

Neuropathology Donor Consent Form

(for completion by an individual before death)

Thank you for taking the time to consider the gift of brain donation. Your interest in helping research into neurological diseases may help to alleviate or prevent the suffering of future generations. We hope you will feel that your donation is a valued contribution to the improved understanding and treatment of neurological diseases.

Before completing this form you should read the information leaflet provided and take as much time as you need to consider your decision. Consent from your next of kin or nominated representative is not legally required but it is unlikely that we would act against the wishes of your next of kin following your death. We recommend therefore you discuss your wishes with your next of kin or nominated representative so they are made aware of your wishes. This reduces uncertainty at a difficult time.

Should you or your family wish to read further information on the progress of the research carried out by the Brain Collection, they can view Newsletters at

<http://www.ouh.nhs.uk/services/departments/neurosciences/neuropathology/default.aspx>

This is a generic consent form allowing research into diseases of the brain and/or spinal cord. If you wish to restrict your consent please specify in Section Two

Your Surname/Family name: _____

First or other names: _____

Male / Female: _____ Date of birth: _____

NHS Number: _____

Address: _____

Town / County: _____

Post Code: _____

Preferred Tel: _____

Section One: Agreement to removal of central nervous system and other tissue

It is very helpful if both brain and spinal cord can be donated especially in cases of motor neurone disease, ataxia and normal control tissue. Please tick 'Yes' to agree, and tick 'No' if you disagree with the option.

I consent to the removal and long term preservation of tissue for research as specified in Section Two.

Yes No Brain

Yes No Spinal cord *Occasionally we do not have the resources to remove spinal cord even when the 'Yes' box is ticked.*

Yes No Other tissue *(Please specify):*

Section Two : Use of Retained Tissue

I agree the tissues may be :

Yes No 1. Stored and used for ethically approved research in an NHS or academic setting.

Yes No 2. Stored for and used for ethically approved research in a commercial setting.

Yes No 3. Stored and used for education/training relating to human health or performance assessment.

Yes No 4. Stored and used for quality assurance.

Yes No 5. Stored and used for clinical audit.

Neurological research often involves genetic analysis of tissue

Yes No 6. Stored and used for genetic (DNA) studies for ethically approved research.

Section Three. Health Records.

The identity of the individual is not normally known to a researcher but it is often helpful to know more about the medical history of the person who has died. We require your permission to obtain this information should we wish to do so. Names will never be identified in any published results of research. You may also be asked to complete a separate medical questionnaire in addition to this form.

I understand that members of the research team may need access to my medical notes if needed and I give my consent to do this (all information will remain confidential).

Tick to confirm

Section Four: After the Research

Brain tissue can be preserved for many years. However it is possible that eventually it is necessary to dispose of the tissue. This will be done in accordance with the law and government guidance in effect at that date.

I understand the hospital may dispose of the tissue when the tissue is of no further use

Tick to confirm

Section Five: Your signature and your witness

Please read through this form and check you are certain of your decisions before signing this form. We need you to ask someone to witness your signature. Your witness can also be your next of kin *.

* If you are unable to sign in person because of your medical condition two witnesses must sign that you have confirmed to them your intention as described in this form.

Your signature: _____

Date: _____

Yes No I confirm that I have discussed my intentions with my next of kin / nominated representative / executor (select as appropriate) as named below.

Name of my next of kin/nominated representative/executor

Address of my next of kin/nominated representative/executor

Contact telephone numbers for my next of kin/nominated representative / executor

Signature of witness (1):

Signature of witness (2) if applicable*

Relationship to donor:

Relationship to donor:

Date:

Date:

Print name:

Print name:

Address

Address

Post Code

Post Code

Any comments:

Section Six: Signature of health professional involved in supporting consent

Some individuals choose to be supported or assisted through this donation process by working with a health professional. If this is the case please ask the health professional to fill in Section Six. If you did not choose to have support, please put a line through this Section, to indicate 'Not applicable'.

I confirm that:

- I have explained to the donor giving consent, the procedures involved.
- I have ensured there are no known objections to the removal of central nervous system tissue
- The following information leaflets have been provided:

Specify title of leaflet(s) - and version (if known)

Signature: _____ Date: _____

Print Name: _____

Job title/Position: _____

Organisational address:

Telephone number and/or bleep number : _____

- I have discussed the case with a neuropathologist:

Neuropathologist's name: _____