

## **If you become a donor will this information be private and confidential?**

Yes. Once the donation has occurred, the tissue is stored securely at the VBBN based in Parkville and is identified only by a unique identification number. Donor details are held securely on computer and in locked files at a separate location to ensure confidentiality.

Researchers have access to the tissue and clinical information which is coded with a unique identification number, so no donor personal details can be identified. No donor is ever identified by name in any publications or presentations that result from the research.

## **What effect will making a brain donation have on funeral arrangements?**

None. The post mortem procedure does not interfere with the normal course of events associated with a funeral.

The post mortem does not affect the ability to have a viewing or open casket funeral as the brain is removed in such a way as to minimise visible marks.

## **Is brain donation the same as tissue or organ donation such as cornea or kidney?**

No. The donated brain is not used for transplant, but solely for research and study under the microscope. Consequently, separate consent is required for brain donation for scientific research.

## **When should plans be made for this procedure?**

It is important to make the necessary arrangements well in advance, since family members need time to discuss this very important issue. Ultimately, your senior available next of kin will be responsible for making sure your wishes are fulfilled.

## **How do I make preparation for a post mortem brain donation?**

By contacting Fairlie Hinton, VBBN Coordinator. You will receive the relevant permission forms and instructions so the necessary arrangements can be organised.

**Tel:** 03 8344 1900 or 0438 530 372  
**Email:** fhinton@mhri.edu.au  
**Mail:** Coordinator VBBN  
National Neuroscience Facility  
Level 3, 161 Barry Street  
Carlton South 3053

## **Can I make a donation to the running of the VBBN?**

The cost of preparing, examining each brain for diagnosis, storing and distributing to researchers is very costly. Monetary donations to the VBBN are gratefully accepted. Donations over \$2.00 are tax deductible. One off or regular donations can be made in the form of cash, cheque or credit card. A bequest donation in your will is a powerful way of showing your support to long term research into neurological and psychiatric illnesses.

The VBBN can provide document to be available at the funeral to facilitate donations in lieu of flowers.

All donations whether large or small will ensure that we are able to provide this vital resource to the neuroscience research community in an attempt to find treatment and cures.

The VBBN is supported by Neurosciences Australia and Australia's National Health and Medical Research Council.

Modified March 2007

# **Victorian Brain Bank Network**

## **Brain Donation for Research**

### **For Diagnosis and Research into Neurological and Psychiatric Disorders**



THE UNIVERSITY OF  
MELBOURNE



**mndRTBv**  
**Motor Neurone Disease Research**  
**Tissue Bank of Victoria**

The aim of the Victorian Brain Bank Network (VBBN) in collaboration with the Australian Brain Bank Network (ABBN) is to provide Australian and international clinicians and researchers with access to brain tissue that can be used for studying different disorders of the brain.

The donation of post-mortem (autopsy) brain tissue for research is of fundamental importance to further our understanding of the causes of neurological and psychiatric conditions and to develop more effective diagnostic tools and treatments for these conditions.

Direct examination of the brain after death opens the door to many of its mysteries. It also allows for correct diagnosis, which can have implications for other family members.

The research-based resource centre has been established to provide a service to medical science. Its purpose is to support medical research, which seeks the causes, and develops treatments and cures for a variety of neurological disorders.

**By encouraging interested persons to make a post mortem brain donation, the resource centre offers the donor the opportunity to support medical research.**

### **What is meant by brain tissue?**

We mean the whole brain. The brain is a very complex structure and it is necessary to look at all the different parts of the brain. In some neurological conditions the spinal cord is also essential for diagnosis and research.

### **Why is brain tissue needed for scientific research?**

Many conditions such as Alzheimer's disease, Depression, Huntington's disease, Motor neuron disease, Multiple sclerosis, Parkinson's disease, Schizophrenia, and other neurological and psychiatric conditions affect only humans. Brains from people affected with these illnesses are

essential for research devoted to finding treatments and cures.

### **Is tissue from normal brains needed?**

**Yes. Progress can be made towards finding the cause of neurological and psychiatric conditions if researchers can compare brains from those affected with to those who were not affected by such conditions. Unaffected spouse or family members may also consider registering as donors.**

### **How will information obtained from a brain examination benefit the family?**

Examination of the brain after death enables clinicians and researchers to accurately diagnose the illness that the donor may suffer and support research into these illnesses. A report stating the final diagnosis will be sent to the donor's doctor and is available for the senior available next of kin to discuss with the doctor. Occasionally post mortem diagnoses are different to those made whilst the donor was alive and could have only been made after a post mortem examination of the donor's brain.

**This resource centre offers the opportunity to support medical research into neurological and psychiatric conditions, which cannot be studied during life.**

This is particularly important for those in whom the neurological disease may have a hereditary or familial association. If you or a close relative have such a disease, this program may then be relevant for a child or grandchild who maybe at risk of developing the disorder.

In time, these donations will come to help those affected and those not yet affected. Active research is now in progress and already many medical and scientific articles have been published using donor specimens.

### **Can I become a donor if I live in regional Victoria?**

Yes. To be useful to researchers, post mortem tissue must be collected and stored as soon as possible after death. This will not always be possible as obstacles of timing and distance may sometime arise; however this should not deter people from registering as donors. In most cases the post mortem arrangements can be made with the nearest regional hospital.

### **What does a brain donation involve?**

The post mortem examination is an orderly procedure supervised by a pathologist. Ideally the procedure should take place within 24 hours after death but can take place up to 72 hours.

### **What happens to the brain tissue?**

Brains are treated in two ways to allow maximum information to be obtained and to ensure the tissue is usable in research for many years to come. Half the tissue is frozen and is used for research. The remaining tissue is fixed in formalin and allows for both neuropathologic diagnosis and research.

If we have to dispose of tissue that is no longer suitable for research it is done in an ethical and respectful manner in accordance with the prevailing institution's procedures.

### **What research is performed on the brain tissue?**

We cannot advise you as to the exact nature of this research as researcher's needs change with time and there are continuing advances in technology allowing for a wider range of scientific research. Researchers will only be able to access stored tissue and clinical information after obtaining approval for their research projects from their institutions Human Research Ethics Committee and the VBBN Scientific Advisory Committee. This is to ensure the tissue is used ethically and is only provided to feasible research projects with scientific merit.