

The Huntington Society of Canada is occasionally approached for information about brain and tissue donation. As an organization, HSC is not directly involved with the process. The individual, or the family, must make direct contact with one of the laboratories listed below. Please note that while only three locations are listed below, other facilities in Canada may also take brain and tissue donation on a limited basis. Please check with your local hospital for information. Each 'Bank' has a set of rules and procedures which they follow. The decision to donate tissue must be made well in advance of an individual losing capacity and should be included with an individual's "Advance Care Plan". Family members should be made aware of a person's wishes related to donation.

Brain, tissue and DNA donation is important to HD research and this type of donation is an important gift. The process for donation can be complex and advance planning is critical. Making a personal decision about this type of donation requires full information on the process and legal issues.

There are differences between provinces in the procedures and requirements. While every effort has been made to ensure the accuracy of this fact sheet, individuals and families are encouraged to contact (phone) the appropriate 'Bank' to receive current information and consent forms. Significant lead time is required to facilitate a smooth process. It cannot be stressed enough that working on this well in advance of the time of donation is critical.

The Huntington Disease BioBank

University of British Columbia (UBC)
Centre for Huntington Disease, Room S179, 2211 Wesbrook Mall
Vancouver, British Columbia, V6T 2B5
Phone: 604-822-7366

<http://cmmt.ubc.ca/facilities-services/centre-for-huntington-disease/dna-and-tissue-bank/>

- The HD BioBank is an invaluable resource for HD research collecting:
 - blood and DNA samples
 - brain tissue from HD patients and unaffected relatives across Canada
- Brain donations ideally are collected within a few hours after death, so patients and family should consider planning well in advance.
- No cost to the family or next-of-kin (but families should verify that all costs are covered or fully understand what costs may not be covered - before proceeding).

Tissue Donation to the Huntington Disease BioBank

Donations of brain or other tissue samples after death are encouraged. Tissue samples are necessary to study the way the DNA changes associated with Huntington disease affect the actual physical characteristics and proteins of the brain and tissues.

It is also important to examine the same features in "normal" brain and tissue samples, so family members without a clinical or genetic diagnosis of Huntington disease are also invited to consider participating in the HD Tissue Banking program to give a sample after their death.

Maritime Brain Tissue Bank (MBTB)

Department of Medical Neuroscience
Faculty of Medicine, Dalhousie University
Halifax, Nova Scotia, B3H 4R2
Phone: 902-494-4130
<http://braintissuebank.dal.ca>

- Resource for researchers working to understand causes of dementia
- Currently accepting tissue from persons with Huntington disease
- Out of province donations can be accepted, but transportation and other associated costs will not be covered by MBTB.

Maritime Brain Tissue Bank (continued)

For a brain to be donated to the MBTB, an autopsy must be performed. Autopsy is a medical procedure and is performed at the hospital by a pathologist. This procedure can be limited to removal of the brain alone from the body. The main reason for autopsy is to establish the cause of dementia by asking a neuropathologist (a doctor who is trained in looking at brain tissues) to examine the brain. After an autopsy, the neuropathologist in charge of the case will make all necessary arrangements to have half of the brain forwarded to the MBTB. The neuropathologist MUST be aware that this donation has been requested.

To Donate a Brain (to MBTB) within Nova Scotia

- A request for autopsy must be made by the family and a consent for autopsy form signed, either at the time of death or, preferably, before. Consent for autopsy forms can be obtained through each Regional Health Authority. This request should be made to the treating physician (usually the family doctor, palliative care doctor or the attending physician at the hospital or nursing home).
- Currently the autopsy consent form does not have a specific area in which to state that donation to the Brain Bank has been requested. A hand written statement should be added indicating a donation is to be made to MBTB.
- The next of kin must then sign the completed form.
- The signed consent form will be included with the patient's chart.
- At the time of death, a physician must sign the Medical Certificate of Death. This is usually the family doctor, palliative care physician or the attending physician in a hospital or nursing home. If the death occurs at home, a physician must be called to the home to sign the Medical Certificate of Death. The remains cannot be transported until this is done.
- When there is a consent for autopsy and the remains must be transported, the medical staff should arrange for transportation. Within Nova Scotia, there is a removal service* that is available 24/7 every day of the year. The removal company will transport the remains to the nearest regional hospital for autopsy. Transportation costs may be covered by the Regional District Health Authority. However, if they are not covered, MBTB is not able to reimburse these expenses.

* In some jurisdictions a local funeral home will transport the remains to the local regional hospital for autopsy.

Douglas - Bell Canada Brain Bank

Douglas Institute, 6875 LaSalle Boulevard

Montreal, Quebec, H4H 1R3

Phone: 514-761-6131 ext. 3313

<http://www.douglas.qc.ca/page/brain-bank>

- Only accepts brains from individuals who are participating in specific clinical research studies involving brain diseases.

Resources

Ongoing support, education and information about Huntington disease is available from the Huntington Society of Canada (HSC). Here is a listing of our Family Services team members: www.huntingtonsociety.ca/family-services-team.

Fact sheets on a variety of other topics including Cognitive Changes in HD, Improving Communication in HD, Tips When Working with Individuals with HD are available at www.hdfactsheets.ca.