### Why Should You Consider Brain Donation?

Neurological disorders including Alzheimer's disease, Lewy Body Dementia, Frontotemporal Dementia, Pick's disease, Parkinson's disease dementia and related disorders are increasingly common as our population ages. Currently these diseases have no cure or treatment to stop the progression of the disease.

Brain donation is critically important to learn more about these diseases to hopefully find a cure, someday. Experiments that harness post-mortem brain tissue are among the most powerful methods to understand how to treat and eliminate these brain disorders. While some progress has been made in understanding these dementias, there are still many unanswered questions about what changes they cause to the cells and molecules in the brain.

Today, powerful new technologies (e.g. genetic analysis, imaging modalities) allow researchers to examine molecular changes in psychiatric, neurodevelopmental, and neurodegenerative disorders that were previously undetectable, offering tremendous opportunities for research using human brain tissue.

Participation will help researchers to better understand neuropathology of brain injuries, symptoms, progression of dementia and potential risk factors. The hopes of people affected by brain diseases rest on the discoveries made possible by tissue donation, which gives an opportunity to find a cure for brain diseases for the future generations.

#### DEC Brain & BioBank's Goals

DEC Brain & BioBank for neurodegenerative diseases and concussion aims:

> To increase the availability of brain tissue and bio-specimens from deceased patients with a history of dementia or concussions.

To increase public awareness of the value of post-mortem brain donation.

To simplify the process of becoming a brain donor.

To make available to qualified researchers high-quality, wellcharacterized human post-mortem brain tissue, quality blood and CSF samples and associated valuable clinical data from patients with a history of dementia or concussions.

## Why Healthy Brain Donation is Needed in Research?

When unraveling the complexities of neurological, neurodevelopmental, and neuropsychiatric disorders, there is no substitute for studying human brain tissue. Access to brain tissue from healthy donors is needed for studies of normal brain structure and function and for use as controls in disease-focused research, where the ability to compare tissues from people with and without a disease is critically important.

### How is Enrollment for the brain donation process done?

Donations are obtained from individuals who enroll before death, and/or from nextof-kin who authorize a postmortem donation. Eligibility for postmortem donation of brain and other tissues is determined by trained staff at the research facility. Notification of a request for postmortem donation may come from surviving family members, treating physicians, hospital systems, donor services, organ and tissue banks, disease advocacy groups, specialized residential facilities, and/or collaborating medical examiners.

## How is Informed Consent Obtained for brain donation?

Trained individuals request and document consent for brain tissue donation from the deceased's next-of-kin or legally authorized representative. Individual requests for release of medical records, questionnaires, and/or interviews with individuals knowledgeable of the deceased are obtained as per brain BioBank policies. All samples (blood, tissue, cerebrospinal fluid) and data will be used by researchers to investigate and learn more about the disease.

#### **Frequently Asked Questions?**

### What happens to the body? Will it interfere with my funeral arrangements?

A brain autopsy is performed to confirm clinical diagnosis following brain donation. Typically, the whole brain and spinal cord are removed and prepared for analysis and future research. No disfigurement occurs as a result of this procedure. The family can plan for an open casket or other form of traditional funeral arrangements and the brain donation process will be undetectable. The brain donation autopsy procedure will not delay or interfere with the family's plans for a funeral, cremation, or burial. Our brain bank works closely with families and funeral homes to ensure that donation does not interfere with funeral arrangements.

#### Are there any costs to the donor or family?

Brain donation is voluntary and has no financial benefits. However, many donors and their families share a common satisfaction knowing that they are contributing to the health and well-being of others affected by similar brain disorders. Brain donation makes studying and discovering cures to neurological diseases possible for future patients. Most donors and their families see this as a legacy that creates a lasting contribution toward improved health of future patients. The DEC Brain & BioBank can occasionally (due to limited funding) cover the cost for transportation of the eligible deceased donor from the location of demise to the designated pathologists and back to the funeral home. Please note that funeral expenses remain the responsibility of the family.

### Will any of my information be shared after donation?

The identity of each donor remains strictly confidential. Specifically, research results are not written in the medical file and the donor's name will not be included in any piece of information sent to researchers. All distributed samples are coded in order to guarantee donor anonymity. Researchers using these de-identified samples through the DEC Brain & BioBank will not return any scientific results to the next-of-kin or family members of donors.

#### I have registered to be an organ donor on my driver's license, can I still be a brain donor for the BrainBiobank?

If the potential brain donor is deemed to be an organ donor at the time of death then due to coordination and scheduling challenges we are unable to accept a brain from the donor.

#### Can anyone in Ontario be eligible for brain

*donation*?Due to limited funding availability, patients not previously seen at LHSC/SJHC will only be assessed on a case by case basis to determine eligibility. Please contact the BrainBank coordinator if you are interested, have a question or would like to find your eligibility. fHow long after death can a decision to donate be made? Who should I contact to make arrangements for donation?

Brain donations should be performed within 24 hours from the time of death in order to ensure optimal preservation of the tissue and maximize the research value. If death is imminent, please contact the BrainBank coordinator.

If you or a family member is interested in registering as a donor, please contact Dr. Elizabeth Finger's BrainBank coordinator at (519) 646-6032. We are happy to answer any questions and concerns you may have with regards to the donation. 

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 DEC Brain & BioBank for

 Neurodegenerative Dementia &

 Concussion



# Brain donation helps brain research

For brain donation information please contact office:

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