About our brain donation program

The brain donation program offers persons living with a dementia the opportunity to contribute their brain to science at the time of their death. Participants must be enrolled in the University of Michigan Memory & Aging Project to participate.

Donated brains are collected and stored by the Michigan Brain Bank to help scientists around the world advance their understanding of brain disease and disorders and contribute to potential treatment options.

Registration is required in advance of death to participate, and there are no costs to donors or their families who participate in the University of Michigan Memory and Aging Project.

Why brain donation is important

Brain autopsies are an extremely important source of information about how the disease affects the anatomy of the brain. This information is used to direct future research into the causes of memory loss, their progression over time, and clues about effective treatment approaches. For example, researchers recently have found that a previously unrecognized abnormality in brains of patients with dementia called Lewy bodies may be present in 40% of persons with Alzheimer’s disease and may account for some symptoms. We would never have learned this unless we conducted autopsies in addition to our clinical care.

What we know about neurodegenerative disorders has only been possible because of the commitment of patients and families who donate their brain to science. Even if individual family members do not benefit directly from a brain autopsy, it can lead to a better understanding of neurodegenerative and psychiatric disorders for future generations and provide an important measure to assess public health and quality of care.

Testimonial from a current UM-MAP participant

It was my decision to participate in the brain donation program at the end of the UM-MAP study. When I realized the problem that I have with Lewy body dementia (LBD) is neurological, I thought to myself “I could take my brain with me to the grave and that would be the end,” but donating my brain gives the opportunity to continue research in LBD after I’m gone, and that to me was incredibly important.

There was some hesitancy from my family, I guess around me departing with a member of my body. Then they realized what my brain would be contributing to research, and all those I would be helping was an extreme positive. My children thought it was a fantastic thing and told me that they were so proud of me for considering it.

One little piece of my brain could lead to a cure, help scientists see what causes this disease, and is a step in preventing further disease advancement for others.

Barry Kaufman, West Bloomfield, MI
**Frequently Asked Questions**

**Why should I consider brain donation?**

For families, brain autopsy offers medical clarity. Learning the precise cause of their family member’s illness may be a tremendous relief and help to ease their own uncertainty and doubt. It gives relatives accurate information about the cause of symptoms, confirming or modifying the diagnosis made during life, and provides relatives with accurate information about their family's medical history which can help with their own care and the planning for their children.

Even if individual family members do not benefit directly from a brain autopsy, it can lead to a better understanding of neurodegenerative disorders for future generations.

**What kind of research is done on my brain tissue after donation?**

Scientists from across the nation submit requests to the Michigan Brain Bank for tissue to support their research. These requests are reviewed by the Brain Bank, and when approved, samples of brain tissue, along with testing results from your UM-MAP visit are sent to scientists for analysis. These studies may lead to improved understanding and advances in the diagnosis and treatment of neurodegenerative disorders and may also result in commercial products or patents.

**Does brain donation affect funeral arrangements or the ability to have an open casket at my funeral?**

With planning in advance, there should be no expected delays in funeral arrangements. The autopsy procedure is performed within the first 24 hours of death. The Michigan Brain Bank staff also work with funeral directors to expedite the transition from the place of death to our medical center, and from there to the funeral home. If all paperwork is complete and submitted in advance, and at time of death, this will assist in preventing any delays.

Also, the removal of brain, spinal cord, teeth (only molars), or hair for our research will not cause any noticeable disfigurement to prevent an open casket.

**Does donating brain tissue for research purposes interfere with religious beliefs?**

Brain donation does not conflict with most religious beliefs. If you have any questions concerning this issue, please contact your religious leader, priest, minister, imam, or rabbi.

**Will my family be sent an autopsy report after my brain donation occurs?**

Yes. By completing a form with the Michigan Brain Bank, you will assure that a written report of the autopsy results will be sent to you. Typically, the report is sent to the family 3-4 months after completion of the autopsy procedure. Once you’ve received the autopsy report, contact your local physician (this will be identified on the form) and they will discuss the autopsy results and its implications with you.

We recommend that you keep the report in a safe place for future reference. The numbers on the report are important because they help family members obtain further information if it is needed in the future.

**Are there any costs or fees involved?**

There is no charge for the arrangement and performance of the autopsy.

If a patient moves to another area, the Michigan Brain Bank Coordinator will work closely with you to locate a local hospital and pathologist to perform the autopsy. In these cases, there may be charges for brain removal that would be responsibility of the family. There are no charges for research testing.

**Who can I contact if I want to talk to someone before deciding?**

Please contact Michigan Brain Bank Coordinator, Matthew Perkins, at perkmed@med.umich.edu or 734-647-7648.

More information is available at alzheimers.med.umich.edu/braindonation or brainbank.med.umich.edu