



# VA Biorepository Brain Bank

Brain Donation: A Precious Gift to Consider

Department of Veterans Affairs

For more information, contact 866-460-1158 | [www.research.va.gov/programs/tissue\\_banking/controls](http://www.research.va.gov/programs/tissue_banking/controls)



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## The Department of Veterans Affairs Biorepository Brain Bank

The VA Biorepository Brain Bank (VABBB) is a human tissue bank that collects, processes, stores and gives out research specimens for future scientific studies. The VABBB provides tissue and health information to scientists studying conditions affecting Veterans such as amyotrophic lateral sclerosis (ALS; Lou Gehrig’s disease) and Gulf War Illness. Scientists studying these disorders must compare brain tissue donated by people affected by brain disorders with tissue from people who ARE NOT affected by these disorders to understand the causes of these disorders. This is why obtaining brain tissue from those WITHOUT brain disorders is critical to research about these disorders. Yet, most brain banks, including the VABBB, have critical shortages of tissue from those without brain disorders (otherwise known as “control tissue”).

### Any Veteran living in the United States may enroll in the VABBB.



We hope that those without brain disorders might consider brain donation to support research on brain disorders affecting Veterans. Your VA benefits and your VA health care cannot be influenced in any way by your agreement or refusal to participate. If you think that you might consider making this generous after-death tissue donation, the rest of this brochure will explain what is involved for you and your family.



## A Living Study

It is never too soon to enroll in the VABBB. The health information that you provide now, while living, will support research now, and upon your death make your tissue donation even more valuable to future research. However, pre-enrollment is not required. Consent can be given by your next-of-kin immediately following death. We encourage interested individuals to talk with their families and friends about their intentions to be a brain donor. Talking about these issues now helps to reduce stress on your family at the time of your death.

## What can I expect if I take part in this study?

If you decide to join this study, we will ask you to read and sign a consent form. We will also need consent from your next-of-kin (e.g., spouse, child, sibling), who will need to confirm your decision to donate after your passing.



The study will collect information about your health by:

- Mailing you a survey about your health and experiences.
- Contacting you 1-2 times per year, to update your information. This contact and the survey will each take about 30 minutes.
- Collecting information from your VA medical record (if you have one). This will not require any of your time.

To protect your privacy, all of your information that we collect will be labeled with a code that does not identify you directly.

## The donation process

No body tissue collection or surgery is required at this time. At the time of your death, your family or someone they designate must call the on-call study researcher. After we receive the permission



from your next-of-kin to proceed, we will make arrangements for the donation.

- The procedure will be done professionally and with dignity at the closest VA Medical Center or at another facility if needed.
- After-death tissue donation will not cost you or your family anything, but the study does not pay for your regular funeral expenses.
- An open casket viewing is possible after donation.
- If your next-of-kin requests it, a copy of the pathology report will be provided when it becomes available.
- **Your decision to donate can be changed at any time.**

### **What are the potential benefits of taking part?**

Your donation may help future efforts in neurological research. However, your taking part in this study will not benefit you directly.



Thank you for thinking about this important issue. Brain donation is usually not considered by those without brain disorders because of the belief that only tissue from those with disorders are eligible. We hope that this brochure has presented information about the critical need for brain donations by those without brain disorders.

Additional information is provided in the **Frequently Asked Questions** section of this brochure. We are always happy to answer any questions you or your family may have. During working hours, we can be reached at our **toll-free office number: 866-460-1158**, or at our office numbers: 857-364-6748 and 857-364-3877.

## **Frequently Asked Questions (FAQs):**

### ***Will my family bear any financial burden if I decide to become an after-death organ donor?***

No, we are responsible for all costs related to your organ donation as well as transportation of your body to and from the site where the donation is recovered. However, we cannot assume the usual costs of the funeral, burial or cremation.

### ***I am in favor of contributing to medical research, but I'm not sure of my religion's position on organ donations. What should I do?***

Most religions support brain and other organ donations. If this is of concern to you, you should consult with your religious leader.

### ***How soon after death must the organs be recovered, and where will this be done?***

The organs you would donate cannot be used for transplantation; therefore the time for their recovery can be slightly longer. We expect to recover the donated organs within 24 hours, although under certain circumstances, the time frame can be extended somewhat. The recovery of the donated organs will take place at the closest VA hospital that is equipped and experienced in performing the procedure or by medical professionals at another facility if the VA facility is unable to perform this in a timely manner.

### ***My family feels strongly about a wake with an open casket viewing. With an organ donation, will this still be possible?***

Yes, the donated organs will be recovered in a manner that will not interfere with an open casket viewing.



### ***What happens to the donated tissue?***

Donated tissue is sent to a VA-approved storage facility for scientific study and storage. Researchers from around the country may request tissue samples to conduct approved ALS research. Requests from researchers are reviewed by a committee of established scientists and approved if the request is scientifically sound.

### ***How will the information that you collect from me be protected?***

All your information that we collect will be labeled with a code that does not identify you directly. Information collected by the VABBB will be kept confidential as required by law. The results of this study may be published for scientific purposes, but your records or identity will not be revealed unless required by law. The VABBB complies with the requirements of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its privacy regulations and all other applicable laws that protect your privacy.

### ***I am listed as an organ donor on my driver's license. Does this automatically make me eligible for brain donation?***

Being an organ donor via your license is a very generous and life-saving donation to the many people waiting for an organ transplant. However, this does not automatically notify brain banks of your intention to donate your brain. A person intending to make a brain donation must sign up with a brain bank such as the VABBB before death. In cases where a person had wished to be a brain donor but was unable to sign up before death, family members may contact the brain bank to approve the donation as long as it is done immediately after death.



## *Who should I talk to about donating?*

Talking with your family and your VA doctor about these issues now helps to reduce stress on your family at the time of your death. It is important that your family and doctor know your wishes in the event you become unable to make your own health care decisions. Please know that you or your family may change the decision about donating at any time. You can also call us at **1-866-460-1158** during office hours and we will be happy to talk with you or you may leave us a message and we'll return your call.

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