



*Neuropathology
Brain Bank
at Mount Sinai*



Approved
02/14/2019-06/01/2019
GCO # 16-1209



Neuropathology Brain Bank
1425 Madison Ave, Room 9-22
New York, NY 10029-6574

T: (212) 659-8660
F: (212) 849-2510
Email: brainbank@mountsinai.org

Hello,

We would like to thank you and your loved ones for being an important part of our research efforts in discovering cures for devastating brain diseases. Research conducted using human post mortem brain and other tissues remains a critical component of translational research programs. Such tissues are of immense value, but finding enough donors is a constant challenge.

The Neuropathology Brain Bank at Mount Sinai (NPBB) was launched to reinforce and expand tissue-based translational research on devastating brain diseases and other neurological conditions to meet the urgent need for this resource. We aim to provide a service not just to physicians and basic scientists, but also to our donors by fulfilling their end-of-life wishes of leaving behind an important legacy.

Post mortem tissue donation is a very personal matter that requires careful consideration and planning. Ultimately, end-of-life decisions depend on the legal next of kin, who will have to provide the consent for the autopsy to be performed. To facilitate this process, we have prepared this welcome packet with the following documents:

- Information pamphlet
- End-of-Life Preparations guide
- FAQ
- Brain Bank Questionnaire
- Anatomical Gift Consent form
- Autopsy Consent form
- Authorization of Release of Medical Information
- Wallet card and coordinator business card

By enrolling in the Neuropathology Brain Bank, you and your loved ones are taking the first step in helping the medical and research community further research into devastating brain diseases and develop potential therapies.

If you have any additional questions please contact our coordinators at (212) 241-8617 or brainbank@mountsinai.org. Once again, thank you for leaving us such an important legacy.

Sincerely,

John F. Crary, MD, PhD
Director, Neuropathology Brain Bank

Ruth H. Walker, MB, ChB, PhD
Medical Director, Neuropathology Brain Bank



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End-of-Life Preparations

We would like to thank you for enrolling in the Neuropathology Brain Bank. Preparation is key to ensure that your wishes are respected in a timely and orderly manner, and for researchers to get the maximum benefit from your donation. All end-of-life decisions are made by the next of kin, so we have put together a step-by-step guide to help you and your family prepare in advance.

Documents which can be prepared before death:

1. Complete the **Brain Bank Questionnaire**
2. Please complete the **Authorization of Release of Medical Information**, to be signed by the next-of-kin
3. Donor or next-of-kin should complete the **Anatomical Gift Consent Form** to declare their intent to donate brain tissue after their passing. This must be done in the presence of two unrelated witnesses.
4. In order for us to proceed with the autopsy, the next-of-kin must sign the **Autopsy Consent Form**

Once completed, please send all the documents to us at brainbank@mountsinai.org or fax to **(212) 996-9785**.

Additional suggestions:

- If possible, we suggest choosing a funeral home to prior to death to assist in funeral preparations. Funeral directors often play a critical role in facilitating brain donation, and it is helpful for us to communicate with them ahead of time.
- If there is a situation where the donor's condition declines, please do contact us (at any time) in order that we can make any necessary preparations. We are available 24 hours.

When death is imminent or upon passing, please contact our coordinator at (212) 241-8660. They will assist with transportation and ensuring that the appropriate documentation is in place.

If you have any further questions, please contact us at (212) 241-8660 or email us at brainbank@mountsinai.org.



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Frequently Asked Questions

Who can participate?

Our program is open to everyone. It is important to obtain post mortem tissues from individuals with a wide range of symptoms and diagnoses. Additionally, it is extremely important to have participation from healthy individuals for comparison.

Does my religion prohibit brain donation?

No religions prohibit brain donation. However, we encourage you to discuss it with your spiritual advisor.

Will my identity be kept confidential?

Prior to analysis, tissue disbursement, or publications, all personal identifiers will be removed to protect your and your family's privacy.

Is there a cost to my family?

There is no cost associated with brain donation and autopsy. We work with the funeral director to arrange transportation. The brain bank does not pay for the funeral costs; however funds are potentially available to pay for decedent transportation if necessary. Please discuss further with our coordinators.

Will brain donation affect funeral arrangements?

Participating in our program and going through the procedure will not delay funeral arrangements. Our coordinators will work with the funeral home and your family to ensure the procedure is completed in a timely manner.

Will the procedure leave any visible scars on my face or body?

The procedure will not alter the individual's appearance in any way regardless of the funeral arrangements. Specifically, it does not interfere with the option to have an open casket funeral.

Will my family receive the results of the autopsy?

Yes. A report containing a detailed summary of the findings from the examination will be provided to your family at no additional cost.

If you have any further questions, please contact us at (212) 241-8660 or email us at brainbank@mountsinai.org.



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Brain Bank Questionnaire

Donor name: _____ Date of Birth: _____

Name of primary next-of-kin: _____ Relationship: _____

Address: _____

Telephone: _____ Email: _____

Name of secondary next-of-kin: _____ Relationship: _____

Address: _____

Telephone: _____ Email: _____

Chosen Funeral Home: _____

Funeral Home Contact: _____ Phone: _____

Current Diagnosis: _____ Age at onset: _____

Is there family history of brain disease Yes No If yes, please provide brief history: _____

What were the symptoms in the early stages?

Was the progression rapid? Yes No Please describe any noteworthy symptoms (if any): _____



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Is the donor: Right handed Left handed Veteran: Yes No Alcohol: Yes No Smoking: Yes No

Highest degree completed: _____ Profession: _____

Name of neurologist/psychiatrist/psychologist: _____

Telephone: _____ Email: _____

Name of neurologist/psychiatrist/psychologist: _____

Telephone: _____ Email: _____

Any other medical conditions: _____

Medications: _____

Order of priority for NEXT-OF-KIN [AGE EIGHTEEN YEARS OF AGE OR OLDER]:

1. PERSON DESIGNATED IN WRITTEN WILL OR LEGAL INSTRUMENT; OR
2. DECEDENT'S SURVIVING SPOUSE; OR
3. DECEDENT'S SURVIVING DOMESTIC PARTNER; OR
4. DECEDENT'S SURVIVING CHILDREN; OR
5. DECEDENT'S GRANDCHILDREN; OR
6. EITHER OF THE DECEDENT'S SURVIVING PARENTS; OR
7. ANY OF THE DECEDENT'S SURVIVING SIBLINGS; OR
8. ANY OF THE DECEDENT'S GRANDPARENTS; OR
9. ANY OF THE DECEDENT'S AUNTS, UNCLES; OR
10. ANY OF THE DECEDENT'S NIECES OR NEPHEWS; OR
11. AN APPOINTED GAURDIAN; OR
12. PUBLIC ADMINISTRATOR ACTING ON BEHALF OF THE DECEDENT

Please email the documents to brainbank@mountsinail.org or fax to (212) 996-9785. We have also enclosed a prepaid envelope for your convenience.