INFORMATION ON TISSUE DONATION

We appreciate your interest in tissue donation. Although tissue donation does not benefit individuals directly, it does contribute to the advancement of medical knowledge of brain disorders.

Please take time to read the following information carefully and 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 at Queen Square have an international reputation as centres of excellence for research into and treatment of neurological disorders. The Queen Square Brain Bank for Neurological Disorders (QSBB) has established a unique tissue collection which is used to study the effects of disease and to support research into a range of conditions including Parkinson’s disease, progressive supranuclear palsy, multiple system atrophy, the dementias and dystonia. It has made a significant contribution to our understanding of the causes of neurological disease and in developing new treatments.

A tissue donation is a gift. Because the brain is a very complicated organ, a whole brain is needed for diagnosis, research, developing medical and scientific tests, education and audit. Examination of the spinal cord may contribute to diagnosis and research. In some cases it may aid research to collect small samples of other tissues such as skin, muscle, peripheral nerve and internal organs. Cerebrospinal fluid (CSF) bathes the brain and spinal cord, and the study of this, along with a blood sample, may also 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.

Some tissue samples are preserved for diagnosis and research. Other tissue is frozen and kept at a low temperature so that it remains valuable for research for many years to come. The research usually begins by examining the tissue under a microscope to identify any disease processes that have affected the brain. We may also analyse the DNA and other genetic material to look for abnormalities that may be specific to some diseases.

Tissues are stored in a locked facility where only certain staff have access. To ensure all information remains confidential, each tissue donation is given a unique code number and records are held securely. To ensure anonymity the same unique code numbers are also used on photographs that may be taken of specimens and microscopic slides and on clinical information released to researchers.
Tissues are provided to researchers in universities in the UK and world-wide for as many research projects as possible. The quality, including ethical aspects of the proposed research is assessed by a committee of the QSBB so that tissue is used appropriately. We also carry out research with the support of industry.

This is in line with the UCL Institute of Neurology’s policy of encouraging research that will lead to new therapies. In these instances intellectual property agreements are set up, which means neither the scientists nor the donors’ families gain a financial advantage.

The Human Tissue Act prohibits trade in human tissues for profit. To offset the considerable expenditure by the QSBB for the banking of 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**

Further 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 carried out by a consultant neuropathologist.

Many neurological conditions are not inherited, and often the close relatives of an affected person are at no greater risk of developing the disease than anyone else. However, in some cases problems with a particular gene can cause these conditions and be inherited. When the neuropathological examination reveals the possibility of an inherited genetic disease, a diagnostic genetic test of the brain tissue may be necessary to determine a definite diagnosis. The next of kin will always be counselled by trained QSBB staff and will be asked to give consent before any diagnostic genetic test is performed.

Results of research are published in scientific journals and are not available on an individual basis. The anonymity of individual donors will be preserved in the research procedure and subsequent scientific publications. However, complete anonymity cannot always be guaranteed in publications, as it is possible donors could be recognisable to those who have known them.

We would be pleased to discuss the diagnosis after the neuropathological examination. This will be provided by trained QSBB staff or appropriate medical or nursing personnel. As research projects may require new information from the next of kin, the QSBB staff may ask their 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 who did not have a neurological disease are of vital importance, providing researchers an understanding of the normal appearance and function of the brain and for comparison with diseased brains.

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 "Consent to Tissue Donation" must be completed and signed and sent to the administrator, Queen Square Brain Bank 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 on their behalf and sign the declaration. Please contact us if there are any queries.

Once the consent to donate has been received by the QSBB, a donor is then registered on our donor scheme and a donor card is issued, which must be carried at all times. A self-assessment form requesting information on health and lifestyle may also be sent to the donor.

All information will be securely stored on our computerised database so that essential clinical information is available to the neuropathologist. The identity and the data collected and stored about all registered donors remain strictly confidential in accordance with the Data Protection Act 1998.
**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 donor becomes seriously ill.

After death, the GP or appropriate medical staff must confirm the death and issue the death certificate.

The donor’s body can then be taken into the care of a local funeral director and refrigerated, preferably within four hours of death. The QSBB can be contacted as soon as possible and will liaise with the funeral director to arrange for the donor’s body to be transported to the nearest hospital where the removal of the tissues can be performed. Before donation takes place the next of kin will be asked to complete and sign the QSBB consent form if the donor had not completed the consent to donate during life. A member of the QSBB team will help to coordinate this. After office hours the QSBB answer phone will give the caller the mobile telephone number of the duty officer to contact.

Only the donated tissues are transferred to the QSBB. The donor’s body can then be returned to the family’s chosen funeral director and the usual funeral arrangements can proceed without delay. 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. However, in view of this some donors may decide not to donate the spinal cord and samples from internal organs. 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 may have had other illnesses that affect the brain, or there may be a delay to the donation due to the circumstances of the donor’s death. For legal reasons some deaths require a post-mortem examination to be performed by Her Majesty’s Coroner. In these circumstances 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 arrange for tissue donation following death, in the knowledge that the donor would not have objected.

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

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

If after signing consent to donate an individual has a change of mind, consent can be withdrawn at any time without having to give a reason.

When tissue is no longer suitable for research, we carefully dispose of it 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 that oversees the use of human samples in research, and the brain banking protocols have been reviewed and approved by the London Central Ethics Committee.

If you are unhappy or wish to 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 then you may wish to make a complaint through the University College London’s complaints procedure (the details of which can be obtained from UCL).