How is brain donation different from the Australian Organ Donor Register?

The Australian Organ Donor Register gives people the opportunity to donate tissue for transplantation whereas the brain donor program is only for scientific research purposes. While organ donors may also become brain donors, separate permission is required for brain donation for scientific research.

Are there any costs involved?

There is no fee for brain donation. Any costs are incurred by the Sydney Brain Bank.

Further information about brain donation

If you require more copies of this brochure, or other specific information about the NSW Movement Disorders Brain Donor Program, please contact the Brain Donor Coordinator at:

Parkinson's Disease Research Clinic
Brain & Mind Research Institute
94 Mallett Street
Camperdown
Sydney NSW 2050
Phone: 02 9351 0702
Email: pd.clinic@sydney.edu.au
Visit: http://sydney.edu.au/bmri

If you are concerned in any way about the conduct of this research, you may contact the Manager, Ethics Administration, University of Sydney, NSW 2006, Phone: (02) 9351 4811, Fax: (02) 9351 7606, Email: gbriody@mail.usyd.edu.au

BRAIN & MIND RESEARCH INSTITUTE

THE UNIVERSITY OF SYDNEY

NSW Movement Disorders Brain Donor Program

Neuroscience Research Australia
Discover. Conquer. Cure.

What is the NSW Movement Disorders Brain Donor Program?

The NSW Movement Disorders Brain Donor Program is a collection of clinical research groups dedicated to the study of Parkinson's disease and related disorders. Clinical data is collected through the Brain & Mind Research Institute (BMRI) Parkinson's disease research clinic (University of Sydney) and associated resarch clinics. Brain tissue studies take place at the Sydney Brain Bank (Neuroscience Research Australia - NeuRA). These research institutes are dedicated to preventing and curing diseases and disabilities of the brain and nervous system.

What is brain donation?

Brain donation is when a person and their family decide to donate their brain for medical research following their death. Brain donation is fundamental to advancing the understanding of neurological diseases.

Once the brain has been obtained, it is taken to the Sydney Brain Bank at Neuroscience Research Australia (NeuRA), a cooperatively managed research resource facility of three institutions – NeuRA, the Australian Brain Bank Network (ABBN) and the Faculty of Medicine, University of New South Wales (www.NeuRA.edu.au/research/facilities/brain-bank). There the brain undergoes a thorough neuropathological examination to determine a final diagnosis. This information is provided to the donor's next-of-kin and their medical practitioners.

Why is brain donation important?

Although over the past decade many advances have been made in our understanding of Parkinson's disease and related disorders there is still no cure for these conditions. Modern brain imaging techniques, blood tests and genetic markers are helping to improve the characterisation of these degenerative diseases but without understanding the changes that are occurring in the brain, the impact of these advances will be limited. In order to develop more effective treatments, studies are needed to identify the specific cellular changes occurring in the brain.

Why consider donating brain tissue?

Brain donation after death is a precious and enduring gift to research. There is a real shortage of brain tissue for scientists, particularly from patients who have been diagnosed with Parkinson's disease or with similar clinical conditions.

Who can register with the NSW Movement Disorders Brain Donor Program?

Our brain donor program concentrates on various neurodegenerative conditions and also unaffected people. People who have been diagnosed with Parkinson's disease and related disorders are invited to consider registering to be a brain donor. It is also very important to obtain tissue from people without this disease for comparison. Sometimes relatives are also interested in brain donation.

Unfortunately not everyone can register. People who have an infectious disease such as HIV, Hepatitis B, Hepatitis C or Creutzfeldt-Jakob disease are unable to participate in the program.

What does becoming a brain donor involve?

Making the decision to donate tissue after death is a very personal one. We recommend that the decision be discussed with family members prior to registration, so that all family members understand the donor's wishes. After consideration and discussion, registration forms are completed with the NSW Movement Disorders Brain Donor Program. To allow for the maximum amount of information to help with this research, donors will be offered free regular clinical assessments through the Brain & Mind Research Institute (BMRI) Parkinson's disease research clinic or other associtated research clinics.

When can brain donation occur?

The brain is removed as soon as is possible after death.

How much of the brain is donated?

The whole brain is removed by autopsy. This is different from a biopsy where only a sample of tissue is removed.

What happens to the tissue?

The brain is treated with the utmost care and respect by the Sydney Brain Bank staff at NeuRA. Some of the tissue is frozen so that it can be used for DNA extraction or biochemical studies. The remaining tissue is fixed in formalin to preserve it for microscopic examination. This information allows comparison between DNA and tissue findings as well as tissue diagnosis and typing.

Tissue samples are processed and held at the Sydney Brain Bank where scientists throughout Australia or overseas may access the tissue for ethically approved research projects.

How is the brain removed? How does it affect the look of the person?

The removal of organs and tissue is no different from any other surgical operation, and is performed by a highly skilled scientist/pathologist. The donor's body is always treated with dignity and respect. The donation of a person's brain does not alter the physical appearance of the body, nor does it affect funeral arrangements.

How will the information be used?

It is possible that the results of the research may lead to discoveries which give a better understanding of Parkinson's disease and related disorders, improve methods of diagnosis, and result in treatment options for people with Parkinsonian disorders. The research outcomes may be published in scientific journals or presented at national or international conferences. In all cases, information will be provided in such a way that the donor cannot be identified.