# DOES MY LOVED ONE QUALIFY FOR BRAIN DONATION?

Your loved one may qualify for brain donation to the BU CTE Center if they meet at least ONE of the following criteria:

- Military veteran
- Contact sport athlete
- Victim of repeated physical violence (e.g. intimate partner and/or child abuse)
- First responder and law enforcement
- Traumatic brain injury with loss of consciousness
- Amyotrophic Lateral Sclerosis (ALS)
- Second Impact Syndrome (SIS)

We also encourage optional tissue donation of the spinal cord, blood, and cerebrospinal fluid (CSF) to help us better understand the effects of trauma on the human nervous system.

Your donation will be **examined neuropathologically** for evidence of chronic traumatic encephalopathy (CTE) and other disorders of the central nervous system.



#### **CONTACT US**

Please contact: **Sophia Nosek** 

Research Program Manager

Boston University
CTE Center



72 East Concord Street, L-5 Boston, MA 02118



snosek@bu.edu



F: 617-358-6544
For imminent brain donation matters:

24/Hour: 617-992-0615



Please scan the QR code for more information on the BU CTE Center and a list of Frequently Asked Questions (FAQs) on brain donation



### UNITE BRAIN BANK



# BRAIN DONATION GUIDE FOR FAMILIES

#### THE PROCESS

The donation process is a **time-sensitive matter**; a full-time brain donation coordinator is available 24/7, 365 days per year to arrange tissue collection.

The study will **pay for all expenses** involved with brain and spinal cord donation. Please note that funeral expenses remain the responsibility of the family.

Brain donation does not interfere with funeral arrangements. **No disfigurement occurs** as a result of this procedure.

Researchers conduct extensive interviews with friends and family of the donor to understand what they were like in life, including questions about athletic and concussion history, educational and occupational history, medical history, and history of cognitive, behavioral, and mood symptoms.

#### **RESOURCES FOR FAMILIES**

AFTER BRAIN DONATION, THE FAMILY OF THE DECEASED WILL RECEIVE:

- A written neuropathology report provided 1-year post-donation
- A conference call with the case neuropathologist
- Opportunities to share their loved one's story and connect with other donor families through work with the Concussion Legacy Foundation (CLF).

#### WHY DONATE?

The purpose of our research is to help understand the **long-term effects of head trauma and brain injuries**, including any association with CTE.

This donation process is an opportunity to help further medical research and to help protect future generations of athletes, military veterans, and others exposed to head trauma. Participation will enable researchers to better understand CTE, including its neuropathology, clinical presentation, and environmental and genetic risk factors.

The identity of donors is confidential, however, many have chosen to allow the BU CTE Center to release their names to draw attention to this important work.

Please note that while you can pledge to donate your brain while you are still living, this is not a legally binding contract between you and the UNITE Brain Bank. Acceptance of the brain donation is contingent upon the UNITE Brain Bank's decision at the time of death.

#### **OUR MISSION**

**BU CTE Center researchers are focused on discovering:** imaging, fluid, and other
biomarkers for CTE, a diagnostic test for
CTE in living persons, genetic and
environmental risk factors for CTE, and
treatment for CTE.

#### THE UNITE BRAIN BANK

The UNITE Brain Bank is the largest tissue repository in the world focused on traumatic brain injury (TBI) and CTE.

The brain bank contains more than 1,700 brains, including over 800 brains that have been diagnosed with CTE using the recently defined NINDS criteria for the diagnosis of CTE.

The brain bank stores and distributes optimally prepared tissue to qualified researchers around the world and shares data and other findings with other researchers. All donated brains are preserved forever in state-of-the-art facilities and used for future studies to advance various areas of CTE research.

Dr. Ann McKee, her team of neuropathologists and other investigators have published a large number of studies focused on CTE.

## PRINCIPAL INVESTIGATOR: ANN MCKEE, MD

- William Fairfield Warren Distinguished Professor of Neurology and Pathology, Boston University School of Medicine
- Director, BU CTE Center
- Director, BU Alzheimer's Disease Research Center
- Chief, Neuropathology VA Boston Healthcare System