

Name of Donor.....Date of Birth.....



EDINBURGH BRAIN BANK

CONSENT FOR DONATION OF CENTRAL NERVOUS SYSTEM TISSUE FOR

DIAGNOSIS AND RESEARCH FOLLOWING DEATH

Please initial boxes

1. I have read the information pack (dated 16th July 2021, Version 2) and wish to consent to a post mortem examination after my death.
2. I understand that if my death takes place at home, my body will be transported to Edinburgh Royal Infirmary mortuary for post mortem examination. There will be no additional cost to my family for this if the approved funeral director is used.
3. I give consent for a post-mortem examination limited to the head (brain) and/or spinal cord to take place following my death.
4. I understand that I can withdraw consent at any time before the procedure has taken place, without giving a reason and without my medical treatment or legal rights being affected.
5. I give consent for my brain to be removed at the time of the limited post-mortem examination and for a range of tissue samples from the brain to be retained for diagnostic purposes and all ethically approved medical research and I am not aware that any family member has an objection to this.
6. I give consent for my spinal cord to be removed at the time of the limited post-mortem examination and for a range of tissue samples from the spinal cord to be retained for diagnostic purposes and all ethically approved medical research and I am not aware that any family member has an objection to this.
7. I give consent for the results of the post mortem examination to be sent to my GP and referring consultant (if appropriate).
8. I give consent for the use of the tissue in any research agreed by the Management Committees of the Edinburgh Brain Bank. I understand that the Edinburgh Brain Bank will undertake custodianship of the donated tissue in full compliance with guidelines agreed by National Research Ethics Committee, Health Improvement Scotland and the UK Medical Research Council.
9. I give consent for tissue samples to be used by researchers in the commercial sector e.g. pharmaceutical companies, to help with the development of new drug treatments and diagnostic tests, which may benefit human health.
10. I understand that neither I, nor my nearest relative, nor family members will receive any financial benefit from tissue donation.
11. I give consent for tissue samples to be used for genetic analysis/study and/or research.
12. I give consent for the tissue to be stored as protein, RNA and/ or DNA.

Name of Donor.....Date of Birth.....

- 13. I give consent for the tissue to be used in projects outside the UK, if approved by the Management Committees of the Edinburgh Brain Bank.
- 14. I give consent for the tissue retained for research to be used as a reference for other clinical cases, for medical education, medical photography, audit and quality control.
- 15. I give consent for access to my medical records and any NHS electronic medical records.
- 16. I give consent for access to psychometric data and other research study information (Note: the researcher does not know the identity of the donor and the identity of donors is never given in publications).
- 17. I agree that all gathered data may be collected and stored on a secure database.
- 18. I agree that my General Practitioner (GP) may be contacted and informed of my involvement in this study.
- 19. I give consent for the Edinburgh Brain Bank to keep indefinitely the tissue donated for research and to lawfully dispose of it when it can be of no further use.
- 20. I confirm I still wish to donate central nervous system tissue for research even in the event that my capacity to make such a decision is diminished in the future.
- 21. I understand that my nearest relative will confirm my wish to donate by completing a Hospital Post-Mortem Authorisation form following my death.

Name of Donor (Print).....

Signature of Donor (if able) or proxy.....

Relationship to donor if signed by proxy..... **Date**.....

Name of Nearest Relative (Print).....

Signature of Nearest Relative.....

Relationship to donor..... **Date**.....

Name of Donor.....Date of Birth.....

Member of Staff Obtaining Consent

I confirm that:

I have explained the procedure of post-mortem examination

I have explained what the process of tissue donation involves

There are no known objections to tissue donation

Name (Print).....

Designation.....

Signature.....**Date**.....

GENERAL PRACTITIONER

Name.....

Address.....

.....

Telephone.....

Thank you for agreeing to donate central nervous system tissue for research.

If you have any queries regarding this form please contact:

Tracey Millar
Research Nurse Manager
Academic Department of Neuropathology
Centre for Clinical Brain Sciences
University of Edinburgh
Chancellor’s Building
Edinburgh BioQuarter
EH16 4SB
Tel: 0131 465 9522
Mob: 07913296845
Email: Tracey.Millar@ed.ac.uk

Professor Colin Smith
Co-ordinator of Post Mortem Research
Academic Department of Neuropathology
Centre for Clinical Brain Sciences
University of Edinburgh
Chancellor’s Building
Edinburgh BioQuarter
EH16 4SB