INFORMATION ON TISSUE DONATION

We appreciate your interest in tissue donation; although this does not benefit individuals directly, it does help advance knowledge of brain disorders.

Please read the following information carefully. You may wish to discuss it with your family, friends or General Practitioner.

An introduction to the Queen Square Brain Bank for Neurological Disorders

University College London (UCL) Institute of Neurology and the National Hospital for Neurology and Neurosurgery have an international reputation for research into and treatment of neurological disorders. The Queen Square Brain Bank for Neurological Disorders (QSBB) has a unique tissue collection which is used to study a range of conditions including Parkinson’s disease, progressive supranuclear palsy, multiple system atrophy, dementia and dystonia. It has made significant contributions to understanding the causes of neurological disease and to developing new treatments.

A tissue donation is a gift. Because the brain is a complicated organ, a whole brain is needed for diagnosis, research, developing medical and scientific tests, education and audit. Examination of the spinal cord and samples of other tissues such as skin, muscle, peripheral nerve, dura (the brain covering) and internal organs can also contribute to diagnosis and research. Cerebrospinal fluid (CSF) bathes the brain and spinal cord, and the study of this, along with a blood sample, may provide useful information and can be obtained at the time of donation. Together the brain, spinal cord, other tissue samples, CSF and blood will be referred to as tissues in this information sheet and in the consent form.

Tissue samples are examined under a microscope to identify any disease processes. We may also request analysis of DNA and other genetic material to look for abnormalities specific to some diseases. Some samples are preserved whilst others are kept frozen so that they remain valuable for research for many years to come. These are stored in a locked facility accessible by authorised staff only.

To ensure confidentiality, each donation is given a unique code number and records are held securely. Code numbers are also used on photographs taken of specimens, microscopic slides and on clinical information. Tissues, clinical data and genetic information are released to researchers in the UK and world-wide for as many studies as possible, which may include genetic research and rarely research involving the use of animals. The quality and ethical aspects of proposed research projects are assessed by a QSBB committee to ensure tissue is used appropriately.
Results of research are published in scientific journals and are not available on an individual basis. Anonymity of donors is maintained although complete anonymity cannot always be guaranteed as it is possible donors could be recognisable to those who have known them.

Research may be carried out with the support of the commercial sector, in line with the UCL Institute of Neurology’s policy of encouraging research that will lead to new therapies. Intellectual property agreements are always set up so that neither the scientists nor the donors’ families gain a financial advantage.

The Human Tissue Act (2004) prohibits trade in human tissues for profit. To offset the considerable expenditure for banking tissue some cost recovery is necessary and researchers are asked to contribute a service fee, as recommended by the Medical Research Council UK Brain Banks Network.

**The importance of correct diagnosis**

Information about many neurological disorders can only be gained by microscopic examination of the brain and related tissues. For research to be precise, a diagnosis made in life must be confirmed by neuropathological evaluation.

Many neurological conditions are not inherited, and often the close relatives of an affected person are at no greater risk of developing the illness than anyone else. However, in some cases problems with a particular gene can cause disease and if the neuropathological examination reveals this possibility, a diagnostic genetic test of tissue may be necessary to determine a definite diagnosis. The next of kin will always be contacted with the support of appropriate medical or nursing personnel to discuss the potential for inheritance and will be asked to give specific consent before any diagnostic genetic test is performed.

We would be pleased to discuss the neuropathological findings with the next of kin, which will be provided by appropriate medical or nursing personnel. Over time research may require additional information from the next of kin, and the QSBB will seek permission to make contact in the future if necessary.

**How to become a tissue donor**

Individuals with a neurological condition and those who are healthy can register on our donor scheme. Tissues donated from people with no neurological illness are of vital importance, providing researchers an understanding of the normal appearance and function of the brain and for comparison with disease.

A donor must be over 18 years of age, reside in the UK, and have discussed the bequest with a relative or appointed representative. The Registration and Consent to Tissue Donation forms must be completed and signed and sent to the administrator at the above address. If a donor is unable to complete the consent form, it is possible for a next of kin or appointed representative to do this and sign the declaration on their behalf. Please contact QSBB if there are any queries.

When consent to donate is received by QSBB, a donor is registered on our donation scheme and a donor card is issued, which should be carried at all times. With permission, a link to an online self-assessment questionnaire requesting medical information may also be sent to the donor. All data will be held on a highly secure web-based database that is used in numerous similar studies within the NHS and is compliant with strict data security guidelines. Access to personal data will be protected and restricted to authorised members of the research team.

Consent is sought to allow clinical information to be obtained from medical records and securely stored on a UCL computer database. A donor’s identity and the data collected and stored remain strictly confidential in accordance with General Data Protection Regulation.
**Actions to be taken at the time of the death of a donor**

It is important that there is as short a delay as possible between death and donation. We would be grateful if the QSBB is informed if a prospective donor becomes seriously ill.

After death, the GP or appropriate medical staff must confirm the death and the donor’s body can then be taken into the care of a local funeral director and refrigerated, preferably within four hours. The QSBB team should be contacted as soon as possible. Outside office hours the answer phone will give the mobile telephone number of the duty officer to contact. If the donor has not completed consent during life, the next of kin will be asked to complete and sign a QSBB post mortem consent form. QSBB staff will liaise with the GP and on confirmation that the Medical Certificate of the Cause of Death is issued, will then liaise with the funeral director to arrange for the donor’s body to be transported to the nearest local hospital where the removal of tissues can be performed.

As brain donation does not require removal of the eyes or lead to disfigurement of the face, it does not prevent open casket or other traditional funeral arrangements. Skin, muscle and peripheral nerve samples can be taken from small incisions on the leg. Removal of the spinal cord results in a long scar on either the front or back of the body, but this or incisions on the leg are not visible once the body has been prepared for the funeral. Only donated tissues are transferred to the QSBB. The donor’s body will be collected by the family’s chosen funeral director and the usual funeral arrangements can proceed without delay. All costs directly related to the tissue removal will be met by the QSBB. Funeral costs must be met by the family.

On occasions the QSBB may be unable to accept a donation. This can be due to a number of reasons such as the donor having other conditions that may affect the brain, or if unfavourable circumstances prevail at the time of death, including the opposition of next of kin. For legal reasons some deaths require a post-mortem examination performed by the Coroner. However it may still be possible to arrange for the transfer and examination of tissues at the QSBB. This would require discussion between the Coroner, QSBB staff and the next of kin at the time of death.

**Important notes**

Even if donor registration was not completed during life, the next of kin or appointed representative may still complete a tissue donation form following death, in the knowledge that the donor would not have objected.

If a prospective donor’s details change, for example address, next of kin, General Practitioner, diagnosis, please notify the QSBB so that records can be amended.

As time passes it may be necessary to alert additional people to the bequest or remind others who may have forgotten.

An individual is free to withdraw consent at any time without having to give a reason. Please note that next of kin can withdraw consent after death. Samples and data will be removed from QSBB records and researchers will no longer be able to access these. However if samples and data have already been used in the research process, complete removal may not always be possible.

When tissue is no longer suitable for research, we arrange careful disposal in a lawful and respectful manner in compliance with the Human Tissue Act 2004 and UCL policies. The QSBB is fully licensed by the Human Tissue Authority, a government regulatory body which oversees consent, storage and the use of human samples in research. QSBB protocols have been approved by the National Research Ethics Service, Committee London-Central.

If you have any comments, wish to withdraw consent or make a complaint about your involvement with the QSBB, firstly please contact the administrator, Queen Square Brain Bank, UCL Institute of Neurology, 1 Wakefield Street, London WC1N 1PJ. Telephone: 020 7837 8370. If this is not satisfactory you may wish to make a complaint through the University College London’s complaints procedure (the details of which can be obtained from UCL).