



Brain Bank Bulletin

Issue 7
Winter
2006

The PDS Tissue Bank is sponsored by the Parkinson's Disease Society

The PDS Tissue Bank at Imperial aims to help understand what causes Parkinson's and assist in the development of better drug treatments by providing high quality brain tissue to researchers working in the field of Parkinson's and related neurological disorders. The Tissue Bank also aims to enhance the public's awareness of Parkinson's, promote the work of the Tissue Bank and increase the numbers of volunteers who are willing to sign up to the donor scheme. The Tissue Bank also aims to collect the tissue so that it is suitable for all research needs and that it is collected in the most ethical manner.

The PINE study and the Tissue Bank

Although Parkinson's disease (PD) is one of the most common neurological conditions, we know relatively little about how common it is in different parts of the world or about how the condition affects people over the whole of their lives. The PINE (Parkinsonism Incidence in North-East Scotland) study is addressing both these issues. Firstly, we are aiming to identify all people with newly diagnosed PD or other similar parkinsonian conditions who live in and around Aberdeen to see how common it is. Secondly, we are inviting all of the people we identify as being newly diagnosed to be followed up throughout their life to gather information on how the condition affects their every day activities, quality of life, mood and memory over time. We will compare the changes with a group of people who do not have PD to see what additional effects Parkinson's brings over and above 'normal ageing'.



Aberdeen Royal Infirmary

One of the problems with doing clinical research into PD is that we know we do not always get the diagnosis correct. The only way to be 100% sure that someone has PD is to look at their brain under a microscope after they have died. When this has been done, studies have shown that 10-25% of people who experts thought had PD turned out not to have the condition. Getting the diagnosis wrong will obviously flaw any research. For example, if patients with conditions that progress more rapidly than PD are misdiagnosed as having PD and included in research like ours, PD will appear to worsen quicker than it really does.

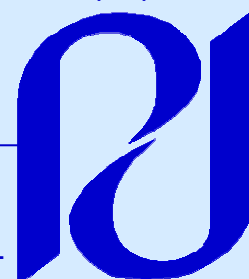
We are, therefore, asking PINE participants (sensitively of course) if they will agree to have a post-mortem examination of their brain to confirm or refute the diagnosis. In the process we are also asking if they would consent to donating their brain to the Parkinson's Disease Society Tissue Bank to contribute to ongoing research into the causes of PD and related conditions. Whilst this can be a difficult issue to discuss, we feel it is crucially important. Animal studies have taught us a great deal about what may go wrong in the brain in PD but ultimately there is no substitute for looking at brains from people with and without PD. After all, there is no natural equivalent of PD in the animal kingdom.

We wish to thank everyone who is participating in the PINE study.

Dr Carl Counsell- Clinical Senior Lecturer in Neurology, Aberdeen University

Different Types of Tissue Requested & Research Areas

Scientific research is a rapidly advancing field with new techniques being developed frequently. Hence, it is vitally important that the Tissue Bank collects and stores its tissue so that it can be used in research using a variety of research techniques, in order to advance Parkinson's research. Consequently, when a tissue donation occurs we handle the tissue in a number of ways so as to maximise its use. Part of the brain and spinal cord is frozen very rapidly or "snap" frozen so as to preserve the cellular components such as enzymes and genetic information. Such tissue can be preserved by keeping it frozen at very cold temperatures e.g. -85°C. This tissue can be supplied to a researcher in the form of thin tissue sections that can for example be used to localise genetic material at the cellular level, or as blocks, so that researchers can, for example, examine the activity of enzymes in a brain region. Alternately, the tissue can be placed in a preserving solution called "fixative". This type of tissue is primarily used to carry out the neuropathological diagnosis of the case i.e. identify whether a person had Park-

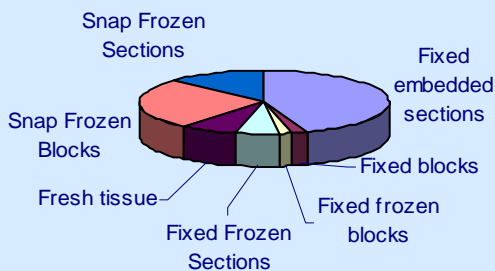


**Parkinson's
Disease Society**

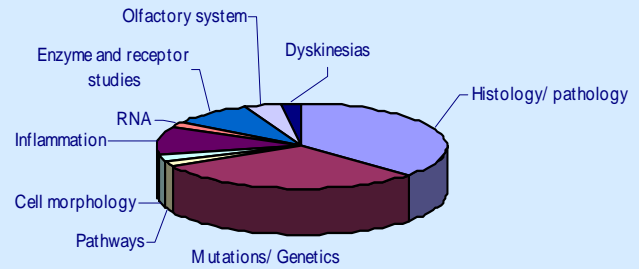
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inson's or not. This type of tissue is also highly popular with researchers too, since they can histologically stain thin sections to identify markers, e.g. alpha-synuclein (a protein implicated in Parkinson's), at the cellular level. The first pie chart below show the types of tissue requested by researchers and as you can see all the different types of tissue offered by the Tissue Bank are being used in research. Whilst the second pie chart, indicates the different research areas utilising the tissue. As the pie chart indicates, a wide variety of research areas, ranging from genetic to drug induced dyskinesias, are utilising the tissue. This demonstrates that the Tissue Bank is fulfilling its role of collecting tissue for a wide variety of uses.

Types of tissue requested



Tissue request research areas



Dr David Dexter (Scientific Director of the Tissue Bank)

How Local Hospitals Help Us Collect Tissue

Hi, I'm Iain and I am the Mortuary Manager at the James Paget Hospital. APT's (Anatomical Pathology Technologists) like me are the people that generally remove the donor material from deceased donors within our mortuaries.

It's a slick operation, to ensure that the donor is brought to our mortuary in a timely manner and to ensure that the donor tissue is removed 'fresh' i.e. as soon after death as possible.

Liaisons between the tissue bank and funeral directors are vital.

Before tissue removal can take place, we must ensure that the correct paperwork is in place:

- The consent of the donor (while alive); Death certificate
- Both of these documents are faxed to us prior to removal.

The nature of the consent and research project depends what tissue is taken and how it is to be stored. Usually tissue is:

- Brain; Spinal Cord and Sample of CSF.

The whole process for removal and reconstruction takes about an hour and is performed by, as a minimum; certificate trained APT, or higher qualified APT depending on the complexity of the case.

The brain tissue is either; 1) collected immediately by a member of the Tissue Bank team and taken back to Charing Cross Hospital for processing; or 2) suspended in formalin fixative to preserve the shape of the brain and stored within a fridge at 4°C for a period of a few weeks. The formalin is changed on a regular basis to ensure full tissue fixing

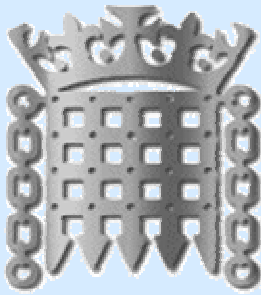
A courier is sent to collect the tissue a few weeks later.

I'm often asked "why I do this?" I usually reply by saying that my family, or I, might get Parkinson's, so any advances in treatment that come from using human donated material could be of direct benefit to me. Also, as a sign of respect, if a donor has gone to the trouble and time to donate their tissue for the good of others, I feel it's my duty to help facilitate that wish, and make it a reality. I and my team are pleased to be part of the 'team'.

Iain Johnstone - Mortuary Manager, James Paget Hospital, Great Yarmouth



James Paget Hospital



Human Tissue Act 2004

The Human Tissue Act 2004 came into effect on the 1st September 2006. The government said that the current consent laws were confusing and needed to be updated. The Act makes clear that where an adult has, whilst alive and competent, consented to donating tissue after their death then that consent is sufficient for the activity to be lawful.

If the family or those close to the deceased person object to the donation, for whatever purpose, when the deceased person (or their nominated representative) has explicitly consented, clinicians should seek to discuss the matter sensitively with them. They should be encouraged to accept the deceased person's wishes and it should be made clear that they do not have the legal right to veto or overrule those wishes. There may nevertheless be cases in which donation is inappropriate and each case should be considered individually.

Where the deceased person has not signed the Tissue Bank Consent Form, and a nominated representative has not been appointed, someone close to them can give consent to the donation of tissue. The Act ranks persons in a qualifying relationship for the purposes of obtaining consent in these circumstances in the following order (highest first):

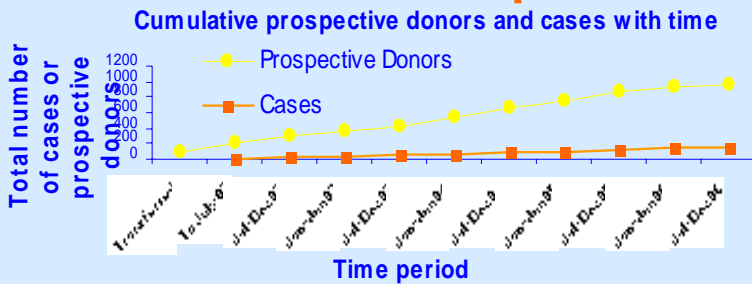
- a) spouse or partner (including civil or same sex partner)
- b) parent or child
- c) brother or sister
- d) grandparent or grandchild
- e) niece or nephew
- f) stepfather or stepmother
- g) half-brother or half-sister
- h) friend of long standing.

The ranking is intended to help those seeking consent to know who to approach and in what order. Consent should be obtained from the person ranked highest.

The above section was amended from The Human Tissue Authority - Code of Practice - Donation of Organs, Tissue and Cells for transplantation (Code 2 July 2006)

The Tissue Bank has always asked for both signatures of the person wishing to donate and their nominated representative (Next of Kin). We will continue to do, because we like to have the full co-operation of the family. If you have any questions regarding this, please do not hesitate to contact us.

Update on Figures



As can be seen from the graph, the Tissue Bank is now rapidly approaching 1000 registered prospective donors. In addition, we have now collected well over 150 brains. The Tissue Bank has also seen an increase in the number of control donors registering with us, with over 40% of those currently registered being prospective control donors. We thank you all for your support.

Change of Address/ Comments Form

Date: _____ Name of Donor: _____ Donor No: _____

Old Address: _____

New Address: _____ Post Code: _____

Date of address change: _____ Contact No: _____



Contact Information

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Clockwise from top left: Dr David Dexter, Scientific Director; Neuropathology Team: Prof Manuel Graeber not pictured; Dr Federico Roncaroli, Dr Stephen Gentleman; Dr Ronald Pearce, Consultant Neurologist; Prof Richard Reynolds, Technical Advisor; Laura McKay, Tissue Bank Secretary; Veena Supramaniam, Research Technician; Louisa McGuinness, Research Technician; Helen Cairns, Research Assistant; Dr Kirstin Goldring, Tissue Bank Manager.

Future Branch Talks



- 31st Oct 06, **Macclesfield** evening;
- 2nd Nov 06, **Rochdale** 7.15pm;
- 14th Nov 06, **Bolton** 7.30pm.
- 23rd-24th March 07, **Jersey**
- 11th April 07, **Bride Valley**

Please contact us if you require further details.



Notices



All the Tissue Bank staff would like to thank the **Guildford and South West Surrey Branch** for donating a freezer to us via the PDS scheme. This piece of equipment is extremely useful in the running of the Tissue Bank, especially with the increased tissue coming to the bank.



Our Team



Please tear this section off and return to us free of charge with your comments or change of address.

Comments/ Suggestions/ Questions:

Please detach slip and return to us in an envelope free of charge using the enclosed label.