

**PASSING THE BATON,
RACING TOWARDS
NEW TREATMENTS**

WHAT IS THE BATON STUDY?

A collaboration between Brown University and the Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital. The BATON study is led by Dr. Eric Morrow, MD, PhD.

The purpose of the BATON study is to collect and store brain tissue in order to conduct research on rare genetic disorders, such as Christianson syndrome (CS) or other neurogenetic disorders.



CONTACT

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**PROVIDENCE-RHODE ISLAND
UNITED STATES**



BROWN

BATON STUDY

THE BROWN UNIVERSITY TISSUE RESOURCE FOR RARE NEUROGENETIC DISORDERS



Who can register as a brain tissue donor for the study?

Parents, guardians, or legal next of kin may register their family member for brain donation with Harvard Brain Tissue Resource Center (HBTRC) at McLean Hospital.

The research community would specifically value donations from individuals with genetic disorders, including people who have Christianson syndrome, or family members, who carry changes in the NHE6 gene or those who do not carry these gene changes.



Brain tissue donation is a very special gift and is critically important to help researchers advance the study of neurological and rare genetic conditions. Studying brain tissue at the molecular and cellular level is the only way for scientists to gain a deeper understanding of how the brain is affected in genetic disorders such as Christianson syndrome. The ultimate goal of the research is to develop new treatments.

How do I participate in the study as a way to prepare for the death of my loved one?

- **CONTACT THE HBTRC:**

For more information or to begin the registration process, please visit the www.mcleanhospital.org/hbtrc/ or contact at: 1-800-BRAIN BANK or (617) 855-2400 Fax: (617) 855-3199 or by E-mail: hbtrc@mclean.harvard.edu

- **COMPLETE THE REGISTRATION PROCESS WITH HBTRC**

When you register, you will have the option to select Brown University's BATON study as the recipient of your family member's tissue donation.

This identifies the brain donations as a part of the **BATON study** and also permits Dr. Morrow and colleagues to gain access to any medical information that is collected by the HBTRC.

Completing the registration process with HBTRC does not obligate you to donate brain tissue at the time of death, but it indicates your intention to your family and care providers. You can change your mind at any time. Even if you do not register in advance, you may still donate your family member's tissue by contacting HBTRC immediately at the time of death.