



Advancing Spasmodic Dysphonia Research through Brain Donation

Finding the causes of a complex neurological disorder such as spasmodic dysphonia is an enormous task and one that a number of researchers and clinicians have dedicated their lives to pursuing. To understand the etiology of spasmodic dysphonia, we must rely, to a large extent, on the analysis of donated brains. Through the study of these brains, important clues about spasmodic dysphonia 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 SD-affected individuals and their families.

The National Spasmodic Dysphonia Association, working with other organizations of the Dystonia Brain Collective, is proud to partner with the Harvard Brain Tissue Resource Center to help solve the mystery of spasmodic dysphonia and other dystonias through brain donation. The Harvard Brain Tissue Resource Center is responsible for collecting, preserving, and distributing human tissue to qualified scientific investigators who are conducting important spasmodic dysphonia research.

Our Scientific Advisory Board chairperson, Dr. Christy Ludlow, represents the NSDA on the research committee which reviews applications from researchers requesting brain tissue. Since the majority of the scientific research studies can be carried out on a very small amount of tissue, each donated brain provides a very large amount that can be used by many different researchers at institutions throughout the U.S. and worldwide. When you enroll as a brain donor, you are giving a very precious gift which will benefit future generations.

Commonly Asked Questions

1. Is there a cost involved to participate as a donor?

No. The NSDA assumes any and 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 in order to participate in this program. The Harvard Brain Tissue Resource Center works 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 analysis.

3. *Do you only need donated brains from SD-affected individuals?*

No. In fact, we need brain donations from both persons who have SD 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. *Does the Harvard Brain Tissue Resource Center accept whole body donations?*

No. The facility is not equipped to receive such donations.

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

Yes. 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 would preclude persons from being donors. You can contact the Harvard Brain Tissue Resource Center at 1-800-BRAIN BANK (1-800-272-4622) for further information if you have any questions or concerns.

8. *Will the family of the donor receive any communication from the Harvard Brain Tissue Resource Center 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.

3 EASY STEPS TO ENROLL AS A POTENTIAL BRAIN DONOR

1. Contact the National Spasmodic Dysphonia Association with any questions about this program or to start the pre-enrollment process either by phone 800-795-6732 or email: NSDA@dysphonia.org
2. Talk to your family about your important decision to further advance dystonia research by becoming a brain donor.
3. Complete and return the Donor Registration Form to the NSDA. A card indicating that you are a brain donor for your wallet will then be mailed to you.