



AutismBrainNet

Advancing research through the gift of brain donation

What is Autism BrainNet?

Autism BrainNet is a program that promotes brain donation. The goal is to create a bank of donated postmortem brain tissue that facilitates research into the biological causes of autism and related neurodevelopmental disorders. Knowledge from these research studies will ultimately improve the quality of life of individuals who are affected by these conditions.

Autism BrainNet works with families, researchers, and providers to promote a greater knowledge of postmortem brain tissue research, and to ensure the most compassionate and smooth donation process for families during a difficult time.

Autism BrainNet is comprised of four biorepositories, or nodes, in the United States and Canada:

- ▶ **Massachusetts General Hospital, Boston, MA**
- ▶ **University of California Davis, MIND Institute, Sacramento, CA**
- ▶ **University of Texas Southwestern Medical Center, Dallas, TX**
- ▶ **Douglas-Bell Canada Brain Bank, Montreal, Quebec, Canada**

Each node follows the high standards set by Autism BrainNet to collect, process, store and distribute the precious gift of donated brain tissue to qualified researchers worldwide. Applications to receive brain tissue are evaluated for scientific merit by the Autism BrainNet Scientific Review Committee.

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

There is still much to learn about the differences between the brains of those who are autistic and those who are neurotypical. For understanding the cellular and molecular biology of autism, postmortem brain research is an essential component. Studying postmortem brain tissue is extremely important for researchers to better understand the neuroanatomical, cellular and molecular changes associated with autism in the human brain.

For more information: Call: **877-333-0999** | Email: **info@autismbrainnet.org**

Visit: **AutismBrainNet.org** | Follow us on social media: **[@autismbrainnet](https://www.instagram.com/autismbrainnet)**



What have researchers learned so far by studying the autism postmortem brain?

Thanks to research facilitated by Autism BrainNet and other organizations, studies of postmortem brain tissue are contributing to many discoveries. These include the following:

- ▶ The brains of individuals with autism show changes in the number and distribution of neurons, as well as differences in the wiring between neurons. This could affect how information is processed and transmitted between brain cells.
- ▶ In addition to neurons, non-neuronal cells, such as the brain's resident immune cells called microglia, may also play a role in autism.
- ▶ The brains of people with autism with and without a genetic diagnosis share similar molecular changes.
- ▶ Autism shares similar gene-activity patterns with other neurodevelopmental or psychiatric conditions, such as attention deficit hyperactivity disorder, obsessive-compulsive disorder and schizophrenia. This partial overlap highlights common targets of pathology that could be leveraged to identify and develop interventions.

What is the process for making a brain donation?

Autism BrainNet makes the donation process as simple as possible for every family. Donor families are treated with respect and compassion and are provided with ongoing support. Here are the steps:

1

When a death has occurred, the family or health care provider should call Autism BrainNet at **877-333-0999** within 24 hours for immediate assistance. If death is near you can call Autism BrainNet to make plans for donation. Our staff is available 24/7 and will walk your family through the donation process. To best preserve the scientific value of the brain tissue, a donation should be received within 48 hours after death. Donation may be possible beyond 48 hours. Please call Autism BrainNet to discuss your circumstances with our clinical team. Autism BrainNet clinical staff will work with the legal next of kin to provide authorization for donation. State law determines the specific order, but the next of kin would generally be a health care agent (if named), spouse, adult children, parents, siblings and then increasingly distant relatives determined by the laws of your state. In the case of minors, parents are typically recognized as the legal next of kin.

2

Autism BrainNet staff will coordinate brain recovery and make arrangements for the donation to be carefully transported to the nearest Autism BrainNet node, where it is preserved and stored for future distribution to approved, qualified researchers.

3

An Autism BrainNet clinician will follow up with the donor family or caregiver to schedule an interview. The purpose of this interview is to learn more about the donor and obtain medical, behavioral and family information. This information may include medical records and neuropsychological, audiological or speech-language evaluations.

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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 **without a diagnosis of autism but with a neurodevelopmental disorder or genetic condition related to autism** (examples are Dup15q Syndrome, Prader-Willi Syndrome, Down Syndrome, Angelman Syndrome, Fragile X Syndrome and other genetic diagnoses). Tissue from individuals with a genetic condition is important because it may help to understand why a particular genetic condition leads to autism in some cases but not in others.
- ▶ Individuals up to the age of 50 **without a diagnosis of autism**, neurologic or psychiatric conditions or severe brain injury. This donation will benefit scientific studies by allowing the comparison of brain tissue from people with and without autism.

Do you have to register with Autism BrainNet to become a brain donor?

No. Autism BrainNet currently does not have a pre-registry for donors. At the time of death, or when death is near, the next of kin or legal representative would need to contact Autism BrainNet at **877-333-0999** to initiate the donation process. You may also communicate a preference for postmortem brain tissue donation in your or your loved one's end-of-life planning documents and share it with your family members.

You can download and print the Intent to Donate Postmortem Brain Tissue for Research form and an Autism BrainNet Brain Donor Card to include in your documentation. Long-term planning will help ensure that a donor's decision is respected.

How is brain donation different from organ donation?

Brain tissue can only be used for research and not for transplantation. Therefore, brain donation is not part of organ donation registries. This is why it is important for families and individuals to learn more about Autism BrainNet if they're interested in becoming brain donors for research. To make a brain donation, the consent of a next of kin is necessary, even if you or your loved ones have registered to be organ donors. Autism BrainNet donors can be both brain and organ donors. Autism BrainNet encourages organ donation to save lives whenever possible.

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

No. Autism BrainNet takes care of all the financial costs associated with the donation.

Does brain donation interfere with funeral plans?

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

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