



Brain Bank Bulletin

Issue 3
Winter
2004

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.

Two years of growth and development

The Parkinson's Disease Society (PDS) is delighted with the progress that has been made in developing the PDS Tissue Bank at Imperial College in the 2 years since the PDS Tissue Bank opened its doors. It is clear that firm foundations have been laid to run an extremely efficient Tissue Bank, to provide tissue for research to laboratories in the UK and around the world and to support Parkinson's research programmes undertaken at Imperial College itself.

The PDS provides support for the Tissue Bank as a major investment in the research infrastructure in the UK. Donated tissue both from people with Parkinson's and from those without a neurological condition (known as 'control' tissue) is a vital resource to researchers seeking solutions to Parkinson's disease. In looking at the progress being made, some highlights are set out below.

Donors – making the vital gift

The Society is very grateful indeed to all those who have made the decision to donate brain tissue for research. The average number of donors making this commitment each month has almost doubled in 2004 compared with 2003 and the number of 'controls' has also increased significantly.

Reaching out widely to prospective Donors

We are very pleased with the efforts the Tissue Bank staff continue to make to travel across the UK to speak to PDS branches and to young people's groups to promote the Tissue Bank as widely as possible. The enthusiasm and commitment of the Imperial team underpin the growth and development of the Tissue Bank.

Supporting Parkinson's Research

We have updated the documentation relating to the supply of tissue and the supply will now accelerate to researchers around the world. We continue to meet all ethical, regulatory and legal requirements, of course, and we will ensure that policies and practices are regularly reviewed.

The Management Board

We put in place the Management Board to strengthen governance and to oversee at a strategic level the operation and development of the Tissue Bank. The Society is very grateful to the members of the Management Board who very kindly give their time and expertise without charge. Under the guidance of Professor Paul Ince as Chairman, the Management Board membership draws on wide ranging expertise including a person with Parkinson's, a carer, a Nurse Specialist and an external tissue user.

External Links

The PDS is very encouraged by the links between the PDS Tissue Bank at Imperial and the Queen Square Brain Bank at the Institute of Neurology. We now have clear website links between the two banks and an external researcher seeking tissue will easily be able to access both tissue banks. We are also pleased that the Director of the Queen Square Brain Bank has joined our Management Board – all evidence of the determination to come together to defeat Parkinson's.

The Team at Imperial

The progress being made certainly reflects the excellent contribution made by the team at the Tissue Bank. The senior members of the team at Imperial have been able to draw on the expertise and experience of Professor Richard Reynolds gained from running the Multiple Sclerosis Tissue Bank. The overall lead for the Tissue Bank is provided by Dr David Dexter as Scientific Director and Dr Ronald Pearce as Clinical Director while Dr Kirstin Goldring manages all aspects of the day to day operations. Professor Manuel Graeber completes the senior team and is in charge of the diagnostic work and leads an associated programme. Our thanks are given to all those who have helped in any way to support and develop the Tissue Bank.

Robert Meadowcroft

Director Policy, Campaigns
and Information

Parkinson's Disease Society



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Parkinson's
Disease Society

Review of PDS Tissue Bank Donor Profiles to June 2004

When a brain donation is made to the Tissue Bank, viewing brain cells stained using special methods down the microscope allows a pathological diagnosis to be made. An essential task in achieving the fullest possible understanding of the changes seen in the nervous system is to review all available clinical information, mainly by studying GP notes and copies of specialist letters. This dual process permits the optimum characterisation of the brain in the so-called 'clinicopathological correlation'.

Analysis of the medical notes of fifty-one tissue donations to the newly established PDS Tissue Bank has revealed a clinical diagnosis of Parkinson's disease (PD) in 92% (47/51) of donations, a 'Parkinson's Plus' syndrome, Multiple System Atrophy (MSA), in 6% (3/51) and Dementia with features of PD in one individual (2%). The average age at disease onset was 65 (range: 32-78) with the average age at death 77 (range: 42-87), thus yielding an average duration of illness of 12 years (range: 2-34 years). This confirms that with modern treatment regimens there is no significant shortening of the lifespan with PD. Approximately one third of the donors were female and the remaining two thirds male, which agrees well with the known gender ratio for PD. A predominantly tremulous presentation was found in 47% of donors with an akinetic-rigid syndrome (stiffness and slowness of movement without tremor) in 29%. Falls or ataxia (impaired walking) were dominant presenting features in 10% followed by autonomic nervous system dysfunction (mainly drooling) in 6% and dementia in one individual. In 6% (3/51) the mode of presentation remains unknown at this time.

Most donors were either reformed smokers or had never smoked (90%) and in the 3 individuals who were active smokers atypical clinical features were present suggestive of possible vascular Parkinsonism (related to blood vessel damage). A positive family history of Parkinsonism was present in 14% of donors. Neuroleptic (dopamine-blocking) drug intake was present at some point in the history of 12% of donors with two further donors disclosing a history of other possible toxin exposure.

Dyskinesia induced by L-DOPA was present in 43% of cases.

Neuropsychiatric features were prominent, including hallucinations and delusions (59%), cognitive decline and dementia (61%), confusion and agitation (53%), depression (37%) and anxiety (27%). Autonomic nervous system dysfunction was also common, including bowel symptoms (mainly constipation) in 73%, bladder dysfunction (51%), speech and swallowing difficulties (53%), blood pressure abnormalities (37%), drooling (33%), sleep disorders (14%), sexual dysfunction (14%) and a seborrheic skin rash and sweating (12%). These features relate both to PD itself as well as to the side effects of drug treatment.

Atypical or unusual features were found in several individuals, including abnormal eye movements in three, focal dystonia (abnormal limb posturing) on presentation in two, prominent drooling on presentation in five, myoclonus (jerky limb movements) in two and hand/wrist contractures (fixed abnormal posturing) in one case.

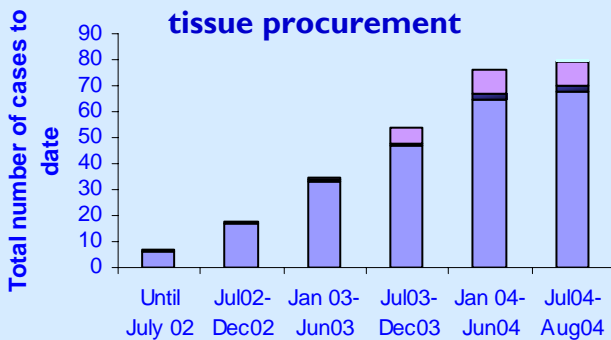
As further donations accumulate it will be possible to analyse these clinical features in more detail, with comparisons of the clinical course for disease onset at varying ages, assessments of the effects of differing drug treatment regimens, the influence of family history and other factors. A standardised collection of clinical data is planned with a prospective questionnaire to be sent out to all registered donors. This will increase the reliability and detail of the clinical histories, all of which will eventually be joined with detailed neuropathological diagnostic assessments. Combining examination of the clinical history with tissue analysis will produce clues regarding potential protective and aggravating environmental, treatment and familial factors as well and will help to indicate the brain regions responsible for specific signs and symptoms.

Dr Ronald K B Pearce
Clinical Director



Tissue Bank Update

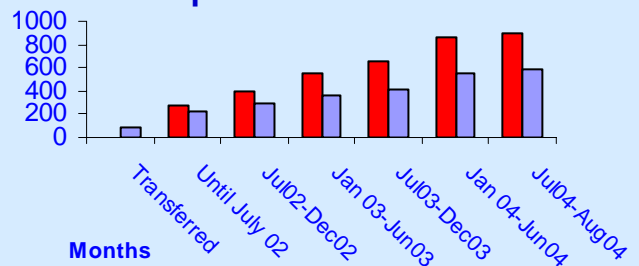
Accumulation of the number of cases of tissue procurement



Time period

Blue: PD
Light blue: Disease control (I)
Purple: Unable to procure
Black: Control

Comparison of prospective donors registering compared to information packs sent out



Purple: Total number of people registered with the tissue bank.
Red: Total number of information packs requested.

As the graphs show, up until the end of August 2004, the Tissue Bank has had just under 900 requests for information, of which 581 had then gone on to register with us as prospective donors. Of those that have registered in the past couple of years, 36% are actually people that do not have Parkinson's or a related disorder, which is vitally important

for research and allows identification of differences between changes in the normal ageing and the Parkinson's brain. To the end of August there have been 71 tissue donations, of which 3 have been from people without Parkinson's.

Dr Kirstin Goldring



Tissue Bank's Second Anniversary

The UK PDS Tissue Bank at Imperial has recently, in mid-August, celebrated its second anniversary of full operation. The first two years have been an exciting and challenging time for the staff at the Tissue Bank. The progress over the past two years has been extremely encouraging and the Tissue Bank continues to play an important role in research into Parkinson's.

We have continued to work hard at increasing the numbers of potential donors registered with the Tissue Bank

In 2003 we had an average of 11 registrations of prospective donors per month. In 2004, our average registration is up to 20 per month.

The number of potential donors registered with the Tissue Bank currently stands at 581. Of the donors that have registered with us we have had 71 tissue donations. These donations are vital to further research into Parkinson's and related disorders. However, for every 20 Parkinson's brains we collect we only receive 1 brain donation from a healthy person. These healthy brains are also vital for research since scientists need to understand how the healthy brain functions and compare it to research results from Parkinson's brain tissue. Since brain tissue is vital for Parkinson's research and that we

have more requests from researchers than we can supply, we are still encouraging people, particularly healthy individuals to register with the Tissue Bank.

The work of the Tissue Bank and research on the tissue collected has been presented in talks to a large number of PDS branches and in a number of articles on Parkinson's. In addition we have published and distributed our first two newsletters to registered potential donors, their next-of-kin, GP's, and mortuary staff who have helped us collect tissue etc. The newsletters have been a great success, with many people writing to say that they welcome the contact with the Tissue Bank and that the articles contained in the newsletter are interesting and informative. Please let us know if there are any issues you would like to be addressed in our newsletter. We have also held annual open days with talks about the workings of the Tissue Bank and research projects using the donated tissue, along with a guided tour of the Tissue Bank. These have proved to be highly successful.

Dr David Dexter

and

Dr Kirstin Goldring



Notices

- ◆ Many thanks to the Durham Branch of the PDS for their very generous donation in memory of Mr & Mrs Wilkinson.
- ◆ If there are any families or husband and wives who are registered with us that would like to help us and the PDS with some publicity, please could you get in touch with us.
- ◆ We would also like to thank those of you who wrote in with suggestions for the name of the newsletter. We hope that you all like the chosen name.
- ◆ Thank you to everybody who made contributions to the Newsletter.
- ◆ We would also like to thank our On-Call staff for all their help and hard work throughout the year.

The On Call Team



Left to right: Linda Moran, Emilie Croiser, Virginia Zbarsky, Anthony Vernon, Louisa Djerbib, Helen Cairns Krishna Datla

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

UK Parkinson's Disease Society Tissue Bank at Imperial College

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Clockwise from top left: Dr David Dexter, Scientific Director; Dr Kirstin Goldring, Tissue Bank Manager; Helen Cairns, Research Assistant; Louisa Djerbib, Research Technician; Laura McKay, Tissue Bank Secretary; Professor Richard Reynolds, Technical Advisor; Dr Ronald Pearce, Consultant Neurologist; Neuropathology Team; Dr Stephen Gentleman, Dr Federico Roncaroli and Professor Manuel Graeber

- ## Future Branch Talks
- 6th October 2004, Oxford evening
 - 18th October 2004, Hitchin 2:30pm
 - 20th October 2004, YAPP&Rs Hampshire afternoon
 - 14/15th October 2004, Northern Ireland
 - 2nd November 2004, Basingstoke afternoon
 - 11th November 2004, Haltwhistle 2:00pm
 - 21st November 2004, Penreth 12:30pm
 - 19th January 2005, Welwyn and Halfield
 - 25th January 2005, Guildford & South Surrey
 - 4th March 2005, Liverpool Central
 - 12th March 2005, NW Somerset
 - 7th April 2005, Sutton, Kingston & Epsom 7:30pm
 - 9th April 2005, YAPP&Rs AGM Rugby
 - 14th April 2005, Bexley & Dartford
 - 26th April 2005, Hillingdon 2-4pm
 - 5th May 2005, Lincoln 2:30pm
 - 15th May 2005, Hull 2-4pm
 - 18th May 2005, York 8-9pm

Please contact us if you require further details.

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.