

Huntington Disease Biobank at the University of British Columbia

TISSUE DONATION AND BANKING INFORMATION FORM

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WHAT IS THE PURPOSE OF TISSUE DONATION?

Individuals who have been diagnosed with Huntington Disease are invited to make arrangements now to donate brain and/or other tissue samples after their death. 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.

Tissues are removed during the course of a complete or restricted autopsy performed by a pathologist in a hospital. Samples are frozen and later used in biochemical testing relating to how and where the Huntington Disease gene expresses itself to make a protein and how and where it interacts with other proteins.

HOW CAN ARRANGEMENTS BE MADE FOR TISSUE DONATION NOW?

If you decide to make the donation of tissue, the following steps should be taken:

- 1) Inform your next-of-kin, family or executor of your wish to be a donor, and of the location of the necessary documents. For persons in a hospital or other care facility the caregivers directly involved must also be informed of the desire to donate tissue.
- 2) Complete Section A of the "Consent under the Human Tissue Gift Act". The "Act" allows you to make provisions for tissue donation at any time during life. Only your name, the date and your signature are necessary on this consent. No witness is required. The signed document then allows a qualified physician, upon death, to remove the tissue you have decided to donate. You may choose to donate any organs or tissues useful to this research. In this case, check the first box. Generally, the donation consists of less than 500 grams each of brain and peripheral tissues. If you wish to impose any restrictions, check the second box, and specify which tissue(s) you wish to donate.

If, however, in the opinion of a physician, the donor is incapable of giving a consent by reason of injury or disease, the next-of-kin must sign section B of the "Consent under the Human Tissue Gift Act", when death is imminent or at the time of death.

Please keep this form in an accessible location in your home, or in the case of a person residing in a hospital or nursing home, attached to his/her chart.

- 3) Because the tissue is removed during the course of an autopsy, consent for post-mortem examination must be signed by the next-of-kin at the time of death, in the presence of a witness. To this end, we have included two copies of the consent. Again, they should be kept in an accessible location in your home, or in the case of a person residing in a hospital or nursing home, attached to his/her chart. The consent could also be signed when death is imminent and later confirmed at the time of death by telephone.

WHO IS THE NEXT-OF-KIN?

If a person other than the next-of-kin signs where such a signature is required the document cannot be considered valid. The next-of-kin is, *in the following order*:

- a) the spouse of any age; or
- b) if none, or if the spouse is not readily available, any one of the children who has attained the age of majority; or
- c) if none, or if none is readily available, either of the parents; or

- d) if none, or if neither is readily available, any one of the brothers or sisters who has attained the age of majority; or
- e) if none, or if none is readily available, the person lawfully in possession of the body other than, where he died in hospital, the administrative head of the hospital.

WILL THE REMOVAL OF TISSUE INTERFERE WITH FUNERAL ARRANGEMENTS?

No. The removal of tissue will not interfere in any way with a normal funeral procedure. A delay of up to twelve hours may be expected, however. In addition to providing tissue for research, an autopsy may also be performed to determine the definite cause of death and may also reveal the presence of infectious or inherited diseases.

HOW QUICKLY MUST THE TISSUES BE REMOVED AFTER DEATH?

After death, the next-of-kin must sign additional consent forms from the hospital performing the tissue harvest and sometimes transport to a particular hospital is necessary before the autopsy can be performed. For most research, it is essential that tissues be obtained within a maximum of 12 hours after death occurs. Delays of up to 24 hours are accepted, but such tissues have limited research potential.

HOW AND WHERE WILL MY TISSUE BE STORED AND USED FOR RESEARCH?

After the tissue is collected, all samples will be coded with unique numerical identifiers and all information related to your samples kept confidential. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator, Tissue Bank Director, Coordinator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without consent of your next-of-kin unless required by law. Paper records will be kept in locked cabinets at the Huntington Disease Biobank in the Centre for Molecular Medicine and Therapeutics at 950 West 28th Avenue in Vancouver. All computer files with identifiable information will be encrypted and kept locked with restricted access passwords known solely by the Directors and his designate.

It is our hope that this Tissue bank will serve as an essential resource for an ongoing program of HD research allowing us to explore new lines of investigation until a cure is found. With that in mind, all samples will be kept for an indefinite period of time but used exclusively for this program of HD research. All HD research proposals using banked samples will have to undergo ethical review by the Clinical Research Ethics Boards at the institutions conducting the research. Only studies receiving a certificate of ethical approval will be allowed to proceed.

WHO WILL USE MY TISSUES FOR RESEACH?

In addition to UBC researchers at the Centre for Molecular Medicine and Therapeutics, the

de-identified tissue samples and corresponding clinical information may also be analyzed by scientific collaborators, including industry collaborators, in other laboratories worldwide, solely for the purposes of HD research. Any outside analysis will be performed in a completely de-identified manner using numerical codes and will follow all protocols outlined in this banking program. Some of the information obtained from future research could eventually be used in scientific publications or presentations using numerical codes to protect the identity of the participants.

WILL MY TAKING PART IN THIS TISSUE BANK BE KEPT CONFIDENTIAL?

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the Investigator or his or her designate by Health Canada and the UBC Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your next-of-kin's consent, nor will any information or records that disclose your identity be removed or released without their consent unless required by law. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

WHAT ARE THE BENEFITS AND RISKS OF PARTICIPATING?

You will not receive any direct benefits from donating tissue; nor will you receive any payment or remuneration for participating. However, the knowledge obtained through HD research made possible by this bank could be of benefit to future generations. There are also no known risks to you personally.

YOUR DECISION TO DONATE YOUR TISSUE IS ENTIRELY VOLUNTARY.

You may refuse or change your mind and withdraw at any time. You do not have to provide any reasons for your decision. If you choose not to take part, it will in no way affect your current or future medical care or treatments, or the medical care of any of your family members.

This consent provides relevant information about the process of tissue banking, why research using tissue is important, and what happens if you decide you would like to have your tissue donated to the bank after your death. We encourage you to discuss tissue banking with your family, friends, and doctor before you decide. If you have any questions or desire further information about this banking program you can contact the Biobank Manager at 604-875-3811.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while considering participating in this banking program, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

CONSENT UNDER THE HUMAN TISSUE GIFT ACT, 1971

A) Consent of Living Donor

I, _____ having attained the age of 18 years, consent to the use after my death of:

- _____ Any needed organs or parts of my body, or
 _____ Only the following organs or parts of my body:

for medical research to be administered by Dr. Michael R. Hayden of the University of British Columbia at the Centre for Molecular Medicine and Therapeutics.

 Signature

 Date

Please provide list of potential next-of-kin contacts below:

Name	relationship	Telephone number

B) Consent of Next-of-Kin

I, _____ being the Next-of-Kin of _____
 _____, hereby consent in accordance with Section 5 of the Human Tissue Gift Act, 1971, to the use after death of the forenamed of:

- _____ Any needed organs or parts of the said body, or
 _____ Only the following organs or parts of the said body

for medical research to be administered by Dr. Michael R. Hayden of the University of British Columbia at the Centre for Molecular Medicine and Therapeutics.

I also consent that, if necessary, the said body may be transferred to another medical facility in Vancouver for harvest of the donated organs or parts.

 Signature

 Date

Relationship to Donor: _____

CONSENT FOR POST-MORTEM EXAMINATION

I, _____, of _____
Name of Next-of-Kin (Print) Address

Telephone: _____

being the Next-of-Kin of _____
Name of Patient in Full

and bearing the relationship of _____, do hereby authorize a post-mortem examination to be performed on the body of the above-named person, for the purpose of removing appropriate tissues for diagnostic and research purposes. The tissue is to be collected, examined, stored and distributed under the direction of Dr. M. R. Hayden or Dr. Blair Leavitt, Department of Medical Genetics, University of British Columbia at the Centre for Molecular Medicine and Therapeutics.

Signature of Next-of-Kin

Date

Name of Witness

Signature of Witness

Date

NOTE: 1. This form must be signed by the Next-of-Kin at the time of death in the presence of a witness. The consent can also be signed when death is imminent, and later confirmed by telephone at the time of death.

NOTE: 2. Two copies of this form must accompany the body, and one should be returned to the Department of Medical Genetics, University of British Columbia at the Centre for Molecular Medicine and Therapeutics, with the tissue donation.