

Post-Mortem Brain and Tissue Donation



UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE
BRAIN AND TISSUE BANK

The University of Maryland Brain and Tissue Bank (MBTB) gratefully accepts brain and other tissue donations from individuals with neurologic, development, movement, and psychiatric disorders as well as from individuals with none of these underlying diseases to serve as unaffected controls. There is no cost to the family to donate. Anyone, regardless of age, is invited to donate. The MBTB generously supports the TSC Alliance® by sharing tissues from individuals affected by tuberous sclerosis complex (TSC) with the TSC Biosample Repository.

Preregistration is not required but simplifies and speeds the process of tissue recovery when death occurs. **Scan the QR code for instructions on how to register in advance for postmortem donation.** If death is imminent and you would like to donate brain tissue, please call the MBTB as soon as possible at 1-800-847-1539.

Successful donation rests on swift and thorough communication between family members, healthcare professionals, and the MBTB. Although the MBTB will make every effort to retrieve tissue in an emergency, tissue recovery may be impossible if there is no advance notice.



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SUDEP Awareness

SUDEP stands for sudden unexpected death in epilepsy. It is a rare but fatal complication of epilepsy with no other known cause of death. While the exact cause of SUDEP is unknown, there are ways you can lower your risk factors and incorporate SUDEP awareness as part of a healthy lifestyle. Empowering yourself or a loved one to take proactive steps is essential.

The most common risk factors of SUDEP include:

- Uncontrolled or frequent seizures
- Tonic-clonic seizures (previously referred to as “grand mal seizures”)
- Generalized compulsive seizures
- The age of seizure onset and number of years the individual has had epilepsy
- Medication compliance
- Sleep deprivation
- History of drug or alcohol use



We understand that this can be a very difficult thing to think about and conversation to have with your loved ones, but awareness is key to stop SUDEP from occurring. **Scan the QR code for “Steps to Reduce SUDEP.”**

It is important to discuss SUDEP with your healthcare team as part of your overall epilepsy care and management plan, even if it is not something they bring up. As it can happen at any age, it is especially important to discuss during the transition phases of your journey, including college, group homes, independent living, healthcare sitters. Talking about it with your close family members and friends is also beneficial to increase awareness and decrease risk to the to your loved one.

