**Why Should You Consider Brain Donation?**

Neurological disorders including Alzheimer’s disease, Lewy Body Dementia, Chronic Traumatic Encephalopathy, 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 and no treatment available to stop the progression of the disease once diagnosed.

Brain donation is critically important. While some progress has been made in understanding these disorders, there are still many unanswered questions to be addressed about what changes they cause to the cells and molecules in the brain. The limited supply of donated brain tissue is a barrier to progress in understanding these diseases.

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 disease and risk factors. The hopes of people affected by brain diseases rest on the discoveries made possible by tissue donation which gives an opportunity to individuals to help find a cure for brain diseases for the future generations.

**London Brain BioBank’s Goals**

London Brain Biobank for neurodegenerative diseases and concussion aims to:

1. To increase the availability of diseased and healthy brains and related bio-specimens by increasing public awareness of the value of post-mortem brain donation and to simplify the process of becoming a donor.
2. To integrate and make available to qualified researchers high-quality, well-characterized human post-mortem brain tissue, blood, CSF and associated clinical data to the research community.

**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 of all ages 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.

**Enrollment**

Donations are obtained from individuals who register before death, and/or from next-of-kin who authorize a postmortem donation. Eligibility for postmortem donation of brain and other tissues is determined by trained staff at the research facility. Research staff 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.

**Informed Consent**

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?*

Following brain donation, a brain autopsy is performed to confirm clinical diagnosis. 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 an open casket or other traditional funeral arrangements and the donation process will be undetectable. A Brain donation autopsy 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 arrangement.

 Are there any costs to the donor or family?

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 London Brain Biobank assumes all financial responsibility 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 London 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, does this include my brain?*

No, organ donation and brain donation are separate matters. The sticker on your driver’s license does not give brain banks permission to receive a brain.

*Can I donate brain as well as my body?*

Yes. A brain donation would not necessarily rule a patient ineligible for a whole body donation. Whole body donations require pre-registration with a medical school. Many academically housed body donation programs will accept a donation in spite of previous brain donation. Please inquire with the program/study coordinator prior to registration.

*How 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 study coordinator.

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

 

***London Brain Biobank for Concussion and Neurodegenerative Dementia***



***Brain donation helps brain research***

***For brain donation information please contact office:***

 **Dr. Elizabeth Finger, MD, FRCPC, FAAN**

Lawson Health Research Institute, Cognitive Neurology & Alzheimer Research Centre, Parkwood Institute-Main Building, Room A2-127A, St. Joseph’s Health Care London,

 550 Wellington Rd, London, ON N6C 0A7

 Phone: (519) 646-6032, Fax (519) 646-6226

 **Mailing address:**

 **Dr. Elizabeth Finger, MD, FRCPC, FAAN**

St. Joseph’s Health Care, P.O. Box 5777, Stn B, London, On N6A 4V2

