

Prince of Wales Medical Research Institute, Barker St, Randwick, NSW, 2031. Ph. (02) 9399 1000 Fax (02) 9399 1105  
 Department of Pathology, D06, University of Sydney, Sydney, NSW, 2006. Ph. (02) 9351 2414 Fax (02) 9351 3429

## BRAIN DONATION FOR AGEING & NEURODEGENERATION RESEARCH

### PARTICIPANT'S CONSENT FORM – PARTICIPANT'S COPY

SESAHS Approval No: 03/192

CSAHS Approval No: CH62/6/2003-096

1. I, \_\_\_\_\_ (NAME OF PARTICIPANT including title),  
 of \_\_\_\_\_ (ADDRESS including postcode),  
 born \_\_\_\_\_ (DATE OF BIRTH), with the agreement of my next of kin:  
 \_\_\_\_\_ (NAME OF NEXT OF KIN/RELATIONSHIP),  
 of \_\_\_\_\_ (ADDRESS including postcode),  
 request that all reasonable measures be taken to ensure that an examination of my brain be carried out for medical research following my death. I agree also to participate in the following aspects of the research programme described in the Information Brochure accompanying this form. These include ongoing participation in health surveys, access to medical and research records, DNA extraction from brain samples, indefinite storage of brain and DNA samples, analysis of brain/DNA samples for research, and scientific sharing of de-identified brain/DNA samples. *(Delete and initial any aspects you do not wish to participate in).*
2. I acknowledge that I have read the Information Brochure, which explains why I have been selected, the aims of the research programme, the nature and possible risks of participation in the study, and that the statement has been explained to me to my satisfaction.
3. I have been given the opportunity to ask any questions relating to any possible harm suffered as a result of participation and I have received satisfactory answers.
4. I understand that I can withdraw from the research programme at any time without prejudice to my relationship with the participating institutions.
5. I agree that any data gathered may be published, provided that I cannot be identified.
6. If findings are made that have implications for my family, I would like my family/my family doctor to be contacted. *(If you choose for the relevant person not to be informed please delete and initial).*
7. I understand that if I have any questions relating to participation in this research, I may contact the investigator who will be happy to answer them.
8. I understand that I will not receive any financial benefit from my participation in this study.
9. I acknowledge receipt of a copy of the Information Brochure.

\_\_\_\_\_  
**Signature of Research Participant**

\_\_\_\_\_  
**Signature of Next of Kin**

\_\_\_\_\_  
**Signature of Witness**

\_\_\_\_\_  
**Please PRINT name**

\_\_\_\_\_  
**Please PRINT name**

\_\_\_\_\_  
**Please PRINT name**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Telephone**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Telephone**

\_\_\_\_\_  
**Date**

## BRAIN DONATION FOR AGEING & NEURODEGENERATION RESEARCH

### WITHDRAWAL OF CONSENT (PARTICIPANT) – Return to Brain Donor Programme Prince of Wales Medical Research Institute, Barker St, Randwick, NSW, 2031

I withdraw my consent to participate in the research programme named above and understand that such withdrawal will not jeopardise any treatment or my relationship with the institutions involved in this research. Please arrange for my tissue samples and/or information to be destroyed/retained in a deidentified way *(please delete whichever is applicable).*

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Please PRINT Name**

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## BRAIN DONATION FOR AGEING & NEURODEGENERATION RESEARCH

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#### What to do when the donor dies?

- Notify the researchers as soon as possible after death using the 24 hour contact details below.
- If the donor dies at home or in a nursing home, the General Practitioner is required to certify the death and supply a death certificate before the donor's body can be moved. If the donor dies in hospital, the attending doctor will sign the death certificate.
- Funeral directors appointed by the family are informed.
- The researcher will then contact the funeral director and make the necessary arrangements for the body to be taken to a hospital for removal of the brain.
- Two documents must accompany the donor:
  1. The death certificate
  2. A signed consent form
- Researchers will inform the funeral directors when the procedure is completed so normal funeral arrangements can be resumed

#### 24 HOUR CONTACT NUMBERS

Brain Donor Coordinator 132 222: quote pager #201531  
(02) 9036 7117 (b.h.)

Prof Glenda Halliday 132 222: quote pager #87392  
(02) 9819 6947 (home)  
(02) 9399 1104 (b.h.)

Assoc Prof Jillian Kril (02) 9214 4335 (pager)  
(02) 9036 7118 (b.h.)

**This procedure will not interrupt the normal funeral arrangements and will not result in any additional cost to the family. If you have any queries regarding any of these procedures or any questions about the research programme, please do not hesitate to contact us on the numbers given above.**

#### PLEASE RETAIN THIS FORM

At the time of death, this form and the death certificate must remain with the body.

If you are concerned in any way about the conduct of this research, you may contact the Research Ethics Secretariat, Prince of Wales Hospital, Randwick. Ph (02) 9382 3587, fax (02) 9382 2813, e-mail [brehenyk@sesahs.nsw.gov.au](mailto:brehenyk@sesahs.nsw.gov.au) or at Concord Hospital Ph (02) 9767 6233, fax (02) 9767 7883, e-mail [turner@email.cs.nsw.gov.au](mailto:turner@email.cs.nsw.gov.au)