McLean HOSPITAL
HARVARD MEDICAL SCHOOL AFFILIATE

Harvard Brain Tissue Resource Center
"From Knowledge Will Come a Cure"

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

HARVARD BRAIN TISSUE RESOURCE CENTER (HBTRC)

Sabina Berretta, M.D. - Director
Phone: 1-800-BRAIN BANK or (617) 855-2400 ♦ **Fax**: Office hours (617) 855-3199 – After hours (617) 850-8711
E-mail: Office hours HBTRC@MCLEAN.HARVARD.EDU - After hours HBTRCoc@mclean.harvard.edu
Website: http://mcleanhospital.org/hbtrc/

HBTRC Registration ID_____________

Registration for Brain Donation

PLEASE FOLLOW OUR INSTRUCTIONS CAREFULLY TO HELP US PROTECT YOUR INFORMATION

Instructions and Confidentiality Notice

Thank you for considering registering as a brain donor. The HBTRC gratefully accepts registrations from people with and without brain disorders. Please review the information in pages 1 and 2 of this survey before completing this form.

This form is designed to capture information that will be essential to the donation process. It is divided into two sections, one containing Personally Identifiable Information (PII) (**pages 4-5**) and the other containing Protected Health Information (PHI) (**pages 3, 6-8**). Examples of PII are legal name, date of birth, postal address, phone numbers, e-mail address. Examples of PHI are clinical diagnoses, dates of hospitalization, medications. This information is protected by the Health Insurance Portability and Accountability Act (HIPAA). It is important to us to collect it and store it in a very secure manner. For this reason, we ask that you fill the forms including PII only in pages 4-5 and PHI only in pages 6-8.

Because the completed form will contain information that is considered to be personal and confidential it must ***NOT*** be sent by conventional e-mail. Please send it by regular postal mail (see below), FAX (617--855--3199) or use the secure portals that HBTRC staff members will provide to return the completed form.

Harvard Brain Tissue Resource Center
MRC, Mailstop 138
McLean Hospital
115 Mill St.
Belmont, MA 02478

*** CONFIDENTIALITY NOTICE ***

The documents accompanying this PDF form contain confidential information belonging to the sender that is legally privileged. This information is intended only for the use of the individual or entity named above. The authorized recipient of this information is prohibited from disclosing this information to any other party and is required to return or destroy the information after its stated need has been fulfilled, unless otherwise required by state law. If you are not the intended recipient, you are hereby notified that any disclosure, copying, distribution, or action taken in reliance on the contents of these documents is strictly prohibited. If you have received the PDF form in error, please notify the McLean Hospital Privacy Officer at 617-855-4680 to arrange for their destruction or return.

FOR RECORDS PROTECTED BY FEDERAL CONFIDENTIALITY RULES (42) CFR PART 2: This information has been disclosed to you from records protected by Federal Confidentiality Rules (42 CFT Part 2). The Federal rules prohibit you from making any further disclosure of this information unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR Part 2. A general authorization for the release of medical or other information is NOT sufficient for this purpose. The Federal rules restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement. During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy.

HBTRC Registration ID______________

• What is the mission of the Harvard Brain Tissue Resource Center (HBTRC)?
The mission of the HBTRC is to promote research on brain disorders. We do this by collecting and storing brain and related tissue samples and distributing them to researchers within the US and across the world. Their research plays a key role in advancing knowledge on the human brain and understanding how it is affected by brain disorders. As it builds on this research, the scientific community aims to continue to improve treatment and prevention of these disorders.

• What is the purpose of registering as a brain donor?
By registering you express your intention to eventually become a brain donor. Registration is also a helpful way to inform your family of your wish to become a brain donor, and make sure they know to call the HBTRC (immediately) at the time of death. We rely on the legal next of kin to contact the HBTRC in order to carry out a request to donate.

• Can people unaffected by brain disorders register as brain donor?
Yes! In order to perform research brain disorders, it is vital to collect brains from people without brain disorders, which the HBTRC gratefully accepts. We also gratefully accept registrations from people with neurological, psychiatric and neurodevelopmental disorders.

• Does this registration represent a consent to a brain donation?
No, this registration is non-binding and does not represent a consent to donate tissue samples. In addition, being registered as a donor with the HBTRC is not needed to proceed with a brain donation.

• Is an organ donor also automatically a brain donor?
No, organ donation for medical purposes (organ transplant) does not include brain donation, which is exclusively for research purposes. However, the two are compatible with each other. Organ donors can also be brain donors.

• What is the purpose of the information collected in this form?
The information you are providing in this form will be very helpful in many ways. Personal data is needed to generate a Globally Unique Identifier (GUID), an anonymized code that can be used to protect and keep secure your Personal and Health Information (see below). Gathering clinical information is of critical importance to investigators, as it helps them to connect clinical history and symptoms to brain changes, and thus to interpret their results accurately.

• How will my personal and clinical information be protected?
Your information will be stored securely using encrypted electronic storage and locked facilities. Distinct sets of codes will be assigned to your Personal and Health Information, so that only de-identified tissue samples and health information will eventually be provided to researchers.

As part of your participation in the study, and our efforts to protect your information, a unique subject number will be assigned to you. This is done by translating Personally Identifiable Information into a GUID, a computer-generated alphanumeric code that is fully anonymized and unique for each research subject. A GUID will allow researchers to see if you have been involved in more than one research study or database. If you have participated in more than one study or database, this unique subject number will help connect information across studies. This subject number will also allow your de-identified data to be combined with data from other research studies to increase the likelihood of meaningful analysis. Only this subject number and not your personal identifiable information will be accessible to other investigators.

HBTRC Registration ID______________

This unique subject number may make it possible for a study doctor who used this unique subject number in another study that you took part in to identify you.

• What are the costs and benefits related to registering as a brain donor?
There are no costs to you or your family related to registration and brain donation. In addition to making a precious contribution to science, a benefit to the donor's family is the possibility of receiving a neuropathology report, if requested. This report is often very useful to the family to better understand their relative's medical condition, if present. Please note that your samples and information may be used by investigators to develop a new product or medical test to be sold, and may benefit if this happens. There are no plans to pay your family if your samples or information are used for this purpose.

Referral Information

- How did you hear about the HBTRC?

……

……

- Were you referred to the HBTRC by the Brain Donor Project? ☐ Yes ☐No

- Are you registering on behalf of one of the following Entities?

If so, mark the correct one.

☐ Rett syndrome.org
☐ Tourette Association of America
☐ International FOXG1 Foundation
☐ CHDI Foundation
☐ Lupus Research Alliance
☐ International Foundation for CDKL5 Research
☐ Dystonia Medical Research Foundation
☐ ROHHAD Fight
☐ Foundation for Research and Education in Eating Disorders (FREED)
☐ Brown U. Tissue Resource for Rare Neurogenetic Disorders (BATON study)

- Do you give permission to the HBTRC to share identifiable information with the Foundation? ☐ Yes ☐No*

** Please note: if NO is selected:*
(a) de-identified, anonymized, information will be shared with the Foundation
(b) de-identified information might still lead to identification in rare disease cases

HBTRC Registration ID______________

Personally Identifiable Information (PII) (*Required)

(Registrant's name exactly as it appears on the **Birth Certificate**, please no abbreviations. Please, make sure that the information provided below is accurate. It will be used to generate an anonymized code (GUID) to protect the Registrant's privacy).

Registrant Full Name				
Prefix	*First Name	*Middle Name	*Last Name	Suffix

*Date of Birth (MM/DD/YYYY):	*Community/Town of Birth:
*Country of Birth:	Sex at Birth and Gender Identity (optional):

Contact Information (*Required)

* Registrant Current Name (*if different from above*)

First ………………………………… Middle ……………………………… Last ……………………………………………………………

*Address1: ………

Address2: ……

*City: ……

*State: ………………………………………………………… *Zip/Postal Code: ……………………………………………………

*Phone1: ……………………………………………………… ☐ Home ☐ Cellphone

Phone2: ……………………………………………………… ☐ Home ☐ Cellphone Fax: ………………………………………

*E-Mail: ………

HBTRC Registration ID______________

Personally Identifiable Information (PII) Legal Next-of-Kin (LNOK)

Contact Information (*Required)

LNOK hierarchy:
1. Legal Executor of Estate ♦ 2. Spouse ♦ 3. Adult Child ♦ 4. Parent ♦ 5. Adult Sibling ♦ 6. Adult Grandchild ♦ 7. Grandparent ♦ 8. Adult who exhibited special care and concern for the decedent ♦ 9. Adult who acts as a Guardian

LNOK Full Name

Prefix	*First Name	*Middle Name	*Last Name	Suffix

*Relationship to Donor: ………

*(LNOK) Address1: ………

(LNOK) Address2: ………

*(LNOK) City: ………

*(LNOK) State: ……………………………………… *(LNOK) Zip/Postal Code: ……………………………………………

*(LNOK) Phone1: ……………………………………… (LNOK) Specify (Home/Cell): ……………………………………

(LNOK) Phone2: ……………………………………… (LNOK) Fax: ……………………………………………………

*LNOK E-Mail: ………

Person Completing Form:

Self ☐ LNOK ☐ Health Care Proxy ☐ Name: ……………………………………………………………………

Other ☐ Name: ……………………………………… Relationship: ……………………………………………………

If Registrant is a minor or incapacitated, are you the Legal Guardian? Yes ☐ No ☐ N/A ☐

Send Registration Packet to:……………………………………………………………………………………………

*Date Completed (MM/DD/YYYY): ______________________________________

HBTRC Registration ID______________

Protected Health Information [PHI] Clinical Information (*Required)

* Primary Diagnosis: ……………………………………………………………………………………………………

(Registrants with no brain disorders, please mark as "Non Applicable" and skip to the next page)

* Main symptoms: ……………………………………………………………………………………………………

……

……

*Age at onset of symptoms - When did the symptoms start?

……

……

*Age when a clinical diagnosis made?

……

……

* Brief Medication History: ……………………………………………………………………………………………

……

……

……

* Did the symptoms lead to hospitalization – if so, how many times?

……

……

……

HBTRC Registration ID____________

Protected Health Information [PHI] Clinical Information (Optional)

PHI (Other) – Is there any other information you would like to share with us?

………

………

………

………

………

………

Diagnoses other than brain disorders (e.g. diabetes, high blood pressure).

………

………

………

………

………

If you have ever experienced stress related to a psychological or physical trauma, or sustained head or neck injuries, and you feel comfortable sharing this information with us, please do so

………

………

………

………

………

………

McLean HOSPITAL
HARVARD MEDICAL SCHOOL AFFILIATE

Harvard Brain Tissue Resource Center
"From Knowledge Will Come a Cure"

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

HARVARD BRAIN TISSUE RESOURCE CENTER (HBTRC)

Sabina Berretta, M.D. - Director
Phone: 1-800-BRAIN BANK or (617) 855-2400 ♦ **Fax**: Office hours (617) 855-3199 – After hours (617) 850-8711
E-mail: Office hours HBTRC@MCLEAN.HARVARD.EDU - After hours HBTRCoc@mclean.harvard.edu
Website: http://mcleanhospital.org/hbtrc/

HBTRC Registration ID______________

Registrant's Protected Demographic Information (Optional)

Race: ☐ Caucasian ☐ Black or African American ☐ Asian ☐ Native American or Alaska Native
☐ Native Hawaiian or other Pacific Islander ☐ Other ……………………………………………………………………….

Ethnicity: Hispanic/Latino ☐ Yes ☐ No

Education: ……

Employment: ……….

Marital Status:………………………………………………. Living Situation: ………………………………………………………………

May we contact you?

Do you authorize the HBTRC to contact you for follow up via phone or other secure means of communication?

☐ Yes Print Name: ……………………………………………………. Signature: ……………………………………………………
☐ No

Please do not hesitate to call us with any questions or concerns at 800.272.4622, during normal business hours.

Please do not write in this box – Restricted to HBTRC staff

Registrant's GUID#: ……

HBTRC Staff Name: ………………………………………………………………………………………

Date: ………