

Partners Human Research Committee

APPROVAL Effective Date

9/6/2018

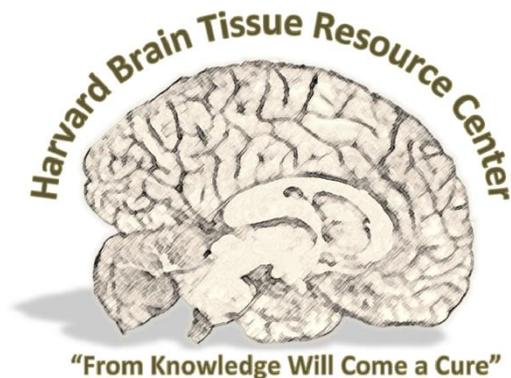


# Harvard Brain Tissue Resource Center

at McLean Hospital

Belmont MA 02478

*A brain donation is a gift of  
knowledge*



Phone: 1-800-BRAIN BANK or (617) 855-2400

Fax: (617) 855-3199

E-mail:

(office hours) [HBTRC@mclean.harvard.edu](mailto:HBTRC@mclean.harvard.edu) -

(after hours) [HBTRCoc@mclean.harvard.edu](mailto:HBTRCoc@mclean.harvard.edu)

Website: <http://mcleanhospital.org/hbtrc/>

## HBTRC - Program Description

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 US 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 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 Institute of Mental Health (NIMH), National Institute of Neurological Diseases and Stroke (NINDS) and Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Website: <https://neurobiobank.nih.gov/>

## BRAIN DONOR REGISTRATION

Becoming a prospective tissue donor is easy. Any person 18 years of age or older can contact the Harvard Brain Tissue

Resource Center (HBTRC) at 1.800.BRAIN.BANK (800.272.4622) to learn more about becoming a donor. Or you can download a Registration Form from our website (see below) and mail or Fax it to the HBTRC at the following address:

**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. HBTRC must rely on your legal next of kin/legally authorized representative to contact 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 care takers 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 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.

For more information about registering for a brain donation, please consult our website:

**<http://mcleanhospital.org/hbtrc/>**

Or call us at:

**1-800-BRAIN BANK or (617) 855-2400**

## STEPS FOR A SUCCESSFUL BRAIN 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 1-800-BRAINBANK (1-800-272-4622)
- 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 donation from people that 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 fill a questionnaire about the brain donor.

## Things you should know

- The Identity of each donor will remain strictly confidential.
- The HBTRC provides a variety of portals to send confidential information securely.
- 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 Harvard Brain Tissue Resource Center (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 the following categories:

**Normal Controls** (no brain disorders)

In order to perform research brain disorders, it is vital to collect brains from individuals without brain disorders (controls), which the HBTRC gratefully accepts. Control brains allow us to expand our knowledge of the human brain and to understand what changes occur in people suffering from brain disorders.

**Psychiatric Disorders**

Bipolar disorder  
Borderline personality disorder  
Depression  
Obsessive compulsive disorder  
Post-traumatic stress disorder (PTSD)  
Schizophrenia

**Neurological Disorders**

Amyotrophic lateral sclerosis (ALS)  
Corticobasal degeneration  
Frontotemporal dementia  
Huntington's disease / HD relatives "at risk"  
Lewy body disease  
Multiple sclerosis (MS)  
Multiple system atrophy (MSA)  
Parkinson's disease  
Pick's disease  
Progressive supranuclear palsy (PSP)  
Seizure disorder and epilepsy  
Traumatic brain injury (TBI or chronic traumatic encephalopathy)



## Neurodevelopmental Disorders

Autism spectrum disorders  
Batten's disease  
Down's syndrome  
Fragile X syndrome  
Intellectual disability  
Pediatric developmental disorders (PDD)  
Tay-Sachs disease

## Special Collections

- Dystonia (Dystonia Medical Research - Foundation  
[www.dystonia-foundation.org](http://www.dystonia-foundation.org))
- Restless legs syndrome (Restless Legs Syndrome  
Foundation - <http://www.rls.org/>)
- Rett's syndrome (International Rett Syndrome Association -  
[www.rettsyndrome.org](http://www.rettsyndrome.org))
- Tourette syndrome / Tourette syndrome family members  
(Tourette Syndrome Association - [tsa-usa.org](http://tsa-usa.org))
- Cohen Brain Collection (Post-traumatic Stress Disorder and  
Traumatic Brain Injury)

