

FAQS About Tissue Donation through the STOP SUDEP Research Program

1. Does the donor family incur any expense for the donation?

There is no financial cost to the family for donation to research. The donor family is responsible for regular funeral/mortuary or cremation expenses, or an official autopsy if requested to determine cause of death.

2. Will the body be suitable for viewing and/or available for a timely funeral after donation?

Yes. A traditional, open-casket funeral service can still take place, even though tissue has been donated. Highly skilled professionals perform the recovery procedures, and the appearance of the donor is unchanged.

3. How is tissue recovered?

As soon as death occurs or is imminent, someone should contact Dr. Alica Goldman at STOPSUDEP@bcm.edu. In the event of death, Dr. Goldman will work with your family members, funeral director, hospital or nursing home staff to arrange for the transfer of the body, if applicable, and the tissue recovery at an appropriate location.

4. What tissue is recovered?

Any amount and type of tissues is of value. Whole brain donation is invaluable to Dr. Goldman's research on mechanisms of Dravet syndrome and epilepsy related death, but Dr. Goldman is also banking smaller samples of brain tissue and/or blood. Any contribution is much appreciated by researchers in their quest to better understand, treat and hopefully prevent or cure Dravet syndrome and related epilepsies.

5. How much time does the contact have to notify the scientist at Dr. Goldman?

Naturally, it is very helpful to receive notification as soon as possible. Medical research involves study of living cells and tissues, which have a limited viability after death. However, you can contact STOPSUDEP@bcm.edu at any time, either before or after death.

6. Is the body transported to Baylor College of Medicine?

No. Recovery of tissues and organs is performed at your local hospital, funeral home, or other designated institute. The necessary arrangements to transport the recovered tissue will be made by Dr. Goldman and her staff.

7. What happens to the tissue that is donated?

The tissue will be stored in the tissue bank housed and closely supervised at Baylor College of Medicine. Whole brain donations are housed at Harvard Brain Bank in collaboration with Dr. Hanna Kinney, a highly regarded pathologist and scientist in the area of sudden death. A panel of researchers is carefully scrutinizing use of tissue samples for specific investigations of epilepsy and epilepsy-related mortality. The identity of the donor is protected according to the ethical standards of the Baylor and Harvard institutional Review Boards and is not disclosed to researchers other than Dr. Goldman and her staff.

8. For what types of studies will the donated tissue be used?

The study for which tissue will be provided is a NIH-funded study on genetic analysis of Sudden Unexplained Death in Epilepsy (SUDEP) and NIH funded multicenter US-based collaborative

projects of the SUDEP Research Consortium. All of these investigations seek to gain a better understanding of the mechanisms of SUDEP in order to establish effective prevention or intervention. As new research projects develop, tissue will also be made available for use by other researchers as well.

9. Can you pre-register as a tissue donor?

Yes, you can pre-register a loved one with Dr. Goldman at any time by emailing her at STOPSUDEP@bcm.edu.

10. Why donate tissue?

Tissue donation continues the legacy of the patient in their brave fight against epilepsy. Understanding of the molecular risk factors that predispose patients to epilepsy and SUDEP is critically dependent on having human tissue available for study. Many significant research projects cannot be performed on animal models or model cells. A tissue donation can aid scientists in understanding and treating Dravet syndrome and related epilepsies. Valuable information attained from this gift will improve the longevity and quality of life for future generations of individuals suffering from epilepsy.

Thank you for taking the time to consider the possibilities offered through the gift of tissue donation.