

#### Wisconsin Brain Donor Program

Wisconsin Alzheimer's Disease Research Center UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH



# Be a part of the solution.

### Become a registered brain donor with the Wisconsin Brain Donor Program and join the fight against Alzheimer's disease.

We created this brochure to help with decision making. Share and discuss it with your family, friends, and spiritual advisors. This pamphlet cannot address every question. We welcome you to call us and discuss your questions and concerns.

#### Why consider brain donation?

There is currently no cure for Alzheimer's disease or early memory loss. Brain donations from those with and without memory problems give researchers important material to help discover why some people develop memory loss and why others do not.

Every brain is unique and tells an important story. A brain from a single donor can be used in multiple research projects that investigate the treatment and prevention of Alzheimer's disease and related dementias.

#### Who can donate?

Only participants in our research studies and their biologic parents can enroll in the Wisconsin Brain Donor Program. However, healthy older individuals without memory difficulties are also encouraged to contact us to be considered for enrollment.

All donation costs are covered for those accepted into the donor registry. Participation is voluntary; enrollees are free to withdraw at any time.



#### What is the Wisconsin Brain Donor Program?

The Wisconsin Brain Donor Program is a repository of biologic specimens collected after death for the purpose of advancing Alzheimer's disease and related dementias research. Through donated brains, tissue, blood, and cerebral spinal fluid, the Wisconsin Brain Donor Program can actively participate in helping advance knowledge of neurodegenerative diseases.

If you would like more information, or to register to be a future brain donor, please contact us.

Wisconsin Brain Donor Program 600 Highland Avenue J5/1M Clinical Science Center Madison, WI 53792-2420

Office phone: (608) 265-4000 24-hour pager: (608) 265-7000, ID# 5332 adrc.wisc.edu/brain-donation

### **Common Questions about Brain Donation**

# Why is brain donation important?

A brain autopsy at the end of life is the most conclusive way to confirm Alzheimer's disease. The human brain is complex and some research is difficult or impossible to do with living people. Information from the autopsy helps scientists better understand Alzheimer's disease and related dementias.

## Who benefits from my donation?

For many donors, knowing they will be contributing to science and potentially helping their community or family is a rewarding experience. A donation can also offer family members information about their loved one's brain health and medical conditions at the time of death. It may encourage family members to make choices in their lives that will lead to better long-term health.



A section of hippocampus of a patient with Alzheimer's disease reveals an abundance of neurofibrillary tangles, seen here as black deposits.

## What will my family receive?

Your family will receive a pathology report after the autopsy is completed. This report provides a diagnosis and will summarize findings regarding the brain. If there are questions about the report, a follow-up conference can be arranged with the doctor who prepared the report.

## When is the donation performed?

Ideally, the donation should be completed as soon as possible, within 16 hours of death.

## Who performs the procedure?

Donations are done under the guidance of a board-certified neuropathologist (a doctor who specializes in diseases of the brain and nervous system).

## Will donation affect my funeral arrangements?

Brain removal does not cause disfigurement and does not interfere with funeral arrangements or viewing of the deceased. Donation takes about 1 hour (not including transportation) and is a common procedure that funeral directors and morticians are familiar with.



A section of frontal lobe of a patient with Alzheimer's disease examined using beta-amyloid antibody. Here brown deposits of amyloid plaques are evident in a large number.

# Where is the procedure performed?

Donations are customarily performed at University Hospital in Madison. Transportation is arranged by the donor's funeral home or cremation provider and paid for through the Wisconsin Brain Donor Program.

## Where are samples stored?

Donated tissues are retained for perpetuity in -80° C freezers located in the Wisconsin Institute for Medical Research (WIMR) biorepository connected to University Hospital in Madison.

#### What if I change my mind?

You or your family can always change your mind about donating. Brain donation is a gift. We strongly encourage you to talk with your family, friends, and spiritual advisors before making your decision so they know your wishes and can help ensure it occurs.

### Brain Donation Research Studies

Brain donation is an important tool that helps scientists understand the development and progression of Alzheimer's disease (AD). Studies that utilize samples from the Wisconsin Brain Donor Program can be vastly different in scope. Below are two current studies utilizing resources from the Wisconsin Brain Donor Program.



Dr. Engelman

Dr. Corinne Engelman's GROW study will utilize donated brain tissue and information from donors' living relatives to search for genetic similarities that may contribute to Alzheimer's disease risk, the pace and extent of Alzheimer's disease brain changes, and similarities in changes in their thinking and memory skills tests. These results may help scientists learn more about the biological causes of Alzheimer's disease and identify prevention and treatment methods.



Dr. Kind

The neighborhoods in which you lived throughout your life have an effect on your overall health. Utilizing public records, including U.S. Census data and city directories, Dr. Amy Kind and her research team will create detailed residential histories of research participants from the Wisconsin Brain Donor Program and the University of California-San Diego Brain Bank. The research team will then link lifetime residences with data sources that describe county- or neighborhood-level characteristics, such as the Neighborhood Atlas (www.neighborhoodatlas.medicine.wisc.edu). This data, paired with autopsy results, will allow Dr. Kind to determine connections between neighborhood disadvantage and Alzheimer's disease risk.

Wisconsin **Brain Donor** Program FACTS The Wisconsin **Brain Donor Program** was established in



donation powers decades of research

More than

1,350



are registered

to donate

Brain autopsy is the 'gold standard' way to diagnose Alzheimer's disease and

other brain conditions



from 450+ individuals available for request from scientists worldwide

Donations

#### For More Information

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