



UK PDS Tissue Bank at Imperial College Newsletter, Issue 1, Winter 2003

The Parkinson's Disease Society (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 strives 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 tissue in an ethical manner and in a way that it is most suitable for all research needs.

Welcome to the First PDS Tissue Bank Newsletter

The UK PDS Tissue Bank has been in operation for just over a year. This and future newsletters aim to acquaint you with the work and progress of the Tissue Bank as well as the staff you will come in to contact with. There will also be information on Tissue Bank events such as Open Days and talks planned for local PDS branch meetings etc.

We will run articles on specific needs of the Tissue Bank e.g. the need for healthy volunteers to sign up (Pg.2), and how the Tissue Bank can get the most benefit from your tissue donation (Pg.2). There will also be articles dedicated to answering readers' questions on topics ranging from the Tissue Bank and the donation process to how our brain works and how it helps us move!

Additionally, we will keep you informed of our latest research news. e.g. see



Pg. 3 where Professor Graeber's team here at Imperial College is using donated brain tissue to compare gene expression between the Parkinson's brain and healthy brains.

We hope you enjoy reading the newsletter and find it informative. If you have any questions, comments or suggestions about the newsletter please do not hesitate to contact us. If your PDS branch would like some newsletters for its meetings do let us know!

Dr David T. Dexter,
Scientific Director

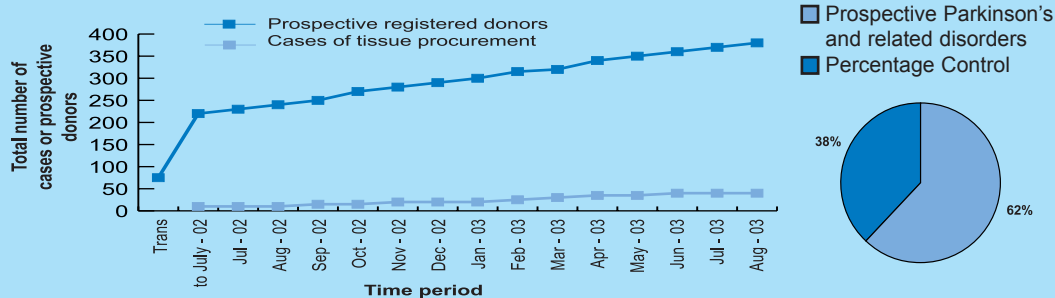
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The Tissue Bank is funded by the Parkinson's Disease Society, UK

The Story so far...

Prospective donor registration and tissue procurement



These figures show the success of the Tissue Bank to date in recruiting donors. In the graph, the first point on the upper line shows the number of prospective registered donors who transferred from the old Tissue Bank, the second point is these transferred donors plus those registering between January and July 2002. The remainder are the monthly totals as further people register. On average there are 12 new registrations per month. The lower line shows the number of cases (36) of tissue procurement to date, of which only one was from a control donor.

The pie chart demonstrates that of the approx 400 prospective donors currently registered, 62% are suffering from Parkinson's or a related disorder and 38% are healthy volunteers. We need to increase this percentage of "healthy" donors as even though they comprise 38% of the registered donors, we have still only had one case of tissue donation from a control donor.

Thanks to all our registered donors and their families for all your support!



Tissue Bank Open Day 2003

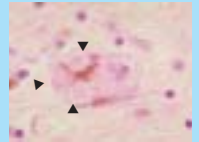
The Open Day took place at the Charing Cross Campus of Imperial College on March 28th, 2003. Its aim was to explain how the Tissue Bank is run and give insight into some of the research that depends on it, along with a chance to see the laboratory facilities. Despite a train strike, approximately 70 people attended, including PDS members, registered prospective donors, relatives of donors and those simply interested in finding out more.

Linda Kelly, Chief Executive PDS, gave the welcome address and stressed the importance of the Tissue Bank and research at Imperial. This was followed by a talk by Dr Dexter on the aims of Parkinson's research and why human tissue is so vital for its progression. He also described the donation procedure and what is involved for a prospective donor and their family. Dr Linda Moran then outlined some of the research being



Professor Graeber's group using tissue from the Bank.

Dr. David Dexter answering questions on the Open Day



Arrows show Lewy Bodies. These can be seen down the microscope in the Parkinsonian brain.

Everyone was then given a chance to tour the Tissue Bank laboratories and see sections of brain tissue down the microscope. Professor Graeber was at hand to explain what they were seeing and its importance in Parkinson's (see above). Other groups were given information by Dr Goldring on the tissue that has been donated to the Tissue Bank to date, as well as the statistics of prospective donors registered with the Tissue Bank.

Following the event, we received a number of new prospective donor registrations. Many of the people that came along expressed how much they had enjoyed the day and said that they found it very informative. For those who were unable to attend this year, we are planning to make this an annual event.

Dr Kirstin Goldring, Tissue Bank Manager

How your Relatives can help us get the most out of your Donation!

Researchers are using some of the most up-to-date techniques to solve Parkinson's. For this, the Tissue Bank needs to supply them with the highest quality brain tissue we can. This means we must collect, process and freeze the tissue as soon after the death of a donor as possible (24 hours being ideal).

Once a donor has died there is a complex series of events that the Tissue Bank must organise and carry out. These include: liaising with the family regarding the donation of the tissue, finding a local hospital that is willing to help remove the tissue, transportation of the donor to this hospital with the help of the funeral directors, sending a member of the Tissue Bank team out to collect the tissue, and processing and freezing of the brain tissue on its arrival at our facility.

All of these steps take time not only to arrange but also to carry out. Rapid tissue retrieval provides material suitable for the most research requirements and hence has maximum impact in fighting Parkinson's.

We are honoured to be able to carry out your last wishes and appreciate that it is a very sensitive time for your family when they are dealing with loss. However, they can help the Tissue Bank tremendously to get the most out of your donation. They could

notify us before you die, if you are gravely ill, and then we can set up many arrangements in advance dramatically saving time in tissue retrieval. Alternately, if your next-of-kin or the health workers looking after you could let us know immediately that you have died we can also act very quickly.

To assist with this, the Tissue Bank can issue duplicate donor cards to your next-of-kin or your health worker so that they have your donor details and our emergency contact number close at hand. We send copies of your and your next-of-kin's consent forms for your tissue donation to your GP to put with your records, but can also issue further copies should you go into hospital or nursing home so they are also fully aware of your wishes. Please share this newsletter with your family and health worker so they know why it is important to process your donation quickly. It also keeps them informed of what research the tissue is being used for. If you have any questions or require further copies of donor cards/newsletter etc do not hesitate to contact us.?

Our 24 hour bleep number for emergencies is: **07693 55 44 66** (this number can be found on your donor card). All other enquiries: 0208 383 4917.

Dr David Dexter, Scientific Director



Why the Tissue Bank needs Healthy Volunteers!

The brain is an amazingly complex organ. However, as everyone knows, when it does not work so well it can produce disorders like Parkinson's, Alzheimer's and Multiple Sclerosis. If we are to understand what happens to the brain in Parkinson's and other disorders, we need to first understand how the healthy brain functions e.g. how our brain works when we move to lift a cup of tea, or how dopamine-producing cells (the cells that die in Parkinson's) stay healthy in a non-Parkinson's brain.

This tissue from healthy donors is also important as it acts as a "control" or indicator of healthy function in all research into Parkinson's. Currently only about 1/3rd of the total people signed up to the Tissue Bank are healthy volunteers and of the last 36 actual tissue donations collected by the Tissue Bank, only one was from a healthy donor. This shortage of healthy tissue is not lim-

ited to Parkinson's research alone. Tissue banks supplying tissue for research into other neurological disorders face the same problem.

Tissue banks are now working closer together and, where possible, sharing tissue donated by healthy donors, since different parts of the brain are affected in different disorders. Hence, healthy tissue donated to the PDS Tissue Bank will benefit research not only into Parkinson's, but also into many of these other disorders.

If you know of a healthy person that might consider signing up to the Tissue Bank donor scheme, please show this newsletter to them. Further information on the donor scheme can be sent out to interested individuals or found at our website (see over).

Dr David Dexter, Scientific Director

Professor Graeber's Team: Unravelling the Brain's Genetic Secrets!

Symptoms experienced by people with Parkinson's are a result of damage within specific areas of the brain. What causes this damage is unknown, but there is growing evidence for genetic involvement in some Parkinson's cases. The genetic information in our cells is responsible for stimulating the production of proteins, which are essential building blocks in our cells. If abnormal levels of proteins are formed then this can alter the function of brain cells and cause them to die.

There are about 30,000 genes in our cells. In the past, to examine them all would have required an army of scientists and many years of work. Professor Graeber and his team, using tissue from the PDS Tissue Bank and some of the latest technology, are examining the gene expression in brains of Parkinson's and healthy volunteers. The revolutionary "gene chips", only about 2cm (one inch) square, being used are like having a laboratory on a chip. They allow the examination of the expression of 15,000 genes at once. Hence using only two "gene chips" the expression of all of our genes can be analysed.



From left to right: Dr David Dexter (Scientific Director, TB), Prof. Manuel Graeber (Neuropathology), Dr Linda Moran (Research Associate), Emilie Croisier (Research Technician), Dawn Duke (Laboratory Technician), Dr Ronald Pearce (Clinical Director, TB)

This work is already revealing that many genes in Parkinson's brains are up-regulated or "switched on more" whilst other genes are down-regulated or "switched off more". It is hoped that when this work is complete they will be able to identify the mechanisms involved in nerve damage in the Parkinson's brain. If this is the case, it may help identify new approaches for the drug treatment of Parkinson's. We will keep you updated on this important area of research using brain tissue donated to the PDS Tissue Bank!

Change of Address/Comments Form (see over)

Date: **Name of Donor:**

Donor No:

Old Address:

New Address:

Date of address change:

PTO



Contact Information

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The staff are (clockwise from bottom right):
Dr Kirstin Goldring: Tissue Bank Manager
Louisa Djerbib: Research Technician
Dr Yasmin Hadi: Tissue Bank Secretary
Helen Cairns: Research Assistant

Branch Talks

Members of the Tissue Bank team are more than happy to come out and give talks about the Tissue Bank to local PDS and YAPP&R branches. To date we have given talks at the following local PDS branches: Aberystwyth, Bath, Barnet, Beccles, Brentwood, Byfleet, Cheltenham, Christchurch, Croydon, Doncaster, Horsham, Leicester, Lincoln, Malmesbury, North Herts/Stevenage, Northampton, Poole, Rugby, Sevenoaks, Worthing, the Scottish branch meeting in Sterling and the Northern Ireland branch meeting in Cookstown.

We would like to thank everyone at those branches who made our visits possible. Their help is very much appreciated! We also have the following branches booked in for the near future: Bradford (Oct 15th), Dumfries (Oct 20th), Halifax (Nov 8th) and Oldham (Nov 26th)

Just let us know if you are interested in us visiting your local group!

Dr Kirstin Goldring, Tissue Bank Manager

Research Requests

Enquiries and requests for tissue (* tissue already supplied):

- Imperial College London - 1) Professor Manuel Graeber*
2) Professor David Brooks 3) Dr Abhi Vora*
- National Institute of Mental Health, USA - Dr Ellen Sidransky*
- Cambridge University - 1) Dr Jules Griffin 2) Dr David Rubinstein
- St Georges Hospital, London - Dr Richard Parsons
- National Cancer Institute, Maryland - Dr Soni Anderson
- Heinrich Heine University, Duesseldorf - Dr Carsten Korth

The Tissue Bank Staff !

**If you have any suggestions
or comments please do not
hesitate to contact us!**



**This newsletter was
drafted and designed
by Dr. Yasmin Hadi**

Left to Right:

Dr David Dexter: Scientific Director
Professor Manuel Graeber: Neuropathologist
Professor Richard Reynolds: Technical Advisor
Dr Ronald Pearce: Consultant Neurologist

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

Comments/ Suggestions/Questions:

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