



VA Biorepository Brain Bank

National Posttraumatic Stress Disorder Brain Bank

Department of Veterans Affairs

For more information, contact 800-762-6609 | www.research.va.gov/programs/tissue_banking/PTSD/default.cfm

VA Boston Healthcare System IRB
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The Department of Veterans Affairs (VA) Biorepository Brain Bank
National Posttraumatic Stress Disorder Brain Bank

The VA Biorepository Brain Bank (VABBB) National Posttraumatic Stress Disorder Brain Bank (PTSD Brain Bank) is a human tissue bank that collects, processes, stores, and gives out research specimens for future scientific studies. Presently, the PTSD Brain Bank is obtaining neurologic tissue specimens from Veterans and non-Veterans who have been diagnosed with PTSD or MDD presently or in the past. We also accept donations from those without PTSD or MDD. PTSD can occur after experiencing a traumatic event. A traumatic event is something terrible and scary that you see, hear about, or that happens to you, like:

- Combat exposure
- Child sexual or physical abuse
- Terrorist attack
- Sexual or physical assault
- Serious accidents, like a car wreck
- Natural disasters, like a fire, tornado, hurricane, flood, or earthquake

During a traumatic event, you think that your life or others' lives are in danger. You may feel afraid or feel that you have no control over what is happening around you. Most people have some stress-related reactions after a traumatic event; but, not everyone gets PTSD. If your reactions don't go away over time and they disrupt your life, you may have PTSD.

MDD is a mood disorder that causes persistent feelings of sadness and loss of interest. You may experience irritability, sleep disturbances, and physical problems associated with MDD. These symptoms can affect day-to-day activities and may require professional treatment.

VA has made a major commitment to understanding and treating PTSD and MDD. As part of this commitment, VA funded the PTSD Brain Bank. We are enrolling Veterans and non-Veterans who have been diagnosed with PTSD or MDD presently or in the past.

We also accept donations from those without PTSD or MDD who may be interested in making an after-death tissue donation to support scientific investigations.

Participation in this research involves filling out surveys by telephone, mail or on a secure Internet web site. These surveys will ask for things like your name, birthdate, sex, education level, and race or ethnic group, as well as details of your military service. Some questions will ask whether you have been exposed to chemicals at home, work, or when you were in the military. Other questions will ask about your mental health history, including whether you are currently experiencing PTSD or MDD symptoms or if you have experienced these symptoms in the past. You will be asked to complete a brief test of memory and concentration. We will also ask about the physical and mental health history of you and your family. We will also ask for permission to review your VA (if you have one) or other medical records. The neurologic tissue that you donate, consisting of your brain 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 person who would like to donate tissue after death may take part in the PTSD Brain Bank. 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 surveys about your current and past health history. We will update this information every year by telephone or by mail. The telephone call and surveys should require around 2 hours to complete. 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 PTSD Brain Bank database so that we can follow your health and care over time. This will not require any of your time. All 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, 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 PTSD research and treatment. 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. 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 number: 800-762-6609**, or at our office number: 857-364-4198, or use QR code on last page to fill out Permission to Contact Form.

Frequently Asked Questions (FAQs)

Why enroll now? I plan to live for a long time.

The health information that you provide now, while living, will support research now, and upon your death make your tissue donation much more valuable to future research.

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 hope to recover the donated tissue within 24 hours, although the time frame may be longer in some circumstances. The organs will be recovered by medical professionals at the closest equipped VA hospital, or other facility if the VA is unavailable.

What if I already have my decision to donate written in my will?

By the time your will is read, it will be too late to recover your organ donation. Enrolling now and telling your family that you want to donate is the best way to ensure that your wishes are carried out.

Will my family have to pay anything if I decide to donate?

No, we pay for all costs related to your tissue donation, as well as transportation of your body to and from the site where the procedure is done. However, we cannot pay for the usual costs of the funeral, burial, or cremation.

After tissue donation, is an open casket viewing still possible?

VA clinicians will attempt to recover donated tissue in a respectful manner that will not interfere with an open casket viewing.

What happens to the donated tissue?

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

I don't know my religion's position on organ donation. What can I do?

Most religions support organ donation as a charitable act of giving. If this is a concern, you should consult your religious leader.

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 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 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?

It is important that your family and doctor know your wishes. 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. You or your family may change the decision about donating at any time. If you have more questions, or would like to enroll, please call us at our **toll-free number: (800)762-6609**, or use QR code to fill out **Permission to Contact Form**.



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