The Human Brain and Spinal Fluid Resource Center

Email: brainbnk@ucla.edu
Office: (310) 268-3536
Fax: (310) 268-4768
Pager: (310) 389-5199

VA Greater Los Angeles Healthcare System
West Los Angeles Healthcare Center (127A)
11301 Wilshire Blvd
Los Angeles, CA 90073

RESEARCH DONOR ENROLLMENT PACKET

Thank you for your inquiry into our "Gift-of-Hope" tissue donor program.

I have enclosed our Donor Enrollment forms along with answers to some frequently asked questions. A postage-free, pre-addressed envelope is also enclosed for your convenience.

Your participation in the program generally involves no expense at all to the donor family. Our Donor Coordinator will assist you in arrangements for tissue donation .

Like you, we are strongly dedicated to helping researchers find the answers and ultimately a cure to neurological disorders. We hope and anticipate that your involvement in our "Gift-of-Hope" program will help to make this a reality.

When completed forms are received a donor card will be mailed to you. If donor is in a nursing home a letter with telephone numbers and instructions are mailed to the nursing home. If donor has chosen a mortuary a letter is also sent on how to contact us.

Again, I wish to express our appreciation for your interest. Vital research depends upon the thoughtfulness of people like you. Should you have any questions at all, do not hesitate to call us at (310) 268-3536, email or write to:

Donor Coordinator (127A)
Email: brainbnk@ucla.edu
Human Brain and Spinal Fluid Resource Center
West Los Angeles Healthcare Center
11301 Wilshire Blvd.
Los Angeles, CA. 90073

Help us find the cause and prevention of neurological and psychiatric diseases.

Please share these forms with your Next of Kin so they know of their responsibility to help make this donation happen.

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FREQUENTLY ASKED QUESTIONS ABOUT DONATION TO THE GIFT-OF-HOPE" DONOR PROGRAM

1. **WHAT IS THE PURPOSE OF A BRAIN DONATION?** Brain donation is a valuable gift. One brain provides a basis for studies by numerous researchers throughout the United States as well as other countries. "Animal models" of human mental illness and many neurological disorders simply do not exist. Even with improved clinical research methods such as genetic linkage studies or PET and CAT scans, MRI (NMR) and other imaging techniques, our understanding of the biochemistry and pathology of the brain is best achieved through the use of postmortem human brain tissue.

2. **WHO CAN DONATE?** Any legally competent adult can request to donate their brain to be used for research after their death, just as they can request to donate any other organ. Those who maybe incompetent, or otherwise unable to sign, may provisionally donate through their guardian. However, it is the responsibility of the next of kin/guardian to authorize tissue to be removed for research at the time of death.

3. **ARE THERE ANY RESTRICTIONS** Use of a respirator to aid in breathing maybe allowed but we wish to know this at the time of death. A decision will be made on a case by case basis. As heart, kidney, and liver donors must necessarily be on a respirator at death, we regret that persons wishing to donate those organs cannot donate a brain to our Center. We cannot accept donations from highly contagious or neurological transmissible diseases (i.e. tuberculosis, any hepatitis, Jacob-Creutzfeldt disease).

4. **WHAT ABOUT A BODY DONATION VERSUS A DONATION OF BRAIN AND OTHER ORGANS?** Most medical schools do not accept body donations from persons who have donated any type of tissue. One usually must make a choice between donating their organ(s) versus donating one's entire body to a medical school. Please check with your local medical school for their policy. For donors who also wish to donate corneas, skin, bone when donating one's brain to this Center please check with your local hospital's transplant office for their policy.

5. **WHAT HAPPENS WHEN THE DONOR DIES AND WHAT PROCEDURES MUST BE FOLLOWED AT THE TIME OF DEATH?**
   - A) At the time of death, the next of kin or a member of the donor's medical care team should call our Donor Coordinator. During office hours (310) 268-3536; 24 hour pager (310) 389-5199. In the unlikely event that you do not receive a response when paging, please call the VA switchboard at (310) 478-3711. They will provide additional phone numbers to reach us.
   - B) An after death telephonic informed consent from the Next of Kin **must be obtained** **BEFORE** any tissue maybe removed even if the donor is registered in our Gift of Hope Program.
   - C) It is also important to have the tissue removed as quickly as possible, before embalming or other funeral preparations. We prefer to obtain specimens for research within 6-12 hours after death but special circumstances may cause this window of time to be extended. REMINDER: the next of kin must be available immediately after death in order to provide the telephonic consent for removal of tissues for research.
   - D) It is important that our Donor Coordinator speaks with the person removing the tissue to ensure that our research protocol is followed. It is also important that the Donor Coordinator speak with the funeral home/ mortuary personnel to coordinate this donation.
   - E) We will arrange for the tissue specimen to be sent to our Center.
   - F) After the tissue is removed, the body is released to the family for the arranged funeral services.

6. **MUST THE DONOR BE TRANSPORTED TO OUR FACILITY?** No. The tissue is removed at a facility close to the place of the donor's death. Only the brain and other authorized tissue are sent to our Center.

7. **WHO IS RESPONSIBLE FOR ARRANGING FOR TISSUE REMOVAL?** At the time of death the Resource Center's Donor Coordinator will contact a trained person who will remove the tissue for research purposes. Donor/family member may help us prior to death by contacting local hospitals in their area to obtain names of pathologists for the Donor Coordinator to contact.

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FREQUENTLY ASKED QUESTIONS con't

8. **AT WHAT LOCATION WILL THE TISSUE BE REMOVED?** In our recent experience the majority of donors are passing away in a home hospice program or a nursing care facility. Therefore, the limited tissue removal will be carried out at the funeral home/mortuary the family has chosen.
Even if the donor dies in a hospital, the tissue removal may still take place in the funeral home/mortuary as some of the smaller hospitals do not have autopsy facilities. This situation is dealt with on an individual basis.
If the family has chosen a cremation service it is possible that the crematorium may not have the facility to let us remove the tissue. This situation is dealt with on an individual basis.

9. **WHAT DOES THE FUNERAL HOME/MORTUARY HAVE TO KNOW AND DO?** We suggest the issue of donating tissue for research be discussed by the donor/next of kin with the chosen mortuary at the time of the decision to use them. Once we are notified of a mortuary that the family has chosen we will send them a letter to be placed in their files on how to contact us at the time of death so the donation can take place expeditiously.

10. **WHAT HAPPENS TO THE BODY IN THE AUTOPSY SUITE/MORTUARY?** After the brain and other tissue have been removed, the body is released to the funeral director for whatever arrangements the family has made. An open casket or other traditional funeral arrangements is possible. The exact funeral and burial details, however, remain the responsibility of the donor's survivors or estate.

11. **IS THERE ANY COST?** The Center pays for the tissue removal, transportation of specimen to us and if necessary use of facility where tissue is removed. Funeral arrangements and expenses remain the responsibility of the donor and family.

12. **HOW CAN DONOR'S SURVIVORS DETERMINE WHO IS NEXT-OF-KIN?** The hierarchy of legal relationships is fairly consistent from state to state. Generally, all legal guardianships, powers of attorney, and other court-appointed relationships end at death. The surviving legal next-of-kin is the first to fulfill one of the following requirements:
    (1) Spouse (unless divorced or legally separated)
    (2) Adult child (if more than one, all must agree)
    (3) Parent
    (4) Sibling (if more than one, all must agree)
    (5) Other relative (niece, nephew, grandchild, etc)
    (6) Executor or Administrator (if already appointed)

13. **WHAT NEEDS TO HAPPEN?**
When you enroll in our Gift of Hope program we will request you to provide us with your medical history. This helps us maintain comprehensive information for later correlation with research studies conducted by scientists.
Next of kin is contacted by the Coordinator after donor's death to express condolences as well as gratitude for the donation. Even though the next of kin has given a telephonic informed consent to remove tissue after death for research, we are required to obtain and keep on file an original signed informed consent. At this time, we also send authorization for release of donor's medical records for their signature and return to us. As with all information, these records are kept strictly confidential.

14. **HOW DO I BECOME A DONOR?** Simply let us know of your wish to become one by COMPLETING THE ENCLOSED FORMS AND RETURNING THEM TO US. Your consent to donate is only useful if your next of kin knows of your desire to make this donation as they must be willing and available to give telephonic consent at the time of death. Donor should also discuss this with **all** family members so there is no confusion of the desire to donate.

PLEASE PRINT OR TYPE ALL FORMS

Please feel free to write, call or email us about any other questions you may have.

REMINDER: Even if you are a register donor in our Gift of Hope Program, your next of kin must be willing and available to give telephonic informed consent at the time of death to make this donation happen.

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"GIFT-OF-HOPE" DONOR ENROLLMENT APPLICATION

Date: _____

Person completing form: ○ **Donor** ○ **Next of kin/family member for donor**

If donor completing form and your next of kin does not live with you may we contact them to give them information on what they need to make this donation happen? ○ Yes ○ No

Name of Donor: _____ Date:_____

Donor's Home Address: _____ (*see below)

City, State: _____ Zip Code _____

Home telephone: _____ Cell Phone: _____

Office phone: _____ Email: _____

Current age: _____ Date of Birth: _____ Sex: [_] Social Security # _____

Next of Kin's Name: _____ Relationship: _____

Next of Kin's Home Address: _____

City, State: _____ Zip Code: _____

Home telephone: _____ Cell Phone: _____

Office phone: _____ Email: _____

***If DONOR lives in a Nursing/Assisted Living Facility**	***If DONOR is on a Hospice Program**
Date of admission to facility: _____	Date of admission to Program: _____
Name of Nursing/Assisted Living Home: _____	Name Hospice: _____
Address: _____	Address: _____
City, State: _____	City, State: _____
Zip Code: _____	Zip Code: _____
Telephone: _____	Telephone: _____
Contact person:_____	Contact person/casemanager:_____

ALL of Donor's Diagnoses	Age symptoms first appeared	Age at diagnosis	Is there other family members with same disease ? Yes/No	Relationship of family member with same disease to donor

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Does donor have children? ◯ Yes ◯ No If yes, how many: _____

Are all children in agreement with this postmortem donation to research? Yes No

May we have the contact information for the eldest child as an alternate contact if they are NOT already listed as Next of Kin. ◯ Yes ◯ No

Donor's Eldest Child's Name: _____

Home Address: _____

City, State: _____ Zip Code: _____

Home Phone: _____ Cell Phone: _____

Office Phone: _____ Email: _____

Is Donor a Veteran? ◯ Yes ◯ No If yes, branch of service _____, dates of service from____ to ____

Any overseas locations?_____

How did you hear about our Gift of Hope Program? _____

Handedness: ◯ Right Handed ◯ Left Handed ◯ Ambidextrous:

Race:_____(Caucasian, Asian, Hispanic African/American, etc)

Ethnicity (English/German, etc):
Mother's side: _____ Father's side: _____

Current Height: _____ ft _____ inches Current weight: _____ lbs.

Has donor ever been diagnosed with tuberculosis?
◯ Yes ◯ No If yes, when [age/year]? _____ / _____

Treatment given	Current status	Residual

Has the donor, or any blood relatives ever been diagnosed. or told they had, Creutzfeldt-Jakob disease?
◯ Yes ◯ No If yes, age/when _____

Has the donor ever been diagnosed or suspected to have any infectious communicable disease such as
◯ Yes ◯ No If yes, when [age/year]? _____ / _____

Viral hepatitis B	Treatment Given	Current status	Residual
Viral hepatitis C			
HIV/AIDS			
Syphilis			
Other (specify):			

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Has the donor had chronic pain disorders/symptoms? ○ Yes ○ No
[For example but not limited to: low back pain, headaches, and neuropathy]

Dates	Disorder/symptoms	Treatment(s)

Has donor participated in any clinical trial(s)? If yes, give the following information:

	Date(s)	Name of Trial	Location of Trial	Dr. in Charge
1				
2				

	Name of medication	**Amount taken**
1		
2		

MEDICATIONS: Taken on a regular basis

Name	Dosage	Dates	Name	Dosage	Dates

Note: Continue medications lists on the last page if necessary.

Physician who made the neurological diagnosis:

Name: _____ Phone: _____

Address: _____ City, State, Zip: _____

What symptoms have you had in the past and what are current symptoms related to your neurological disease.	Age	Year

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Was head and spinal cord MRI part of your diagnostic workup? ○ Yes ○ No

Where	Age	Year	Results or who might we contact for results

Have you had any head or spinal cord MRI since? ○ Yes ○ No

Where	Age	Year	Results or who might we contact for results

Disability Level: ☐ Check here if not applicable

Started to use	Age	Year	Comments
Cane			
Walker			
Wheelchair			
Unable to walk			
Bed ridden			

EDUCATION:	Yes	No		
High school Diploma	○	○		
Attended College but did not complete	○	○	No. of Years:	
			Name of Degree	Field of Study
Associate College Degree	○	○		
Post Graduate College Degree	○	○		
Certificate of training	○	○		

PAST MEDICAL HISTORY:

Childhood Diseases: ☐ measles ☐ mumps ☐ chicken pox ☐ Other (specify): _____

_____

OCCUPATION:

At Enrollment: _____ If retired, what was your occupation?

_____

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SMOKING HISTORY

Status: ☐ Never smoked ☐ Occasional use ☐ Previous Use ☐ Current Use ☐ Unknown

Type: ☐ Cigarette ☐ Pipe ☐ Cigar ☐ Other

Age Started:_____ Smokes /day (Number):____ Years Smoked (number):_____ Age Stopped:_____

ALCOHOL CONSUMPTION:

Status: ☐ Never drank ☐ Occasional use ☐ Previous Use ☐ Current Use ☐ Unknown

Type: ☐ Beer ☐ Wine ☐ Liquor (type): _____

Age Started:_____ Drinks/day (Number)_____ Years Drank (number):_____ Age Stopped:_____

Was drinking excessive in last 5 yrs.? ◯ Yes ◯ No

DRUG ABUSE:

Were recreational drugs used in last 5 yrs.? ◯ Yes ◯ No

Status: ☐ Never used ☐ Occasional use ☐ Previous Use ☐ Current Use ☐ Unknown

Drug type: ☐ Cannabis ☐ Opium ☐ Coca Derivative ☐ Synthetic Compound ☐ Other

Age Started:_____ Years drugs used:_____ Age Stopped:_____

DID DONOR EVER HAVE CHEMO or RADIATION THERAPY? Yes ◯ No ◯ Not applicable ◯

Age Started_____ Age Stopped:_____ What type of therapy? _____

ADDITIONAL COMMENTS:

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PLEASE PROVIDE NAME/ADDRESS FOR DOCTORS YOU MAY SEE OR HAVE SEEN AND ANY FACILITIES WHERE YOU HAVE BEEN TREATED

Current Neurologist:

____
Medical Group Name:

Doctor Name: ______________________

Dates seen: From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

Current Primary Care Doctor

____
Medical Group Name:

Doctor Name: ______________________

Dates seen: From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

TYPE OF DOCTOR______________________

____
Medical Group Name:

Doctor Name: ______________________

Dates seen From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

TYPE OF DOCTOR______________________

____
Medical Group Name:

Doctor Name: ______________________

Dates seen From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

TYPE OF DOCTOR______________________

____
Medical Group Name:

Doctor Name: ______________________

Dates seen From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

TYPE OF DOCTOR______________________

____
Medical Group Name:

Doctor Name: ______________________

Dates seen From ________ to __________

____
Address

____
City, State Zip code

Telephone : ________________

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TYPE OF DOCTOR_____

_____
Medical Group Name:

Doctor Name: _____

Dates seen From _____ to _____

_____
Address

_____
City, State Zip code

Telephone: _____

Hospitals/Medical Centers where treated:

Dates seen From _____ to _____

_____
Name

_____
Address

_____
City, State Zip Code

Telephone: _____

Hospitals/Medical Centers where treated:

Dates seen From _____ to _____

_____
Name

_____
Address

_____
City, State Zip Code

Telephone: _____

TYPE OF DOCTOR_____

_____
Medical Group Name:

Doctor Name: _____

Dates seen From _____ to _____

_____
Address

_____
City, State Zip code

Telephone: _____

Hospitals/Medical Centers where treated:

Dates seen From _____ to _____

_____
Name

_____
Address

_____
City, State Zip Code

Telephone: _____

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Dates seen From _____ to _____

_____
Name

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Address

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AT WHAT LOCATION WILL THE TISSUE BE REMOVED?

Immediately following a death, the removal of tissue for research purposes will be carried out at an autopsy facility, funeral home/mortuary, or hospital in the local area.

Even when a donor dies in a hospital, the tissue removal may still take place at another location, as some hospitals do not have autopsy facilities. If the family has chosen a cremation service it is possible that they may not have the facility to allow removal of the tissue. This situation is dealt with on an individual basis. We have a 6-8 hour window of time for removal of tissue for research purposes.

Donor Name: _____

If you have chosen a mortuary please indicate:

Mortuary Name _____

Contact person _____

Address _____

_____

Zip code: _____

Telephone #: _____

Fax # _____

Please indicate to the mortuary/funeral home/cremation service your desire to have tissue removed for research purposes

Is the body to be cremated? ○ Yes ○ No

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This form is **NOT the OFFICIAL** authorization for collection of postmortem tissue.

Instead it is to be used as a guideline when upon death the next of kin and/or legal representative is contacted. The next-of-kin will be contacted at the time of death and be asked to sign the official consent form.

_____
Name of Donor

For the purpose of scientific research and in the hope of furthering medical knowledge the above donor is requesting their next of kin and/or legal representative to sign the official OFFICIAL Consent for Collection, Retention and Distribution of Tissue for Research.

The Next of Kin will be asked to indicate authorization for collection, retention, and distribution for the purposes of researching the causes of many different psychiatric and neurological diseases

	YES	NO
*Brain	○	○
*Blood	○	○
*Cerebrospinal Fluid (the fluid surrounding the brain)	○	○
*Spinal Cord	○	○
Eyes	○	○
*Trigeminal Ganglia (a nerve around the base of the skull)	○	○
Sciatic Nerve (a nerve that runs from around the kidney to the middle of the thigh)	○	○
Dura Matter (outer layer of tissue surrounding the brain)	○	○
Hair	○	○
Temporal Bones(Inner ears)	○	○
Testes	○	○

*indicates the most frequently requested tissue from scientists

	YES	NO
*Pituitary (a gland located at the base of the skull)	○	○
*Thymus (a gland located around the neck)	○	○
*Lymph Nodes (located at the base of the neck or the armpit. Function to collect waste products)	○	○
Spleen (an organ that lies in the upper part of the abdominal cavity on the left side.	○	○
Heart	○	○
Liver	○	○
Lungs	○	○
Skin	○	○
Urine	○	○
Pancreas	○	○

Do you wish to receive a copy of the neuropathology report (microscopic examination of the tissue that confirms/negates clinical diagnosis)? ○ Yes ○ No

It is further directed that upon the donor's death, their medical histories be released to the Bank to provide information critical for scientific studies.

Expected person to sign: _____ Date _____
Next of Kin

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PLEASE GIVE THIS COPY TO YOUR NEXT OF KIN

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Spleen (an organ that lies in the upper part of the abdominal cavity on the left side.	○	○
Heart	○	○
Liver	○	○
Lungs	○	○
Skin	○	○
Urine	○	○
Pancreas	○	○

Do you wish to receive a copy of the neuropathology report (microscopic examination of the tissue that confirms/negates clinical diagnosis)? ○Yes ○ No

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Submit by Email