

Dear Postmortem Brain Donation Program Participant,

Thank you for choosing to enroll in our postmortem brain donation program. There are several necessary steps to the enrollment process. The information you are about to provide will facilitate and enhance the donation process. Please follow the instructions below and use our stamped return envelope to mail the documentation back to the *Mount Sinai NIH Brain and Tissue Repository (NBTR)*.

Please take the time to review the information we have provided in order to familiarize yourself with our program.

1. This electronic package is segregated into bordered and non-bordered pages for clarity and contains the following documents that should be signed and returned at two different times. (we strongly recommend that you retain a copy of each signed form):

Pencil Bordered Forms – to be completed and mailed back to the NBTR, as soon as possible, by the potential donor or person acting on behalf of the potential donor:

- a. NBTR Enrollment Card
- b. Next of Kin (NOK) Information Form
- c. Health Care Proxy Form (please note that this form is not required, but it is **highly recommended**)

Place the completed documents into the stamped return envelope and mail it back to us.

Block Bordered Forms - signed by next of kin of the donor at the time of death (the NBTR donation coordinator can guide you at this point):

- a. Permission/Consent for Brain Donation Form
- b. Two Medical Record Release Forms
 - I. One partially pre-filled blanket form
 - II. One blank form you can use for specific institutions/physicians

2. The non-bordered portion of the package includes general information regarding the NBTR, as well as information on advanced directives. Completion of the advance directive forms is recommended when applicable but, not necessary for participation.

After we receive this documentation, we may contact you to discuss any questions that might arise. Thank you for your commitment to donate your brain to science through the Mount Sinai NIH Brain and Tissue Repository; you have our enduring appreciation and respect.

Vahram Haroutunian, Ph.D.
Professor, Departments of Psychiatry and Neuroscience
The Mount Sinai NIH Brain and Tissue Repository

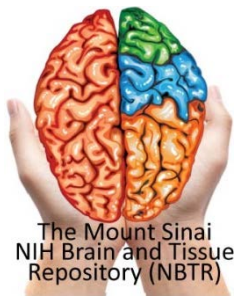


What is the NIH Neurobiobank?

The NIH Neurobiobank is an effort by the National Institutes of Health to coordinate the network of brain banks it supports in the United States. The brain tissue is collected, evaluated, stored, and made available to researchers in a way consistent with the highest standards for research. It also ensures protection of the privacy and wishes of donors. Brain tissue is precious. Networking these centers makes it more likely that precious tissue can be made available to the greatest number of scientists.

As with donation of organs and tissues for transplantation, the best way to donate brain tissue for research is to contact a brain bank in advance.

The NIH Neurobiobank website www.neurobiobank.nih.gov has answers to questions about brain donation, links to brain banks across the country, and information on how arrangements are made to donate the brain for research.



Program Description:

Mission: To promote understanding of the human brain in health and disease and brain features that govern behavior and cognition through detailed and direct study. The Mount Sinai/JJ Peters VA Medical Center NBTR banks and distributes tissue specimens to research laboratories, including laboratories at Mount Sinai, for expert study and the advancement of knowledge.

Characteristics of the NBTR:

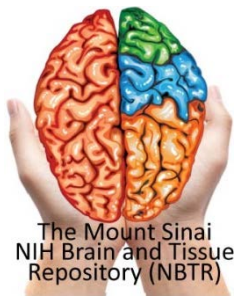
- The Mount Sinai/JJ Peters VA Medical Center NBTR has been in continuous operation since 1982.
- Brain specimens are banked in both flash frozen and formalin fixed form for maximal utilization. In addition to brain, cerebrospinal fluid, muscle tissue, and DNA are banked for most cases.
- Frozen specimens are stored in redundant -80 °C freezers.
- All specimens are characterized by detailed, state-of-the-art neuropathological assessments.
- The postmortem delay in preserving these brain specimens is among the shortest in the world.
- Brain tissue specimens have been distributed to hundreds of laboratories within and outside the US.

History of the Mount Sinai / JJ Peters VA Medical Center NBTR

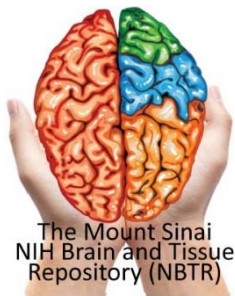
- The NIH Brain and Tissue Repository (NBTR; formerly known as the Mount Sinai Brain Bank) was established in 1982 as an Alzheimer's disease (AD) brain bank and was expanded to include specimens from persons with schizophrenia and serious mental illness in 1990. In 2013, the Brain Bank expanded its mission further to include multiple other brain associated disorders.
- Dr. Vahram Haroutunian has directed the NBTR from inception.
- Results of studies using specimens from the NBTR have been published in over 350 peer-reviewed articles in scientific journals including: Nature, Science, and JAMA, among many others.

Studies using specimens from the NBTR have contributed to:

- The understanding of the chemical deficits in the brain during AD and the development of the current FDA approved treatments for AD.



- Our understanding of the order in which neuropathology develops in AD.
- The expression of RNA in different brain regions at different stages of AD and the vulnerability of the brain at different ages and stages of dementia.
- Knowledge of dementia similarities and differences in young-old persons (65-85 years) vs. oldest-old persons (above 85 years).
- The relationship between cardiovascular disease risk factors and dementia.
- The relationship between diabetes and Alzheimer's disease and the potential of anti-diabetes therapies in reducing the burden of AD.
- The association between high blood pressure medication and reduced Alzheimer's disease neuropathology.
- The relationship between depression and dementia.
- How biochemical pathways in the brain are affected in schizophrenia.
- The differences in RNA expression in different brain regions of persons with schizophrenia.
- Identification and broad acceptance of specific nervous system abnormalities in schizophrenia.
- The role of other helper cells (glia) of the brain in the development of schizophrenia.
- Analysis of brain changes in schizophrenia at the level of systems and networks.
- Initiation of unique medication trials with a new class of drugs for the treatment of schizophrenia.
- Identification of the unique neurobiology of suicide and biological features that could predict vulnerability to suicide and aggressive behavior.

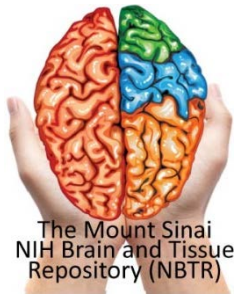


What to do at the time of death and what to expect:

- At the time of death immediately contact:

24-Hour Autopsy Hotline: 212-807-5541

- Be prepared to be contacted by the Brain Tissue Donation Program Autopsy Coordinator.
- You will be asked to read, understand, and sign the following items:
 - a formal consent to autopsy and brain tissue donation.
 - a formal Release of Medical Records form.
 - a HIPAA form describing what information will be collected regarding the deceased.
- The Autopsy Coordinator will arrange for the transportation of the deceased to our morgue facilities if none are available at the site where death occurred.
- The Autopsy Coordinator will work with you to arrange for the transportation of the deceased to your funeral home of choice after the autopsy has been completed.
- Members of the Brain Tissue Donation Program may contact you at a later date for additional information regarding the donor and/or for your help in securing medical records.
- The detailed neuropathology evaluation of the brain will take several months, but you will be able to contact the Brain Tissue Donation Program if you wish to receive a copy of the neuropathology findings.
- The Brain Tissue Donation Program will distribute tissue specimens to investigators to promote the better understanding of the brain in health and disease.



NBTR Team

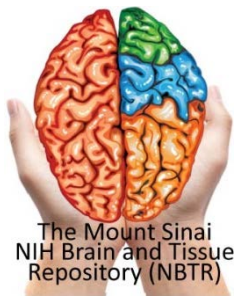
- Program Director:** V. Haroutunian, Ph.D.
Professor, Psychiatry and Neuroscience
- Donation Coordinators:** Danny Benitez; Maxwell Bustamante;
Joshua Arneson
- Clinical Assessment:** Stephen Panopoulos, MA

Contact Information:

- General Email:** NBTR@mssm.edu
- Office:** Room 5F-04
James J Peters VA Medical Center
130 West Kingsbridge Road
Bronx, NY 10468
- Telephone:** 718-584-9000, Extension 6083
- Fax:** 718-741-4746

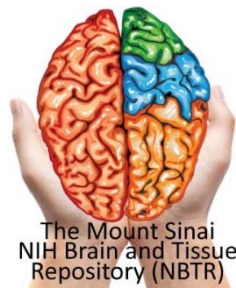
24-Hour Autopsy Hotline (Time of Death):

212-807-5541



Important Facts to Keep in Mind:

- Indicating your intent to participate in research on the enclosed forms is not a binding commitment. You may change your mind at any time
- NBTR investigators and staff will review the participant's medical records and will interview knowledgeable persons regarding physical and mental health of the donor
- The procedures for brain tissue donation are ethical and respectful
- Brain tissue donation will not affect funeral or burial arrangements that the family may choose. There is no disruption to the participant's appearance and no significant postponement to funeral arrangements.
- Families will incur no costs as a result of study participation.
- The whole brain is retained for neuropathologic diagnosis and subsequent research.
- Following autopsy, a neuropathology report is available to the participant's family and/or designated physicians. Our staff is always available to discuss the findings if requested.
- The AUTOPSY HOTLINE, 212-807-5541, is staffed 24 hours a day, seven days a week. The operator will provide instructions at the time of death.



NIH Brain and Tissue Repository Enrollment Card

Prefix: _____ (Ms, Mr, Mrs, etc.) *Required
*First Name: _____ *SSN Last 4: _____
Middle Initial: _____
*Last Name: _____ Suffix: _____ (Jr, Sr, etc)
*Address: _____

*City: _____ State: _____ Zip: _____
*Phone: (____) _____ - Mobile: (____) _____
Preferred Contact Method (circle): Phone Mail Email (____)
*Date of Birth: ____ / ____ / ____ *Sex: Male ____ Female ____

* I offer to donate my brain/spinal cord and related specimens to the NIH Brain and Tissue Repository for research/medical education:

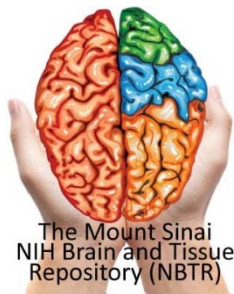
Brain Only Brain/Spinal cord

I wish to enroll in *NIH Brain and Tissue Repository* maintained by the *Mount Sinai School of Medicine / JJ Peters VA Medical Center*. I understand that by enrolling in the registry I am giving legal consent to the donation of Brain only or Brain/Spinal cord (as specified above) in the event of my death. I also understand that all pertinent medical records will be reviewed and duplicated as necessary and persons who know me may be interviewed. Specifically Personal Health Information relating to medical, psychological, psychiatric and neurological status; Name: first, last, middle names; Address: including apartment number, street, city, county, zip code, telephone number, fax number; Dates (day, month, year): including date of birth, date of admission(s), date of discharge(s), date or dates associated with medical or psychiatric diagnoses, date or dates associated with receipt of medications, date or dates associated with laboratory tests and medical or psychiatric procedures; and Medical record(s) number will be reviewed and information retained for research purposes. However, NO information that may identify me, other than age, will be intentionally revealed to anyone unless required by law. I understand that this document is for NBTR information and a declaration of my current intent. I may change my mind at any time. Authorization and consent for brain and tissue banking will be sought and may be given by my next of kin after my death.

Signature

Date

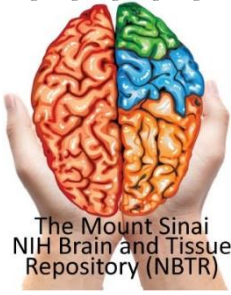
Mail to: **NIH Brain and Tissue Repository**
Attention: Alex Cline
James J Peters VA Medical Center
130 West Kingsbridge Road
Room 5F-04D



Next of Kin Hierarchy

Please use the list below to identify your next of kin on the included *Next of Kin Form*. This individual should be the person highest on the order of priority list below. The individual whom you identify will provide the final postmortem consent for donation.

1. Health Care Agent/Proxy (a Health Care Proxy designation form is included in this package for your convenience)
2. Spouse/domestic partner
3. Children (in order of birth)
4. Parents
5. Siblings
6. Authorized guardian
7. Authorized or under the obligation to dispose of the body (e.g., hospital administrator)



Next of Kin Form

Dear Program Participant,

Please identify the next of kin (NOK), who will confirm and authorize the brain tissue donation. We ask this in advance to prevent confusion during a time that can be very difficult for loved ones. Informing us of the next of kin, and advising that person of the donor's desire to participate, removes an unnecessary stress on them during the postmortem period.

Please ensure compliance with the included Next of Kin Hierarchy and identify the person highest on that list.

I am _____
Name: (Please Print: First Middle Last)

Signature Date: (mm/dd/yyyy)

In the event of my death, my next of kin is: _____
(Name: First, Middle, Last)

Contact information:
(phone) (____) (____) (____) (email) _____
(____) (____) (____) _____

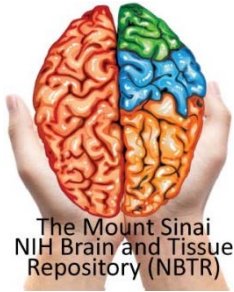
Relation: (Please Circle one) (Address)
1. Health Care Agent/Proxy 5. Sibling _____
2. Spouse/Domestic Partner 6. Authorized Guardian _____
3. Adult Child 7. Other Authorized Individual _____
4. Parent _____

Should the above person be unable or unavailable for whatever reason please contact:

(Name: First, Middle, Last)

Contact information:
(phone) (____) (____) (____) (email) _____
(____) (____) (____) _____

Relation: (Please Circle one) (Address)
1. Health Care Agent/Proxy 5. Sibling _____
2. Spouse/Domestic Partner 6. Authorized Guardian _____
3. Adult Child 7. Other Authorized Individual _____
4. Parent _____



NIH NeuroBioBank
Facilitating Research and Creating Awareness
Brain and Tissue Repository (NBTR)
 JJ Peters VA Medical Center
 130 West Kingsbridge Road
 Room 5F-04D
 Bronx, NY 10468
 Phone: 718-584-9000 x1848
 Fax: 718-741-4746
 Email: NBTR@mssm.edu

PATIENT AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION TO NBTR

Patient's Name: _____
 (Last) (First) (Middle)

Unit Number _____ Date of Birth ____/____/____ Phone: _____
 Month/Day/Year

Address: _____
 (Street) (City) (State) (Zip)

Please check the box that describes the person filling out this form and fill in required information:

I authorize any and all medical facilities to disclose medical information about my:

Please request/check all that apply:

- Emergency Room visit on: _____ Any/All Date(s)
- OPD Clinic visit, specify clinic _____ Any/All Date(s)
- Private MD/Provider: _____ All Providers
- Hospitalization from: _____ Any/All to: _____ Any/All
- Ambulatory Surgery: _____ Any/All
- Specify (i.e. lab tests, operative reports): _____ Any/All

Records to be disclosed Do Include Do Not Include HIV-related information. (check one)

Return to: NIH Brain Tissue and Tissue Repository
 JJP VA Medical Center, Psychiatry Research
 130 West Kingsbridge Rd
 Room: 5F-04D
 Bronx, NY 10468
 Attn: Mr. Alexander Cline

Contact Numbers: Phone: 718-584-9000 ext. 1848/6083; Fax: 718-741-4746

Reason for Disclosure: Patient Request Other: Research Project Participation

I understand that this authorization is valid for one year from this date or until _____ and may be revoked by me at any time except to the extent Mount Sinai has already taken action based on my authorization.

SPECIFIC UNDERSTANDINGS

I understand that this consent may include disclosure of Alcohol and Drug Abuse records and/or Psychiatric records and or HIV-related information (indicating that I have had an HIV-related test, or have HIV infection, HIV-related illness or AIDS, or that could indicate that I have been potentially exposed to HIV).

If I am authorizing the release of HIV-related information, the recipient(s) is prohibited from re-disclosing any HIV-related information without my authorization unless permitted to do so under federal and state law. I also have a right to request a list of people who may receive or use my HIV-related information without authorization. If you experience discrimination because of the release or disclosure of HIV-related information, you may contact the New York State Division of Human Rights at (800) 523-2437/(212) 480-2493 or the New York City Commission on Human Rights at (212) 306-7450.

By signing this authorization form, I am authorizing the use or disclosure of my protected health information as described above. This information may be re-disclosed if the recipient(s) as described on this form is not required by law to protect the privacy of the information, and such information is no longer protected by federal health information privacy regulations.

Patient

Signature: _____

Date: _____

Personal Representative

Signature: _____

Date: _____

Authority: _____

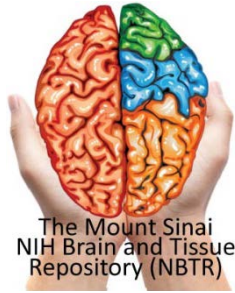
Phone: _____

Address: _____

Date: _____

{Personal Representative to sign only if patient is a minor or incompetent}.

To request records or to revoke authorization, send a written request to releasing provider.



NIH NeuroBioBank
Facilitating Research and Creating Awareness
Brain and Tissue Repository (NBTR)
 JJ Peters VA Medical Center
 130 West Kingsbridge Road
 Room 5F-04D
 Bronx, NY 10468
 Phone: 718-584-9000 x1848
 Fax: 718-741-4746
 Email: NBTR@mssm.edu

PATIENT AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION TO NBTR

Patient's Name: _____
 (Last) (First) (Middle)

Unit Number _____ Date of Birth ____/____/____ Phone: _____
 Month/Day/Year

Address: _____
 (Street) (City) (State) (Zip)

Please check the box that describes the person filling out this form and fill in required information:

- I authorize any and all medical facilities to disclose medical information about my:
- Please request/check all that apply:
- Emergency Room visit on:(Date(s)) _____
 - OPD Clinic visit, specify clinic:(Date(s)) _____
 - Private MD/Provider:(Name; Date(s)) _____
 - Hospitalization from:(Date(s)) Admission _____ Discharge _____
 - Ambulatory Surgery:(Date(s)) _____
 - Specify (i.e. lab tests, operative reports): _____

Records to be disclosed Do Include Do Not Include HIV-related information. (check one)

Return to:
NIH Brain Tissue and Tissue Repository
JJP VA Medical Center, Psychiatry Research
130 West Kingsbridge Rd
Room: 5F-04D
Bronx, NY 10468
Attn: Mr. Alexander Cline

Contact Numbers: Phone: 718-584-9000 ext. 1848/6083; Fax: 718-741-4746

Reason for Disclosure: Patient Request Other:Research Project Participation

I understand that this authorization is valid for one year from this date or until _____ and may be revoked by me at any time except to the extent Mount Sinai has already taken action based on my authorization.

SPECIFIC UNDERSTANDINGS

I understand that this consent may include disclosure of Alcohol and Drug Abuse records and/or Psychiatric records and or HIV-related information (indicating that I have had an HIV-related test, or have HIV infection, HIV-related illness or AIDS, or that could indicate that I have been potentially exposed to HIV).

If I am authorizing the release of HIV-related information, the recipient(s) is prohibited from re-disclosing any HIV-related information without my authorization unless permitted to do so under federal and state law. I also have a right to request a list of people who may receive or use my HIV-related information without authorization. If you experience discrimination because of the release or disclosure of HIV-related information, you may contact the New York State Division of Human Rights at (800) 523-2437/(212) 480-2493 or the New York City Commission on Human Rights at (212) 306-7450.

By signing this authorization form, I am authorizing the use or disclosure of my protected health information as described above. This information may be re-disclosed if the recipient(s) as described on this form is not required by law to protect the privacy of the information, and such information is no longer protected by federal health information privacy regulations.

Patient

Signature: _____

Date: _____

Personal Representative

Signature: _____

Date: _____

Authority: _____

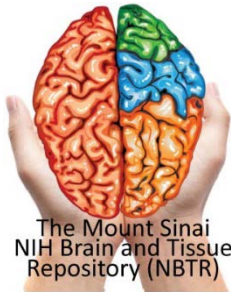
Phone: _____

Address: _____

Date: _____

{Personal Representative to sign only if patient is a minor or incompetent}

To request records or to revoke authorization, send a written request to releasing provider.



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Fax: 718-741-4746
Email: NBTR@mssm.edu

PERMISSION / CONSENT FOR BRAIN DONATION Request for Consent of an Anatomical (Brain) Gift

Date: _____ Time: _____

I hereby authorize that a harvesting of brain tissue be performed on the body of my

_____ Mr./Mrs./Miss _____
Relationship (please print) Name of deceased: first, middle, last (please print)

for diagnostic and research purposes. I understand that tissue and bodily fluids may be removed and retained for diagnostic and research purposes and shared with qualified researchers. I have no reason to believe that this anatomical gift is contrary to the decedent's religious or moral beliefs.

I also understand that all pertinent medical records will be reviewed and duplicated as necessary. Specifically, Personal Health Information relating to medical, psychological, psychiatric and neurological status; Name: first, last, middle names; Address: including apartment number, street, city, county, zip code, telephone number, fax number; Dates (day, month, year): including date of birth, date of admission(s), date of discharge(s), date or dates associated with medical or psychiatric diagnoses, date or dates associated with receipt of medications, date or dates associated with laboratory tests and medical or psychiatric procedures; and medical record(s) number will be reviewed and information retained for research purposes. However, NO information that may identify the donor, other than age, will be intentionally revealed to anyone outside of the research team unless required by law.

Permission for Brain Donation is Granted:

(Signature, consenting next-of-kin) (Name: first, middle, last - please print)

(Signature, Witness) (Name: first, middle, last - please print)

Address and telephone number of next-of-kin giving consent for autopsy.
Address: _____ Telephone Number: _____

City State ZIP

DOB and Social Security # (for coding purposes only) of Deceased: _____



ERIC T. SCHNEIDERMAN
Attorney General



Dear New Yorker:

Planning end-of-life care is a complex matter. Although it is hard to talk about the final phase of life, it can be a great gift to our family and loved ones to prepare them in advance for the sometimes difficult and distressing decisions that must be made.

For those who wish to plan in advance, New York law can help. Ultimately, your decision to accept or reject medical treatment really depends upon your personal wishes, values, and beliefs. This guide explains your right to choose medical treatments and describes the steps you can take under state law to help ensure that your personal health care decisions are known and honored if you are unable to speak for yourself.

Preparing a few simple legal forms known as advance directives can help ensure that your wishes are respected and that your health care decisions stay in the hands of people you trust. This guide includes sample advance directive forms with tips on how to use them.

We hope that you find this guide to be helpful.

Sincerely,

A handwritten signature in black ink that reads "Eric Schneiderman". The signature is fluid and cursive, written in a professional style.

Eric T. Schneiderman

You can obtain a copy of the New York State Health Care Proxy Form that appears on the next page at no charge by visiting:

The New York State Attorney General's Health Care Bureau
at

www.ag.ny.gov/bureaus/health_care/pdfs/hc_proxy_form.pdf

or

The New York State Department of Health at

http://www.health.state.ny.us/professionals/patients/health_care_proxy/form.htm

You can obtain a free copy of a Living Will Form in English or Spanish by visiting the New York State Bar Association at:

www.nysba.org/Content/NavigationMenu/PublicResources/LivingWillHealthCareProxyForms/Living_Will_and_Heal.htm



HEALTH CARE PROXY FORM

(1) I, _____
hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) **Optional: Alternate Agent**

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely.

(Optional: If you want this proxy to expire, state the date or conditions here.)

This proxy shall expire (specify date or conditions):

4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary):

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification (please print)

Your Name _____

Your Signature _____ Date _____

Your Address _____

(6) Optional: Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of: (check any that apply)

Any needed organs and/or tissues

The following organs and/or tissues _____

Limitations _____

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) **Statement by Witnesses** (*Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.*)

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date

Date

Name of Witness 1

(print) _____

Name of Witness 2

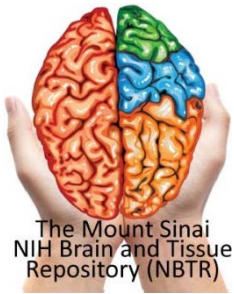
(print) _____

Signature _____

Signature _____

Address _____

Address _____



Dear Postmortem Brain Donation Program Participant,

We would like to thank you for choosing to enroll in our postmortem brain donation program. Your future donation of brain tissue to the *Mount Sinai NIH Brain and Tissue Repository (NBTR)* is a wonderful, altruistic and generous commitment to furthering brain health and understanding brain function.

Your donation contributes to the effort to overcome, through understanding, treating, and ultimately solving, the many diverse brain-associated disorders on which our researchers and others are currently working, including neurological and psychiatric disorders. Research on the brain also advances our knowledge of normal brain function throughout the lifespan. We again want to sincerely thank you for your commitment to donate your brain to the *Mount Sinai / JJ Peters VA Medical Center NIH Brain and Tissue Repository*; you have our enduring appreciation and respect.

V. (Harry) Haroutunian, Ph.D.

Professor of Psychiatry and Neuroscience

Director: Mount Sinai NIH Brain and Tissue Repository (NBTR)