



# Autism BrainNet

Advancing research through the gift of brain donation.

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## What is Autism BrainNet?

Autism BrainNet works with researchers and the communities affected by autism and other neurodevelopmental conditions to develop a sensitive and effective strategy for acquiring postmortem brain tissue. The donations will produce a resource that facilitates the highest quality research into the causes of these conditions. The data generated will be shared to enable the development of treatments that improve the quality of life of individuals who are affected by them.

Autism BrainNet includes three sites, also called nodes, in the United States:

- ▶ **Beth Israel Deaconess Medical Center**, Boston, MA
- ▶ **University of California, Davis MIND Institute**, Sacramento, CA
- ▶ **University of Texas Southwestern Medical Center**, Dallas, TX

Autism BrainNet also has international partnerships with:

- ▶ **Douglas-Bell Canada Brain Bank**, Montreal, Quebec, Canada
- ▶ **Oxford University**, Oxford, United Kingdom

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.

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

There is still much to learn about how the human brain works and the differences in how the brain of a person who has ASD works. Studying postmortem brain tissue is extremely important for researchers to better understand the cellular and molecular changes associated with ASD in the human brain and to help identify new and effective treatments.



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## 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 have led to many discoveries. These include the following:

- ▶ The brains of individuals with ASD show changes in the number and distribution of neurons, as well as differences in the wiring. This could affect how information is processed and transmitted between brain cells.
- ▶ Alongside neurons, non-neuronal cells, such as the brain's resident immune cells called microglia, may also play a role in ASD alterations.
- ▶ Despite ASD genetic and behavioral heterogeneity, similar changes in molecular mechanisms that help regulate gene activity are found in ASD-related conditions with different genetic causes.
- ▶ ASD 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.

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## 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 or is near, the family or healthcare provider calls Autism BrainNet at **877-333-0999** for immediate assistance. Our staff is available 24 hours a day, 7 days a week, and will walk your family through the donation process.

2

An Autism BrainNet clinician will work with the legal next of kin to obtain consent 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.

3

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.

4

An Autism BrainNet clinician will follow up with the donor family to schedule a video meeting or home visit. The purpose of this visit 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 between the ages of 2 and 50 **without a diagnosis of autism** or other neurologic or psychiatric conditions. This donation will benefit scientific studies by allowing the comparison of brain tissue from people with and without ASD.
- ▶ Individuals with Angelman syndrome, Dup15q syndrome, Phelan-McDermid syndrome, Prader-Willi syndrome or other **genetic diagnosis associated with autism**. Autism BrainNet partners with several family organizations to facilitate donations from families of individuals with these genetic changes. Tissue from individuals with a genetic diagnosis is important because it may help to understand why a particular genetic condition leads to autism in some cases but not in others.

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## 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, 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 ones' healthcare directive or preplanning documents and share it with your family members.

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## 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 most 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 donate brain tissue, 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.

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## 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.

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## Does brain donation interfere with funeral plans?

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

### For more information

Call: **877-333-0999** | Email: **info@autismbrainnet.org** | Visit: **autismbrainnet.org**

Follow us on Facebook and Twitter: **@autismbrainnet**