



VA Biorepository Brain Bank Brain Donation to Support Research on ALS and Related Disorders

For more information, contact 866-460-1158 | www.research.va.gov/programs/tissue_banking/ALS



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The Department of Veterans Affairs (VA) 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. Presently, the VABBB is obtaining neurologic tissue specimens from Veterans who suffer from amyotrophic lateral sclerosis (ALS).

ALS is a neurologic disease affecting the central nervous system, specifically the brain and spinal cord. At this time, neither the cause nor prevention of ALS is known. Medical researchers are examining environmental, toxic, genetic, traumatic, medical, and occupational influences as possible contributors to the development and progression of ALS. Veterans have a higher risk of developing ALS compared with non-Veterans; however, the reasons for this higher risk are currently unknown.

VA has made a major commitment to broadening knowledge of this destructive disease. As part of this commitment, VA funded the VABBB. We are enrolling Veterans who have ALS or its related forms, such as primary lateral sclerosis (PLS), progressive bulbar palsy (PBP), and progressive muscular atrophy (PMA), who may be interested in making an after-death tissue donation to support scientific investigations. Veterans without ALS or other neurological diseases are also eligible to participate in the VABBB, because it is important to also study Veterans without neurological disease in order to learn more about the causes of ALS. Participation in this research involves nothing during your lifetime other than a single, small blood sample, permission to review your VA medical records, and occasional telephone calls from our staff to see how you are doing. The neurologic tissue that you donate, consisting of your brain, cerebrospinal fluid (CSF) and spinal cord, would be collected after your death.



We hope that you might consider such a significant donation, but you are under no obligation to do so. 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.

Who can take part in this study?

Any Veteran with ALS, ALS-related conditions, and those without neurological disease in the United States may enroll in the VABBB. If you are interested in participating, you will be asked to read and sign some consent forms. In addition to your consent, we will also need the consent of your next-of-kin (e.g., spouse, child, sibling) because this person will need to confirm your decision to donate after your passing. Even after signing the consent forms, you still have the right to withdraw at any time if you so desire.

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

We will ask you to complete a survey about your health history. We will update this information every six months to a year by telephone or by mail. The telephone call and questionnaire should each require around 15 minutes to complete. You will be asked if you would like to provide an optional small blood sample (approximately 20 ml or 2 tablespoons). If you agree to provide this blood sample, we would make the arrangements to collect your sample. We will also look at your VA medical record (if you have one) to collect information about your health from time to time and add that information to the VABBB database so that we can follow your health and care over time. All of your information that we collect will be labeled with a code that does not identify you directly.



The body tissue that you donate will be collected at the time of your death and will not require any surgery or collection procedures at this time. Upon 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 would make arrangements for the tissue donation. The procedure will be done professionally and with dignity at the closest VA Medical Center or by medical professionals at another facility if the VA facility is unable to perform this in a timely manner. If your next of kin requests it, a copy of the pathology report will be provided when it becomes available.

What are the potential benefits of taking part?

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

Thank you for thinking about this important issue. Additional information is provided in the **Frequently Asked Questions** section of this brochure and on the VABBB website. 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.



The VABBB is supported by funding from the Research and Development Service of the Department of Veterans Affairs.



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.

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.



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.

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.

