



Advancing Dystonia Research Through Brain Donation

Solving the Mystery

Finding the causes of a complex neurological disorder such as dystonia is an enormous task and one that hundreds of researchers and clinicians have dedicated their lives to pursuing. There are multiple forms and causes for dystonia. Secondary dystonia can result from disease, other disorders such as stroke, birth or brain trauma, infections, and exposure to certain medications or toxins. Dystonia can also be a symptom of other diseases, some of which may be hereditary. About half the cases of dystonia have no connection to disease or injury and are called primary or idiopathic dystonia. A carrier may or may not develop dystonia and the symptoms may vary widely even among members of the same family.

To understand the dystonias we must rely, to a large extent, on the analysis of donated brains. Through the study of these brains, important clues about dystonia can be discovered. When scientists examine samples from donated brains and compare different age groups, genders and so forth, they can begin to gain a better understanding and knowledge of this complicated disorder, which will lead to development of novel therapeutics and treatments. This, in turn, will offer hope for dystonia-affected individuals and their families.

Committed to Finding a Cure

The Dystonia Brain Collective is a collaborative effort of dystonia patient advocacy groups working together to partner with the Harvard Brain Tissue Resource Center to help solve the mystery of dystonia through brain donation. The HBTRC is responsible for collecting, preserving, and distributing human tissues to qualified scientific investigators who are conducting important dystonia research. Since the majority of scientific research studies can be carried out using a very small amount of tissue, each donated brain can be used by many different researchers at institutions throughout the United States and the world.

...the gift of brain donation is priceless!

Is there a cost involved to participate as a donor?

No. The Dystonia Brain Collective assumes any and all costs, so there is no expense to you or your family.

Do I need to live near Massachusetts in order to enroll as a potential brain donor?

No. You can live in any part of the contiguous United States. (Unfortunately, the program is not able to accommodate persons in Alaska or Hawaii). The HBTRC works in conjunction with pathologists and funeral homes through-out the lower 48 States, and they are the ones who actually collect the brain. It is very important that the HBTRC is notified by your next-of-kin or legal representative as soon as possible when death is imminent or has occurred. They are available to accept these emergency calls 24 hours a day, 7 days a week, 365 days a year. Once notified of a donor's passing, the HBTRC staff will make the arrangements for the brain recovery to take place. The person notifying the HBTRC must grant permission for the recovery to take place and for the donor's medical records to be sent to the HBTRC. The brain must be recovered and arrive at the HBTRC within 24 hours from the time-of-death in order to be of value to researchers. The tissue will then be preserved and stored, and made available for analysis by interested researchers.

Do you only need donated brains from dystonia-affected individuals?

No. In fact, we need brain donations from persons who have dystonia and blood relatives who may be gene carriers but are not manifesting symptoms. The latter are used for comparison purposes and are referred to as "control" brains. So please encourage your biological family members to register as donors.

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 may have been on a respirator. However, brain donors can still donate items such as corneas, bone or skin.

Does the Harvard Brain Bank accept whole body donations?

No, the HBTRC is not equipped to accept "whole body" donations and, usually, most facilities that do accept whole body donations will not allow for the removal of brain tissue for research purposes as they want the body

to be intact. So that means that individuals must decide whether they would like to donate their brain and help to advance dystonia research, or donate their entire body to science.

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. The brain recovery process does not cause any disruption in those plans. The brain recovery is performed very discreetly and does not affect the outward appearance of the donor.

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. Those having had brain surgery can still register as donors and these too are important brains to study.

Is there anything that could preclude someone from becoming a donor?

Yes. Unfortunately, if you test positive for HIV or for hepatitis you are excluded as a brain donor. In addition, there may be some other situations that preclude persons from being donors. You can contact the HBTRC for further information if you have questions or concerns.

Will the family of the donor receive any communication from the HBTRC after their loved one has passed away?

Yes. The family will be asked to complete a questionnaire about the donor and will be asked to grant permission for the donor's medical records to be released to the HBTRC. The medical history and questionnaire are both important so the HBTRC 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.

What is the Dystonia Brain Collective?

The DMRF serves as the administrative center for the Dystonia Brain Collective which is a partnership among several dystonia patient groups. The goal is to encourage and facilitate brain donation. Donated tissue is available to qualified researchers for dystonia-related studies.

Can I cancel my registration?

Yes, you can cancel your registration at any time.



Religious Perspectives on Brain Donations

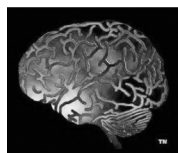
When you enroll as a potential brain donor, you are giving a very precious gift which will benefit many future generations. However, this is a deeply personal decision which must be given careful and thoughtful consideration. It may also raise concerns of a spiritual, personal, and practical nature and those may need to be discussed and explored, and guidance may be needed. For instance, when we consider whether to be a brain donor, this may cause us to examine our innermost feelings about death, ponder whether there is an afterlife and what a soul really is, and question what happens to our bodies after we pass away.

If you need religious guidance to help you resolve some of your concerns or answer these questions, you may wish to consult with your rabbi, priest or minister. Brain donation is accepted by most major religious organizations and does not interfere with planned services.

Making the Decision to Become a Brain Donor

Any person 18 years of age or older can make a decision to become a brain donor. This is an important and personal decision which must be shared with your family so that your wishes may be carried out at the appropriate time. Although an individual can make a personal request to donate his/her brain, ultimately it is the surviving family members who will have the responsibility of notifying the HBTRC to ensure that this unique and valuable gift will be made.

If you have questions, please contact
The Harvard Brain Bank at 1-800-BRAIN BANK (1-800-272-4622)



Harvard Brain Tissue Resource Center
McLean Hospital
115 Mill Street • Belmont, MA 02478
www.brainbank.mclean.org

4 Easy Steps to Register as a Brain Donor

- 1.** Contact any member organization of the DBC with questions about this program, to start the process and have materials sent to you. Call 1-800-377-3978 or e-mail: brainbank@dystonia-foundation.org. You can also register electronically by going to www.dystonia-foundation.org/brain. In addition, you can register separately with the HBTRC so they also have you on file.
- 2.** Talk to your family about your important decision to further advance dystonia research by becoming a brain donor. Your Next-of-Kin or legal representative will be responsible for notifying the HBTRC should the donor's death seem imminent or as soon as possible after death has occurred to authorize brain recovery and the release of the donor's medical records. So they need to be aware of your intention to serve as a brain donor.
- 3.** Complete the one page Brain Donor Registration Form and return it to your organization either by mail or electronically to receive program updates and news as well as laminated donor cards and Medical Intake Forms.
- 4.** Have your treating dystonia specialist (or other healthcare provider) fill out the Medical Intake Forms that are provided to you as completely as possible and retain in your medical file at the doctor's office. At the very least we need a physician-confirmed dystonia diagnosis listing the type(s) of dystonia. These records will be released to the HBTRC post-mortem with your Next-of-Kin or legal representative's authorization. This information is extremely important for our researchers to have.

If Death is Imminent . . .

To initiate the process of brain donation, call the HBTRC (1-800-BRAIN BANK or 1-800-272-4622) if death seems imminent or immediately after the death of the donor. The donor's brain must arrive at the HBTRC within 24 hours from the time-of-death in order to be of value to researchers, so time is of the essence.

The HBTRC representative will need the donor's name, time of death, neurological diagnosis, and location. The HBTRC staff will work directly with a local pathologist in the donor's area to make arrangements for brain removal at no expense to the patient or family. Only the donor's brain will be sent to the HBTRC. The donor's body will not be transported from your local area.

The donor's legal Next-of-Kin or legal representative will be required to sign a "Consent for Donation" following the death of the donor, which authorizes the donation of the brain to the HBTRC.

Congratulations on making an important decision which could help solve the mystery of dystonia!



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