A brain donation is a gift of knowledge to all of us, and it is of critical importance for our understanding of brain disorders.

Studies on the human brain are essential to our understanding of brain disorders. They provide unique access to the brain at the molecular and cellular level, thus allowing researchers to increase our knowledge of changes that happen in the brain of people suffering from these disorders. Such knowledge is critical to prevention and development of new therapeutic treatments.

Scientists from top academic and medical centers request tissue from the HBTRC for their research. Since the majority of these studies can be carried out on a very small amount of tissue, each donated brain provides a large number of samples for many researchers. However, in order to conduct valid experiments, it is necessary to supply researchers with a variety of brain specimens.

The HBTRC is part of the NeuroBioBank—funded by the National Institutes of Mental Health (NIMH), National Institute of Neurological Disorders and Stroke (NINDS), and Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). For more information, visit neurobiobank.nih.gov.

Daytime Contact (8:30am-5pm EST)

Phone: 617.855.2400

Fax: 617.855.3199

Email: HBTRC@mclean.harvard.edu

After Hours Contact (5pm-8:30am EST)

Phone: 800.BRAINBANK (800.272.4622)

Fax: 617.850.8711

Email: HBTRCoc@mclean.harvard.edu

Fax: 617.855.3199

Website

mcleanhospital.org/hbtrc



BRAIN DONOR REGISTRATION

Becoming a prospective tissue donor is easy. Any person 18 years of age or older can donate. To learn more, visit mcleanhospital.org/hbtrc. There, you can find our registration form, which should be returned either through the mail or fax:

Harvard Brain Tissue Resource Center

McLean Hospital / 115 Mill Street, Mail Stop 138 / Belmont, MA 02478

Fax: 617.855.3199

If you have registered for potential brain donation at the HBTRC, it is most important to inform your family and make sure they know to call the HBTRC (immediately) at the time of your death. The HBTRC must rely on your legal next of kin/legally authorized representative to contact the HBTRC in order to effectuate your request to donate your brain.

Being registered as a donor with the HBTRC is not needed to proceed with a brain donation. However, it is often a good way to let your family and caretakers know about your intentions.

At the time of the death of a potential donor, the legal next of kin will need to be available to review and sign an informed legal consent for the donation to the HBTRC. This is because an individual's body becomes the property of their estate at the time of their death.

A registration for brain donation can be withdrawn at any time by writing to the HBTRC.

STEPS FOR A SUCCESSFUL DONATION

- 1** Have a family discussion about brain donation. Don't forget to inform health care providers and funeral professionals.
- 2** At the time of impending death and/or at death, family members, or caretakers, should call 800.BRAINBANK (800.272.4622).
- 3** HBTRC staff members can be reached by phone 24/7 to guide you through the process of brain donation.
- 4** HBTRC staff will first carry out a screening process to determine whether it is possible to accept the brain donation. For instance, the HBTRC may not be able to accept brain donations from people who died because of a stroke, because there may be too much damage to the brain for it to be used for research.
- 5** 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. The complete and signed Informed Consent form must be received by HBTRC staff in order to proceed with the brain donation.
- 6** The HBTRC staff will coordinate with qualified professionals in the area who will harvest the brain tissue at a local facility. Brain recovery often takes place in a funeral home or hospital. The brain needs to be removed and shipped to the HBTRC within hours following the death of the donor.
- 7** Finally, it is essential that the HBTRC also receives detailed information about the brain donor. A few days after the brain donation, the 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 filling out a questionnaire about the brain donor.

THINGS YOU SHOULD KNOW

1

The identity of each donor will remain strictly confidential.

2

The HBTRC provides a variety of portals to send confidential information securely.

3

Religious groups including Protestant, Catholic, Jewish, and other faiths support organ and tissue donation as a charitable gift of life consistent with the basic tenets of these faiths.



THE HBTRC GRATEFULLY ACCEPTS BRAIN DONATIONS FROM PEOPLE WITH AND WITHOUT BRAIN DISORDERS

The HBTRC collects tissue from individuals diagnosed with various brain disorders as well as from individuals not affected by these disorders. We accept donations from individuals with conditions such as the ones listed below. For a full listing, please visit us at mcleanhospital.org/hbtrc.

Normal Controls (No Brain Disorders)

- In order to perform research on brain disorders, it is vital to collect brains from individuals without brain disorders (controls).

Psychiatric Disorders

- Bipolar disorder
- Borderline personality disorder
- Depression
- Obsessive compulsive disorder
- Post-traumatic stress disorder
- Schizophrenia
- Eating disorders
- Tourette syndrome

Neurological Disorders

- Amyotrophic lateral sclerosis (ALS)
- Corticobasal degeneration
- Frontotemporal dementia
- Huntington's disease/HD relatives "at risk"
- Multiple sclerosis
- Multiple system atrophy

- Parkinson's disease
- Traumatic brain injury (chronic traumatic encephalopathy)

Neurodevelopmental Disorders

- Autism spectrum disorders
- Down syndrome
- Fragile X syndrome
- Rett syndrome

Special Collections

- Dystonia Medical Research Foundation
- Restless Legs Syndrome Foundation
- International Rett Syndrome Foundation
- ROHHAD Fight, Inc.
- International Foundation for CDKL5 Research
- Tourette Association of America
- Foundation for Research and Education on Eating Disorders
- International FOXP1 Foundation

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