



The West Virginia University Tissue Bank for Neurological Diseases and their collaborators are trying to learn more about the causes of diseases affecting our brains and nerves. Much of this research needs to be done on human brain, spinal cord, nerve and related tissues. This paper will give you information about the use of human tissues in research and what it means if researchers use the tissue from your family member.

Why is human tissue research important?

If researchers can use human tissues, they can better understand causes of diseases and evaluate potential treatments. Brain tissue obtained at autopsy is a valuable resource to answer such questions.

You and your family's care is always our first priority.

Choosing to donate tissue will not affect their viewing at a funeral and choosing not to participate will not change the care your family will receive in any way at WVUMedicine.

Who can donate tissue and where will the tissue be kept?

Anyone with or without a neurologic condition can give their or a family member's tissue. Your doctor may ask you to donate whether or not your family member was in good health. If you donate their tissue, it will be stored in the WVU Tissue Bank for Neurological Diseases until a researcher asks for a sample to learn more about a particular disease. When tissue is given to a researcher, the Tissue Bank will do its best to see that results cannot be traced back to them or your family. Usually, no information that identifies/names them will be given to a researcher. In some cases, limited information about who your family member is may be given to a researcher so that they can better correlate their results with their medical records.

What type of research will be done with their tissue?

Many different kinds of studies may be done on human tissue including genetic studies. Some researchers may use the tissue to develop new ways to treat or cure diseases or to develop new products, such as drugs and tests for diseases.

Who will do research on the donated tissue?

WVU researchers, researchers at other universities nationally and internationally, and biotechnology companies.

Will you find out the results of the research?

Neither you, your family nor your doctor will receive information about the research done with their tissue; therefore, the results will not appear in their medical records. Results from research using their tissue may not be completed for several years; thus, the results of the research will not immediately help someone but may help people like them in the future. A non-medical summary of tissue findings used to classify their tissues in the Tissue Bank will be available upon request.

Will anyone have access to their medical records?

In order to understand the research test results, researchers may need to know some things about them; for example, their gender, age, health history, family history and treatments. Basic information will be collected at the time of tissue banking. The basic non-identifying information will be given to the researchers by the Tissue Bank staff. Except in special circumstances, researchers will not have access to their medical records.

Will your privacy be protected?

Their and your privacy will be protected. The people in charge of the Tissue Bank will take careful steps to protect any private information about them. Whenever possible, any identifying personal information will be taken off any records associated with their tissue before it is studied and replaced with the code number assigned to their tissue. This will help prevent any research results from being associated with them or your family.

Are there any risks to you for donating their tissue?

There are no medical risks to them or your family. Because the study results will not be entered into their medical record, there should be no risk to your family that your insurance will be affected. As part of this study, no one will be looking at your or other family member's medical records.

Are there any financial considerations?

There will be no costs to you if you agree to donate your family member's tissue for research. Nor will you receive any money for donating their tissue.

Will you benefit from this research?

There will be no direct medical or personal benefit to you as a result of donating their tissues. However, the researchers hope to learn from this research and be able to help others in the future.

Department of Pathology, Anatomy and Laboratory Medicine

2187 Health Sciences North
PO Box 9203
Morgantown, WV 26506-9203

Phone: 304-293-3212
Fax: 304-293-1627

Equal Opportunity/Affirmative Institution