



The decision to become a brain donor creates a legacy through continued participation in research that will help families affected by autism spectrum disorder (ASD). Considering brain donation for research may be difficult, but long-term planning is important to minimize the burden of decision-making at the time of death. Families typically find that facilitating research through donation brings a sense of hope and purpose in the midst of grief.

For more information

Email us: info@autismbrainnet.org

Visit us: douglasbrainbank.ca
autismbrainnet.org

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Autism BrainNet is a program of the Simons Foundation Autism Research Initiative (SFARI), a scientific initiative of the Simons Foundation. SFARI's mission is to improve the understanding, diagnosis and treatment of autism spectrum disorders by funding innovative research of the highest quality and relevance. To learn more about SFARI, visit sfari.org.

SFARI SIMONS FOUNDATION
AUTISM RESEARCH INITIATIVE

A DONATION THAT
LINKS OUR MINDS.

DOUGLAS-BELL CANADA
BRAIN BANK



AutismBrainNet

www.autismbrainnet.org

What is Autism BrainNet?

Autism BrainNet is a network of university-affiliated tissue repositories (biobanks), based in the United States, that provides families the opportunity to donate the brain of a loved one with a diagnosis of autism at the time of their death. Autism BrainNet is composed of three repositories in the United States, one repository in Oxford, England, and one in Canada at the Douglas-Bell Canada Brain Bank (DBCBB) in Montreal, Quebec.

Each site adheres to high standards set by Autism BrainNet to collect, process, store, and distribute this precious resource. This gift helps researchers understand the causes of ASD and related neurodevelopmental conditions. Applications to receive tissue are rigorously evaluated for scientific value. They are reviewed by the Autism BrainNet Scientific Review Committee, and by the Simons Foundation Autism Research Initiative, the funding organization of Autism BrainNet and the largest non-governmental funder of research in autism. Tissue samples are distributed to approved, qualified researchers from around the world, including Canada. Research data and results are collected in a centralized database in accordance with United States privacy laws. All family contact information is protected, remains confidential to Autism BrainNet, and is never shared.

Why is it important to study the brain to understand autism?

Autism is a condition that affects the brain and how it functions. We have still much to learn about the human brain and how the brain of a person with autism works differently. Studying postmortem brain tissue is the best way for researchers to better understand autism on the genetic, cellular, and molecular levels. Through better understanding, autism researchers aim to develop new and effective treatments to improve the quality of life of individuals who have ASD and their families.

What is the process for making a brain donation?

Donor families are treated with respect and compassion, and provided with ongoing support.

Autism BrainNet makes the donation process as simple as possible for every family. Here are the steps involved in donating to Autism BrainNet:

- 1 Read and sign the consent forms for brain donation and send the documents to the Douglas-Bell Canada Brain Bank, as instructed on the forms.**
- 2 Call the Douglas-Bell Canada Brain Bank at 514-761-6131 (ext. 3496) or the toll-free number at 1-866-930-0291 as soon as possible after a death has occurred or as death is nearing.**
- 3 The Douglas-Bell Canada Brain Bank will coordinate retrieval of the brain and transport it safely to the brain bank.**
- 4 An Autism BrainNet clinician will follow up with the donor family to learn more about the donor.**

Does brain donation interfere with funeral plans?

No. Brain donation does not interfere with funeral plans, including having an open-casket viewing.

Is there a cost associated with a donation to Autism BrainNet?

No. Autism BrainNet takes care of all the financial costs related to the donation.

Who can become a brain donor for Autism BrainNet?

Autism BrainNet accepts donations from:

- > Individuals of any age with a diagnosis of autism (with or without other related health conditions)
- > Individuals between the ages of 2 and 50 without a diagnosis of autism or other neurologic or psychiatric conditions. The donation from individuals without autism will allow scientific studies to benefit from the availability of comparing individuals with and without autism.

If you would like to become a brain donor, it is important to let your family know. Your family can help carry out your decision by calling Autism BrainNet and providing consent for donation.

To make a brain donation, call Autism BrainNet

If a death occurs or is nearing and you have questions or wish to begin the donation process, call the Douglas-Bell Canada Brain Bank at **514 761-6131 (ext. 3496)** or toll-free at **1 866 930-0291**.