

RESEARCH INTO THE BRAIN DURING NORMAL AGEING AND DISEASE

Impaired brain function interferes with normal living, and chronic diseases of the nervous system can cause severe impairment of brain function. These diseases include Alzheimer's disease, Parkinson's disease, motor neuron disease, and Huntington's disease, as well as other diseases which manifest principally as psychiatric dysfunction. Much has been discovered concerning each of these diseases, but the basic underlying causes are not yet understood.

We must know more about the effects of diseases on the brain for three reasons:

1. A detailed knowledge of the effects of the disease may provide clues to the underlying cause.
2. A better understanding of the types of brain cells affected may enable us to devise new and effective therapies.
3. To compare the changes between diseased and normally ageing brains.

Why is brain tissue needed?

To improve treatment and understand the causes of disease we need to study the brains from people who die with degenerative neurological disease, and compare them with brains obtained from people dying from a non-neurological cause. The work will be done by scientists from the South Australian Neuroscience Institute and National and International collaborations. In addition, tissue may be provided to other scientists from around Australia and overseas to assist their research into neurological disease. The Brain Bank project is Australia wide, supported by the National Health and Medical Research Council. We need your help to arrange for the collection of your brain after your death.

Is brain donation the same as other tissue and organ donations such as corneas or kidneys?

No. The donated brain is not used for transplantation. Nevertheless it needs to be removed as soon as possible as some important brain chemicals change after death.

Whose brains are needed?

(a) Brains from people with neurological disease.

Brains and tissues from people dying with Alzheimer's Disease, Parkinson's Disease, Motor Neuron Disease, Multiple Sclerosis, Huntington's Disease, Schizophrenia, or other conditions affecting the brain and spinal cord.

(b) Brains from people without neurological disease.

These brains are equally precious. We need to compare diseased and normal brains. In addition we need to demonstrate normal and abnormal brain structure in the education of health care professionals.

Blood Sample

We may ask you to provide a sample of your blood after you agree to join our brain donor program. This sample will be collected by your local doctor or specialist and will be sent to us for storage in our Brain Bank facility.

Tissue Use and Storage

Your brain (and spinal cord, cerebrospinal fluid and blood if these samples have been collected) will be kept in storage such that your proteins, lipids, DNA and RNA will be preserved. Sometimes tissue culture techniques and genetic analysis may be conducted in order to gain insight into the disease process. Any research into the genetic causes of neurological diseases will be of a general nature and not connected with any particular individual. You will be asked to waive rights to any royalties that may arise from the research. Tissue will be made available to researchers from other leading neuroscience centres, and will be subject to the prevailing regulations regarding use and confidentiality. All tissue in storage is identified by code such that you cannot be personally identified. If any tissue is to be disposed of it will be in accordance with the prevailing institutions regulations.

What should you do now to ensure the brain tissue donation occurs after death?

Fill out and return the attached Donor Consent Form and Donor Information Forms, along with any other information you may feel is relevant, to the address provided. Keep a copy, and ensure that your family, your doctors and, if appropriate, the nursing staff of your retirement village or nursing home, are informed of your wish. We will send you a Donor Card. You should keep this in an accessible place with your other medical cards and documents.

What happens if the donor dies in a general hospital?

The medical staff of the hospital, having been made aware of the donor's wishes, will contact the Brain Bank Coordinator, on the telephone number on the Brain Tissue Donor Card, and arrange for the removal of the brain at either Flinders Medical Centre or Royal Adelaide Hospital. Normal funeral arrangements can then take place.

What happens if the donor dies at home, in a retirement village or in a nursing home?

The nursing staff or the attending doctor will contact us, on the telephone number on the Donor Card, to make arrangements for the body to be brought briefly to Flinders Medical Centre or Royal Adelaide Hospital for removal of the brain and other tissues. Normal funeral arrangements can then take place.

Confidentiality

If you become a donor, we ask you to provide us with a general personal and medical background (pages 6 and 7 of this leaflet). In addition we ask you to consent to us obtaining your medical records after your death. It is of the utmost importance that we have a comprehensive history of symptoms and drug therapy, so that we can accurately evaluate the pathological findings. This information will be kept confidential. Researchers will be able to publish the results of their research, however information will be provided in such a way that you cannot be identified.

Costs

Funeral arrangements and expenses remain the responsibility of you and your family. In South Australia we are fortunate to have the support of the funeral directors who transport the donor to either Flinders Medical Centre or Royal Adelaide Hospital for tissue removal, generally with no additional cost to the family (metropolitan area only). There are no costs to the family for the tissue removal and processing.

Withdrawal of consent

You can withdraw your consent to be a donor at any time.

Additional information

If you would like any additional information, please contact: The Coordinator, South Australian Brain Bank, Neurology Unit, Flinders Medical Centre, Bedford Park SA 5042. Tel: 08 8204 4107 or Mobile: 0431 500 880 during normal office hours.

Complaints

The South Australian Brain Bank tissue donor program has been approved by the Flinders Clinical Research Ethics Committee. Any person with any concerns or complaints should contact the Brain Bank Coordinator. If you still have concerns contact the Administrative Officer-Research, Flinders Clinical Research Ethics Committee (08) 8204 4507 during normal office hours.

We are aware that making the decision to donate tissue after death is a very personal one.

We assure you that we will use the tissue for the ultimate benefit of those who suffer from brain disease.

We appreciate that the event of death is an emotional and stressful time for those left behind. We will make every effort to ensure that the donation does not add to the stress. On the contrary, we hope it will be a comfort.

We are grateful for your commitment to medical research and teaching

Please return your consent form and information pages to:

SA Brain Bank Co-ordinator

Neurology Unit, Flinders Medical Centre, Bedford Park SA 5042

Once you return your consent form, you will receive a Donor Card that you should fill in and keep in an accessible place. If you would like any additional information, please contact the Brain Bank Co-ordinator at Flinders Medical Centre on 8204 4107 or 0431 500 880 during normal office hours.

DONOR CONSENT FORM

I,
(name of donor)

of
(address of donor)

agree that after my death my brain / spinal cord / cerebrospinal fluid / blood (delete as necessary) be used for medical research or teaching related to brain disease and that my medical records be made available for that purpose.

- ❖ I consent to providing a blood sample should one be requested []
- ❖ I do not have any neurological disease [] OR
- ❖ I have the following neurological disease: (please specify)
- ❖ I understand that genetic causes of neurological diseases are among the areas of interest for research. I waive all rights to royalties that may arise from the research []
- ❖ I understand that I can revoke my consent at any time []

Signature of donor: Signature of Witness:

(see below for next of kin/ power of attorney authority) Name of Witness:

Date:..... Date:.....

NEXT OF KIN CONSENT

I (Next of Kin/ Power of Attorney)
(name of Next of Kin/ Power of Attorney) (delete as necessary)

of
(Address of Next of Kin/ Power of Attorney)

have no reason to believe that the donor objects to the donation of tissue from his/her body after death, or that another next of kin objects to the donation of tissue from the body of the deceased.

I have no objection to the removal of tissue (as specified above) for scientific research. I understand that the tissue will be stored indefinitely according to standard protocols.

I understand that the above named has waived all rights to royalties that may arise from the research.

I understand that I can revoke my consent at any time .

Signature: Relationship to Donor:

Date:.....

For Brain Bank Use Only:

I, being a Designated Officer of
(name) (Hospital)

....., authorise the removal of the brain and spinal column to be conducted on the body of for the purpose of medical research and teaching related to neurological disease.

Signature:..... Date:

DONOR INFORMATION FORM (PART 1)

Name:

Address:

Telephone:

Date of Birth: Country of Birth:

❖ **I do not have any neurological disease** []

or

❖ **I have one of the following diseases:**

- Alzheimer's disease []
- Parkinson's disease []
- Motor neuron disease []
- Huntington's disease []
- Schizophrenia []
- Other [] (please specify)

My Next of Kin is:

Name:

Address:

Telephone:

Relationship:

My General practitioner is:

Name:

Address:

Telephone:

My Specialist is:

Name:

Address:

Telephone:

DONOR INFORMATION FORM (PART 2 - OPTIONAL)

Marital Status:

Occupation:

Approximate Height and Weight: Height: cms Weight: Kg

Do you have any of the following conditions (please tick):

- High Blood Pressure: [] (year diagnosed)
- Heart Disease: [] (year diagnosed)
- Diabetes: [] (year diagnosed)
- Arthritis: [] (year diagnosed)
- An infectious Disorder: [] (please specify)
- Any other conditions: [] (please specify)

Please list all medications you are currently taking:
.....
.....
.....

Do you smoke tobacco? Yes/No If yes:

How many cigarettes per day: How long have you smoked? years

Do you drink alcohol? Yes/No If yes:

What is your average alcohol intake per day/times per week (standard drinks)?

What do you normally drink? (please circle) Beer Wine Spirits Combination

How long have you drunk alcohol? (please tick)

Most of adult life: [] For less than one year: [] For less than five years: []

How would you describe your diet?

Please circle: Good Fair Poor

Do you take Vitamins? [] Are you a Vegetarian? []

Have you ever been in hospital? Yes/No If yes:

Please provide the name of the hospital, year and reason:
.....
.....
.....

Do you consider yourself to be: Left handed Right handed Ambidextrous (please circle)

Which hand do you use to write legibly? Left Right Either (please circle)

Which foot do you use to kick a ball at a target? Left Right Either (please circle)

If there is any additional information which you think may be relevant, please attach it to this package and return it to us at the address provided.



South Australian Neuroscience Institute

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