

late effects of
traumatic
brain injury
project

Brain Donor Program

What is brain donation, and why is it important?

One of the most compelling areas of medical research is aimed at understanding the human brain and what goes wrong in disease. Research using brain tissue donated following death has allowed researchers to answer important questions about many brain diseases such as Alzheimer's, Parkinson's, and Huntington's. Scientists also use brain tissue to investigate the genes involved in disorders such as schizophrenia, depression, autism, and multiple sclerosis. These studies have helped to identify new avenues for treatment.

Compared to other diseases affecting the brain, very little is known about the long-term effects of traumatic brain injury (TBI) on the brain. This lack of knowledge has limited progress in developing effective treatments. Until now there has not been a coordinated effort to collect and study brain tissue from people with TBI in the United States.

Brain tissue collected following death is necessary to conduct research on human brain-related conditions. This tissue is made freely available to qualified researchers through resources called brain banks, which acquire, store, and distribute it. As methods for studying genes and how they influence growth, behavior, development, and disease become more powerful, brain tissue becomes even more valuable. One donated brain can provide tissue for hundreds of independent research studies.

Studies using donated brain tissue following death are the most promising avenue for researchers to learn how to prevent and cure disorders of the brain. Discoveries made possible by tissue donation provide hope to families affected by brain disease.

What is the Late Effects of Traumatic Brain Injury (LE-TBI) Brain Donor Program?

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The Brain Injury Research Center of Mount Sinai is the lead center for the Late Effects of Traumatic Brain Injury Brain Donor Program, a four-year, \$6 million grant-funded project sponsored by the Foundation for the National Institutes of Health and the National Institute of Neurological Disorders and Stroke. Collaborating sites in the study include:



Brain Injury Research Center
of Mount Sinai



University of Washington
Department of Medicine



Group Health Research Institute



Oregon Health & Science University



Martinos Imaging Center
of Harvard/Massachusetts General Hospital



Uniformed Services University
of the Health Sciences

Why is the LE-TBI Project taking place?

Popular news coverage of postmortem brain findings from retired professional athletes has fueled a growing interest in the long-term effects of TBI. A small but alarming number of former athletes who have donated their brains for research have been diagnosed with a unique type of brain disease called chronic traumatic encephalopathy (CTE). Though not much is known about CTE, it is believed that repeated brain injuries trigger its development.

Over 1.7 million people sustain a TBI in the United States each year, and the prevalence of TBI continues to increase. Compared to the general population, people who survive a TBI can have more medical problems, higher rates of depression, a greater risk of developing dementia, and a shortened life span.

The LE-TBI Project aims to learn more about the long-term effects of TBI in the general population. Since the number of people in the community who have experienced one or more brain injuries is far greater than the number of elite athletes who have experienced repetitive injuries, it is important to understand how TBI affects the brain after single or multiple injuries.

Over 5.3 million people are living with a TBI-related disability in the United States. More research is needed to develop effective interventions.

What is different about the LE-TBI Project?

There is no brain bank in the United States that focuses on collecting brain tissue from individuals who survived a TBI. When brain tissue from TBI survivors becomes available, in most cases very little is known about the person before they died. The LE-TBI Project will address this problem by enrolling living TBI survivors into the LE-TBI Brain Donor Program. All participants involved in the LE-TBI Brain Donor Program at Mount Sinai will participate in an assessment of their cognitive, emotional, and behavioral functioning, an MRI scan, and genomic analysis. Those individuals who die during the course of the study and who consent to brain donation will undergo additional neuroimaging and an extensive neuropathological exam using techniques designed to identify the specific proteins involved in TBI.

To date, this project represents the most systematic and scientifically rigorous effort to develop a more complete understanding of the long-term outcomes of single and multiple TBI. This study is unique in that it involves brain banking – traumatic brain injury has never been studied in the general population with brain autopsy as a major focus.

Who are the doctors working on the LE-TBI Project?

Dr. Wayne Gordon is the Principal Investigator on this grant. Other principals at the Brain Injury Research Center of Mount Sinai include Drs. Kristen Dams-O'Connor, Cheuk Tang, and Vahram Haroutunian. Principal Investigators at the collaborating sites include Drs. Paul Crane, Eric Larson, Daniel Perl, Christopher Kroenke, and Bruce Fischl.

How is brain donation arranged?

At the time of death, or when death is imminent, the next of kin must contact the Mount Sinai Brain Bank's 24-hour Autopsy Hotline at (212) 807-5541. The Brain Bank personnel will obtain written consent for autopsy from the next of kin. Soon after death, the patient will be transported to Mount Sinai labs for preparation of brain tissue specimens.

Who can give consent for brain donation?

Consent for brain donation can only be obtained from your next of kin in the hours following death. By agreeing to this research, you are not consenting to brain donation. You are only signing that this is your intent at this time. By making your wishes known, you ease the burden on your next of kin or guardian.

In New York State, next of kin who may consent to brain donation are identified in the following order:

- Power of Attorney/Health Care Proxy
- Spouse
- Children (18 years or older)
- Parents/Legal Guardian
- Siblings

I have registered to be an Organ Donor. Does this include my brain?

At this time, registering as an organ donor does not identify a person as a brain donor for research – brain donation is a separate process.

What about my religious beliefs?

Some people are unsure whether brain donation is compatible with their religious beliefs. Many world religions recognize and support the concept of brain donation because the information gained has the potential to help people, advance knowledge, and improve medical care. It is best to discuss your questions and concerns with your religious advisor.

Will brain donation affect funeral arrangements?

Brain tissue donation will not disrupt the participant's appearance and will not cause significant postponement to funeral arrangements. The autopsy coordinator will work with the family to arrange transportation to and from our facilities at no cost to the family.

Can I still donate my brain to research if this study is no longer running?

Your next of kin may contact the NIH NeuroBioBank (www.neurobiobank.nih.gov) for information on how to arrange to donate your brain for research in the event that this study is no longer running.

The LE-TBI Project is funded by a grant from the National Institutes of Health/National Institute of Neurological Disorders and Stroke.

We at the BIRC-MS are grateful to our research participants, whose generous contributions allow us to advance science and improve clinical care for survivors of traumatic brain injury.

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What is the Brain Injury Research Center of Mount Sinai?

The Brain Injury Research Center of Mount Sinai (BIRC-MS) has a long history of excellence in diagnosing and treating the cognitive, emotional, and behavioral symptoms resulting from traumatic brain injuries (TBI). Since 1987, our collaborative group of researchers and clinicians has grown to include rehabilitation psychologists, neuropsychologists, psychiatrists, epidemiologists, and biostatisticians.

As part of our commitment to our patients, we are constantly searching for better therapies. We are grateful for those patients and family members who have helped us by their participation in our studies. We believe that postmortem analysis of brain tissue donated by people who have sustained a TBI may provide a key to developing even better treatments.

For more information about the LE-TBI Project or other projects taking place at the BIRC-MS, please call **(212) 241-5152** or visit www.tbicentral.org.

Brain donation is a gift of hope that may offer a better future for TBI survivors and their families for generations to come.

