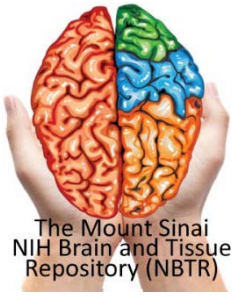


NIH NeuroBioBank
Facilitating Research and Creating Awareness
Brain and Tissue Repository (NBTR)
JJ Peters VA Medical Center
130 West Kingsbridge Road
Room 5F-04D
Bronx, NY 10468
Phone: 718-584-9000 x1848
Fax: 718-741-4746
Email: NBTR@mssm.edu

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.

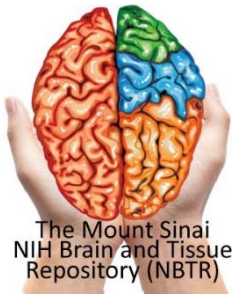
Vahram Haroutunian, Ph.D.
Professor, Departments of Psychiatry and Neuroscience
The Mount Sinai NIH Brain and Tissue Repository

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.



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Email: NBTR@mssm.edu

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:

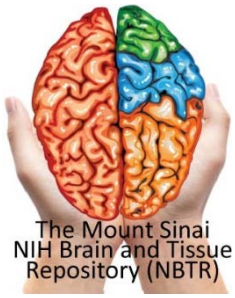
- The Mount Sinai/JJ Peters VA Medical Center NBTR has been in continuous operation since 1982.
- Brain specimens are banked in both flash frozen and formalin fixed form for maximal utilization. In addition to brain, cerebrospinal fluid, muscle tissue, and DNA are banked for most cases.
- Frozen specimens are stored in redundant -80 ^{o}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.



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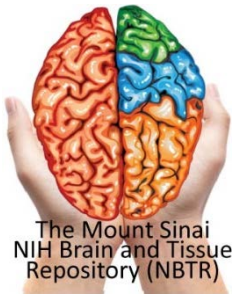
- Our understanding of the order in which neuropathology develops in AD.
- The expression of RNA in different brain regions at different stages of AD and the vulnerability of the brain at different ages and stages of dementia.
- Knowledge of dementia similarities and differences in young-old persons (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.



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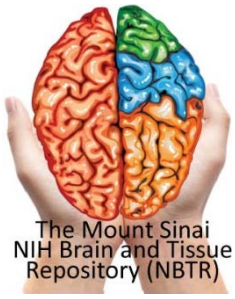
What to do at the time of death and what to expect:

- 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.



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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

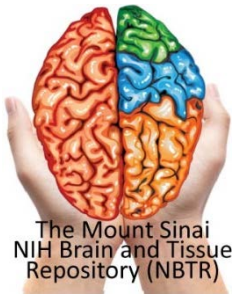
Office: Room 5F-04
James J Peters VA Medical Center
130 West Kingsbridge Road
Bronx, NY 10468

Telephone: 718-584-9000, Extension 6083

Fax: 718-741-4746

24-Hour Autopsy Hotline (Time of Death):

212-807-5541



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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

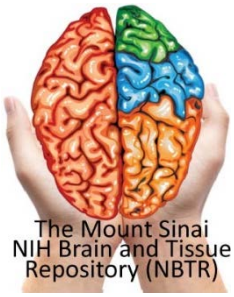
- Brain tissue donation will not affect funeral or burial arrangements that the family may choose. There is no disruption to the participant's appearance and no significant postponement to funeral arrangements.

- 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.



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NIH Brain and Tissue Repository Enrollment Card

*Required

Prefix: _____ (Ms, Mr, Mrs, etc.) *SSN Last 4: _____

*First Name: _____ 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:

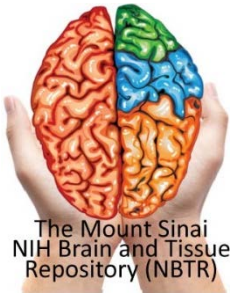
☐ Brain Only ☐ Brain/Spinal cord

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



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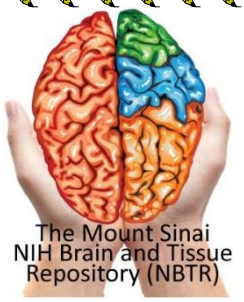
Email: NBTR@mssm.edu

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)



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Facilitating Research and Creating Awareness

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

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 Individua _____
☐4. Parent _____

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

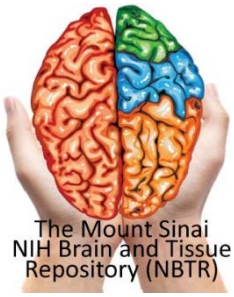
_____
(Name: First, Middle, Last)

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 Individua _____
☐4. Parent _____



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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

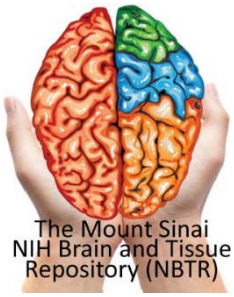
Signature:_____ Date:_____

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.



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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
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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**

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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}

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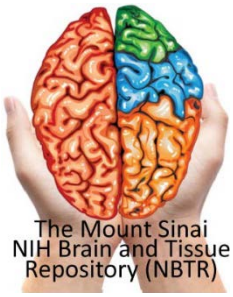

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Email: NBTR@mssm.edu

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:_____

PROXY DIRECTIVE--(Durable Power of Attorney for Health Care)
Designation of Health Care Representative

I understand that as a competent adult, I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decision. In these circumstances, those caring for me will need direction and they will turn to someone who knows my values and health care wishes. By writing this durable power of attorney for health care I appoint a health care representative with the legal authority to make health care decisions on my behalf and to consult with my physician and others. I direct that this document become part of my permanent medical records.

A) CHOOSING A HEALTH CARE REPRESENTATIVE:

I, _____, hereby designate _____,

of _____

_____,

(home address and telephone number of health care representative)

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, my representative is authorized to make decisions in my best interest, based on what is known of my wishes.

This durable power of attorney for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations.

B) ALTERNATE REPRESENTATIVES: If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

2. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

C) SPECIFIC DIRECTIONS: Please initial the statement below which best expresses your wishes.

_____ ☐ My health care representative is authorized to direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, be withheld or withdrawn.

_____ ☐ My health care representative does not have this authority, and I direct that artificially provided fluids and nutrition be provided to preserve my life, to the extent medically appropriate.

(If you have any additional specific instructions concerning your care you may use the space below or attach an additional statement.)

_____

_____

_____

_____

D) COPIES: The original or a copy of this document has been given to my health care representative and to the following:

1. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____
2. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____

E) SIGNATURE: By writing this durable power of attorney for health care, I inform those who may become entrusted with my care of my health care wishes and intend to ease the burdens of decision making which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with my wishes as expressed in this document. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ day of _____, 20

signature _____

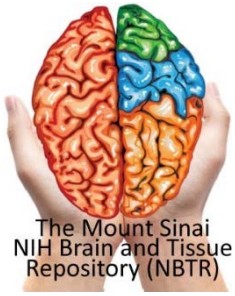
address _____

city _____ *state*_____

F) WITNESSES: I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness*_____
   *address*_____
   *city*_____*state*_____
   signature _____
   date _____

2. *witness*_____
   *address*_____
   *city*_____*state*_____
   signature _____
   date _____



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

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)