

FREQUENTLY ASKED QUESTIONS REGARDING BRAIN DONATION

1. *Is there a cost involved to participate as a donor?*
No. The BEBRF assumes all costs, so there is no expense to the family.
2. *Do I need to live near Massachusetts in order to enroll as a potential brain donor?*
No, but you must live in the United States to participate in this program. The Harvard Brain Bank works in conjunction with pathologists and funeral homes throughout the United States and will communicate with the specialists who actually collect the donated brains. They are then transported to the Brain Bank, preserved, stored, and made available for research.
3. *Do you only need donated brains from blepharospasm-affected individuals?*
No. In fact, we need brain donations from both persons who have BEB/Meige, as well as from those who do not. The latter are used for comparison purposes and are referred to as “control subjects.” So please encourage your family members and friends to also pre-enroll as donors.
4. *If I sign up to be a brain donor, does that preclude me from donating other organs for transplant purposes?*
It may, depending on how long the procedure takes for retrieving the donated organs and how long the donor was on a respirator.
5. *Is the donor's body transported to the HBTRC for brain removal?*
No. The HBTRC will coordinate the brain recovery with a local pathologist in the donor's area. The body remains in the donor's local area.
6. *Will being a brain donor interfere with funeral arrangements or memorial services in any way?*
Absolutely not. You may have any sort of service or remembrance that you and your family desire, as the brain recovery process does not cause any disruption in those plans.
7. *Will the family of the donor receive any communication from the Harvard Brain Bank after their loved one has passed away?*
Yes. The family will be asked to complete a questionnaire about the donor and will also be asked to grant permission for the donor's medical records to be sent to the Brain Bank. The medical history and questionnaire are both important so the Brain Bank can reliably give researchers the correct tissue samples needed for their specific studies. When this information is received and after the tissue has been analyzed by the neuropathologist, the family will receive a copy of the final neuropathology report.
8. *If someone has had the Deep Brain Stimulation (DBS) surgery or another type of brain surgery, does that prevent them from participating as a brain donor?*
No, researchers will want to study these brains and the donor's medical records will provide needed information for researchers.

For more information on brain donation, contact the BEBRF Office: 1-409-832-0788, or email: bebrf@blepharospasm.org