

Francine M. Benes, M.D., Ph.D., Director

617-855-2400 or 1 800-Brain Bank (800-272-4622)

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The HBTRC is asking you to provide consent for removal and transport of your relative's brain, heart, liver, kidney, spleen, adrenal gland, intestine, peripheral nerve and muscle to our facility at McLean Hospital, Belmont, MA, where we collect, process and distribute postmortem tissue specimens to scientists throughout the U.S. and abroad. These scientists use the tissue to conduct research that will further the medical understanding of Rett Syndrome.

**PROCEDURES:** At the time of death, an individual's body becomes part of their estate, and its disposition is decided by the legal next-of-kin or other authorized representative. Although an individual can make a personal request to donate his/her brain, it is the surviving family member(s) or other authorized representative who has the responsibility of deciding whether this donation will be made. You, the legal next-of-kin or other authorized representative (such as the Executor of the donor's estate), are being asked to verify the donor's intention-to-donate. This consent (which has been faxed to you or is being read to you by telephone) will authorize the HBTRC to acquire, store, and share the brain and appropriate medical records of the donor with qualified scientists. The brain will be processed according to standard practices in brain research. Information identifying the donor will be treated confidentially and stored in locked file cabinets with access available only to HBTRC staff and to individual researchers who have received approval by the Director to review information at the HBTRC. Please contact the Director, Dr. Benes, if you have any questions or concerns.

Our HBTRC representative will need to know the donor's name, time of death, neurological or psychiatric diagnosis, and the location of the body. The HBTRC will work directly with appropriate personnel to make arrangements for the brain removal and will provide instructions for its packaging and transport. It is essential that the donation procedure occur within 24 hours from the time of death of the donor. Only the donor's brain will be sent to the HBTRC. You may be charged for the brain removal, but this is a local cost over which we have no control.

#### **DONOR & PATHOLOGIST INFORMATION**

Donor's Name: \_\_\_\_\_

Donor's Date of Birth : \_\_\_\_\_

Pathologist or Diener: \_\_\_\_\_

Donor's Date of Death: \_\_\_\_\_

Location: \_\_\_\_\_

#### **DONATION CONSENT BY NEXT-OF KIN or OTHER AUTHORIZED REPRESENTATIVE**

As the legally authorized representative(s) of the donor, and being his/her (indicate relationship) \_\_\_\_\_, and entitled by law to control his/her remains, you authorize the removal, retention, use, and distribution of his/her whole brain specimen by the HBTRC for research purposes as has been described. You further direct that the medical records of the donor be released to the HBTRC and shared as described to provide information critical to the research. You may withdraw your consent at any time. If you do, the donor's brain will be disposed of in a manner consistent with disposal of biological material, and his/her medical information will be destroyed. However, it will not be possible to retrieve tissue and information that have already been given to researchers. If you decide to withdraw your consent, please contact Dr. Benes in writing.

Dr. Benes or her colleagues have answered all your questions to your satisfaction. You voluntarily agree to make this donation.

#### **Legal Next-of-Kin or Other Authorized Representative:**

Printed Name: \_\_\_\_\_ Address: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Phone: \_\_\_\_\_

Witness Printed Name: \_\_\_\_\_ Address: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Phone: \_\_\_\_\_

#### **Phone or Faxed Consent Given to:**

HBTRC Staff / Printed Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_\_

HBTRC Witness / Printed Name: \_\_\_\_\_ Signature of Witness: \_\_\_\_\_

Date: \_\_\_\_\_