the Bank Statement

News from

The UK Multiple Sclerosis Tissue Bank

ISSUE 1

A newsletter for you

Welcome to our first newsletter, designed with you in mind. Some of you will have already registered as donors, while others will be in the process of deciding whether it is right for you; or may be, you are the relative or friend of someone who has donated tissue. We hope that our **Bank Statement** will keep **all of you** up to date with what is going on here at the Tissue Bank.

In this issue, find out about…

- the aims of the Tissue Bank
- the ways in which the Tissue Bank is raising its profile
- the number of people that have registered as donors
- fulfilling the wishes of those who have already contributed to research
- the research that is using tissue donated to the Tissue Bank
- our new telephone numbers and your new donor card
- the things we would like you to tell us about

What does the Tissue Bank do?

In 1998, the Multiple Sclerosis Society awarded a 5-year grant to Imperial College School of Medicine at Charing Cross Hospital in London to enable the setting-up of a national MS Tissue Bank. The aim of this centralised facility is:

➔ to co-ordinate the collection of tissue donated for MS research from people that had MS and from people that did not have MS, and

➔ to distribute samples of the tissue to scientists conducting research into the causes and treatment of MS.

The Tissue Bank makes available high quality samples of tissue for research into multiple sclerosis.

Letting people know about our work

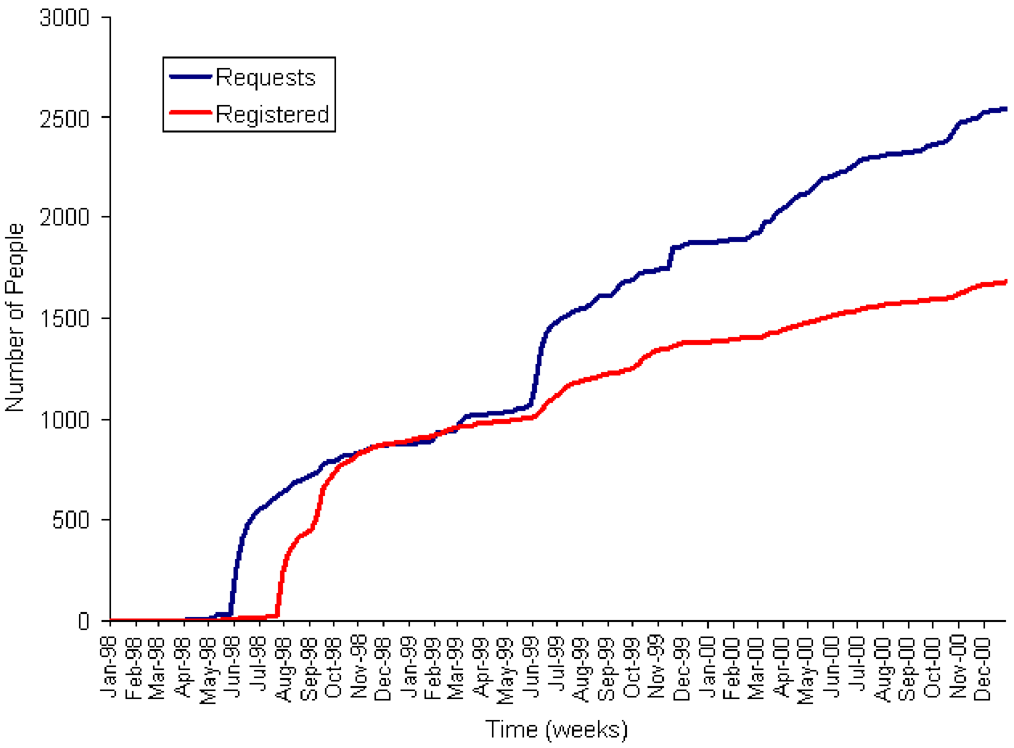
Since the very beginning of setting-up this brand new facility, we have felt it important to share with everyone interested in multiple sclerosis the work of the Tissue Bank and the fundamental importance of tissue banking to research. We want people to have all the information they might need to decide on an individual basis whether becoming a donor is right for them. Over the last three years we have raised our profile by:

- giving talks at over 50 local branches of the MS Society
- publishing articles and letters in the MS Society's MS Matters and TeaMSpirit,
- presenting our work at conferences for specialist MS Nurses
- having our articles published in specialist and general healthcare newsletters
- writing individually to each of the 484 neurologists working in the UK

A facility for tissue donors

Our success in promoting the work of the Tissue Bank, and the generosity and forethought of people wanting to make a special contribution to research is demonstrated by the fact that 1661 people (80% of whom have MS) are currently registered as tissue donors. The graph below shows how the number of people requesting an Information Pack (blue line) and registering as donors (red line) has increased over the last 3 years.

Accumulation of enquiries and registered donors



The steep rise in the number of people registering as donors between August and October 1998 coincided with an invitation to donors originally registered at the Queen Square Bank to re-register at Charing Cross and the publication in MS Matters of the first article about the Tissue Bank. As you will see, there are still about 900 people who have received an Information Pack and have either not yet sent in their registration forms or have decided that tissue donation is not right for them. We are encouraged that the total number of people requesting information and registering as donors is still steadily rising because **we need even more people to register.**

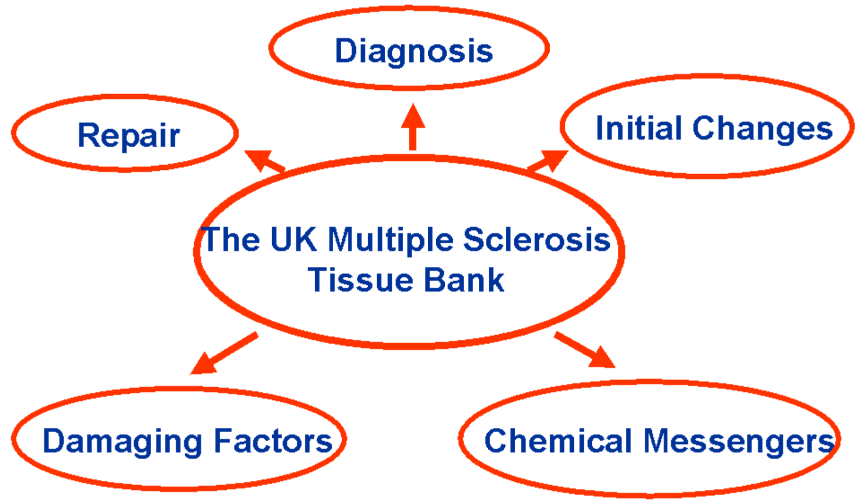
Fulfilling last wishes

Since 1998, we have been in the privileged position of fulfilling the last wishes of 73 MS patients and 14 non-MS patients who wanted to donate tissue for MS research. To ensure that the tissue we collect is suitable for use in the widest range of experiments, we have put in place procedures that allow it to be collected as quickly as possible after death in order to minimise its deterioration (within 24 hours if possible, but we will collect all bequests). This is an important aspect of our work and we are encouraged by the comments received from donors' next-of-kin on “…how efficiently and sensitively the procedure had been handled…”.

Resource for research

The Tissue Bank acts as an essential resource for scientists conducting research into MS. In addition to raising our profile in the MS community, we have also been promoting the Tissue Bank in the scientific community. Consequently we are now supplying tissue to a total of 27 research projects. These studies are being conducted in institutions across the globe from America to Japan, but our preference is to supply tissue to projects being carried out in the country from which the donors were recruited. Each of the 27 projects can be assigned to one of five main categories and any one donation can provide enough tissue for a number of projects in some or all of the five groups.

Five areas of research using tissue



Since there is not enough room to describe all the projects, here are just a few examples of studies from the five groups:

Better diagnosis?

(i) finding better ways to diagnose MS:
Tissue is being supplied to the MRI (Magnetic Resonance Imaging) Unit at the Institute of Neurology, London. In this project, a slice of brain containing MS lesions is scanned using new technology. The lesions are then dissected out, examined under the microscope and compared to the image. This allows any changes on the MR image to be directly compared with what is going on in the brain, helping to set up methods that can later be used in patients. These studies may allow different types of MS to be identified by MRI and may help identify groups of patients that respond favourably to a particular therapy.

What starts it all off?

(ii) identifying the initial changes in an MS lesion:
The formation of an MS lesion can be thought of as a cascade of events that culminate in demyelination. A research group based in Belfast believes that an early step in the formation of a lesion is a subtle change in cells called microglia that are normally resident in the brain. The group is characterising microglia in brain tissue from MS patients containing lesions at different stages of development, MS tissue without any lesions and tissue from people that did not have MS. This study will help us find out whether changes in the microglia start the formation of an MS lesion.

Is a virus the trigger?

Although the exact cause of MS is unknown, it has long been suggested that viruses may trigger the disease. The problem is that viruses are difficult to detect in tissue but a group at the Royal Free Hospital in London has overcome this problem by developing a very sensitive test for viruses. They are using the technique to see if the virus HHV6 (Human Herpes virus 6) is present in MS lesions. Identifying the agent that triggers the formation of a lesion would be necessary for the development of strategies for neutralising the causative agent.

What is the key messenger?

(iii) finding critical chemical messengers:
Chemical messengers released by cells within a developing lesion are central to the cascade of events leading to demyelination. Understanding the role of these molecules is the goal of a number of projects supported by the Tissue Bank. This research could form the basis of developing ways of knocking out the critical messenger(s) and stopping the cascade.

What exactly damages myelin?

(iv) identifying the factors that damage myelin:
It is generally believed that components of the immune system are responsible for damaging myelin in MS. The immune system has a large armoury that it normally uses to combat bacteria, viruses, fungi and parasitic worms that are continually trying to invade our bodies. It is thought that in MS the immune system becomes

overzealous and that as well as killing the invading organisms, it starts to attack myelin. The question that a group in Cardiff is trying to answer is which of the many components that the immune system has at its disposal is used to damage myelin in MS.

How can we promote repair?

(v) discovering factors that promote repair:
At the same time as finding an effective way of stopping any further damage to myelin, we need to find ways of repairing the damage that has already been caused. Our nervous systems have a natural ability to repair damaged myelin, and replace cells (oligodendrocytes) that are destroyed in MS. It is the oligodendrocytes that provide the myelin that insulates nerve fibres, and when we examine MS lesions, we frequently find these cells trying to repair the damaged myelin. Remyelination is therefore a naturally occurring process and the questions that groups in Basel, Paris and at Charing Cross Hospital in London are trying to answer are: why the process is not able to repair all the demyelination and how we can encourage repair in people that have MS?

Changes at the Tissue Bank

…New Logo

The Tissue Bank's new logo is shown on the front of the newsletter. We would like to think that it highlights that the brain and spinal cord are vital for research and that the UK Multiple Sclerosis Tissue Bank acts as an essential resource for scientists working to find the causes and better treatments for MS.

As a result of changes imposed by BT, our **new** telephone numbers are:

…Emergency Donor Line

07 693 300 300

Only for emergencies - e.g. to inform us of the death of a tissue donor. Both the new and the old number (01893 300 300) can be used now, but the old number will not work after 27th April 2001.

...Office numbers

020 8846 7324 (telephone) **020 8846 7500 (fax)**
(use for all enquiries about the Tissue Bank)

…E-mail

msbank@ic.ac.uk> (this stays the same as before)

…Donor Card

Your **new** Tissue Bank Donor Card is enclosed with the new Emergency Donor Line number on it. We have also printed your name, registration date and card number and left a space for you to sign. Please telephone us if you need extra copies of your card.

- put the new Tissue Bank's phone numbers on your registration forms
- let everyone concerned know that the emergency number has changed
- throw away your old yellow donor card - keep your new orange one handy!

Let us know

- of any changes that we need to make to our copy of your consent forms, (eg change of address, next of kin or GP)
- if you do not wish to receive another newsletter
- how we can improve what we do at the Tissue Bank, we value your feedback