



Gulf War Veterans' Illnesses Biorepository Brain Bank

Department of Veterans Affairs

For more information, contact 855-561-7827 | www.research.va.gov/programs/tissue_banking/GWVIB



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About 697,000 men and women served in the 1990-1991 Gulf War. Since returning from the Gulf, nearly 250,000 Veterans have had on-going, medically unexplained health problems.

These problems include symptoms like tiredness, headaches, joint pain, indigestion, breathing disorders, and trouble with sleep and memory. As a group, these illnesses are called Gulf War Veterans' Illnesses (GWVI). We still do not know the exact cause of GWVI. Researchers are studying if exposures to various hazards in the environment during Gulf War service are related to these illnesses.

The **Gulf War Veterans' Illnesses Biorepository (GWVIB) Brain Bank** is seeking Veterans of the 1990-91 Gulf War who would like to participate in research about conditions affecting Gulf War Veterans. Veterans enrolled in the GWVIB complete surveys about their health every six months or so, and upon their death donate their brain and other body tissue for future Gulf War Veterans' Illnesses research. **Veterans can begin helping now by enrolling today, even though the tissue donation may occur many years from now.** This will allow researchers to learn as much as possible about the health of an enrolled Veteran and how it may change over the years. Knowing about the health history of our donors makes the donated tissue even more valuable for Gulf War Veterans' Illnesses research. The GWVIB is open to **all** Veterans of the 1990-91 Gulf War era.

A biorepository is a human tissue bank that collects and stores donated tissue samples for future research studies. The tissue donated to the GWVIB will be used for research into the causes, progression, and treatment of Gulf War Veterans' Illnesses. This is the first national biorepository for Gulf War Veterans, so we do not know how many Veterans will take part. This study will find out how to best set up a Gulf War Veterans biorepository, and if there are enough interested Veterans who will volunteer to donate.

Potential benefits to taking part

Taking part in the GWVIB will not benefit you directly, but your donation may help future GWVI research. We hope that you think about joining the GWVIB, but you have no duty to do so. Choosing to



join or not to join this study cannot change your VA benefits or your VA health care in any way. If you are thinking about joining the GWVIB, the following information will explain what is involved for you and your family.

What you can expect if you take part

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 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, 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.**

Thank you for thinking about this important issue. The answers to some *frequently asked questions* can be found on the next page. 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: (855)561-7827.**



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.

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 tissue. Enrolling now and telling your family that you want to donate is the best way to ensure that your wishes are carried out.

How soon after death must the tissue be recovered?

We hope to recover the donated tissue within 24 hours, although the time frame may be longer in some circumstances.

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?

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

What happens to donated tissue?

Donated tissue is processed for storage and analysis at the VA storage facility. Researchers from around the country may request tissue samples to conduct approved research. Tissue requests are reviewed by an established review process approved by the VA Central Office (VACO) in Washington, D.C.

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.

Who should I talk to about donating?

It is important that your family and doctor know your wishes. 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: (855)561-7827***

