

Parkinson's UK Brain Bank  
Centre for Neuroscience  
Imperial College London  
Hammersmith Hospital Campus  
160 Du Cane Road  
London W12 0NN

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

Tel: **+44 (0)20 7594 9732**  
Fax: **+44 (0)20 7594 9733**  
Email: **brainbank@imperial.ac.uk**

Thank you for your interest in the Parkinson's UK Brain Bank.

This pack aims to answer any questions you may have about becoming a donor. It's important that you feel you have enough information to make the decision to become a brain donor.

Please discuss your decision with the people close to you. It's important they support your decision and understand the donation process so that they can help make sure your tissue is successfully collected.

This pack contains three forms for you to complete if you decide to become a donor:

- **Donor consent form** – this confirms your wish to become a donor.
- **Next-of-kin agreement** – for your next of kin or legal representative to complete to confirm they understand and support your wishes.
- **Information about your health** – a short form that helps us collect key medical information.

After you have completed these we'll also send you the following:

- **Donor lifestyle and medical history questionnaire** – a longer form that asks more in depth about your lifestyle and medical history.
- **A symptoms checklist and drug history** – which we'll send you every two years so that we can track any changes in your symptoms and medications.

To register just complete the forms and pop them in the post in the envelope provided.

When we receive your completed forms we'll add your details to our brain donor register. We'll send you a copy of the forms for your records, a confirmation letter and your donor card.

Yours sincerely

The Parkinson's UK Brain Bank team

In association with  
**Imperial College**  
**London**

Version 1/2011

Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ  
**T** 020 7931 8080 **F** 020 7233 9908 **E** enquiries@parkinsons.org.uk **W** parkinsons.org.uk

**Patron** HRH The Duchess of Gloucester GCVO. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (00948776). Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ. A charity registered in England and Wales (258197) and in Scotland (SC037554).

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## Consent for the procurement of tissue for research into Parkinson's and other neurological disorders

I ..... (print name with title)

of ..... (print full address)

.....  
..... (postcode)

..... (telephone/mobile)

..... (email address)

Please initial in the box below

- In the event of my death, I wish for the Parkinson's UK Brain Bank to collect and store my brain, spinal cord and samples of other tissues and fluids for respectful and ethical use in research, including genetic analysis.
- I have read the information sheet on the donation of tissue.
- I give the Parkinson's UK Brain Bank permission to access clinical information from my medical records once they have retrieved my tissue, and to use it and make it available to researchers on an anonymous basis who come from third party institutions.
- I am aware that my next-of-kin or legal representative should sign the enclosed form to indicate their agreement with my wishes.
- I will tell all healthcare professionals looking after me about my wish to donate tissue to the Parkinson's UK Brain Bank.
- I give permission for my tissue to be used for teaching purposes or for public display within the brain bank premises.

I appreciate how important it is that following my death someone immediately calls the 24hr Brain Bank Donor Line: [07 566 950 965](tel:07566950965) (this contact number will be printed on your donor card).

Signed: ..... Date: .....

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## Agreement of the next-of-kin or legal representative to the donation of tissue

I ..... (print name with title)

of ..... (print full address)

.....  
..... (telephone number)

Being the ..... (relationship)

of ..... (print name of person donating tissue)

Please initial in the box below

- Agree with their wish to donate their brain, spinal cord and samples of other tissues and fluids to the Parkinson's UK Brain Bank
- Do not object, and I am not aware of objections being raised by other relatives, to the Parkinson's UK Brain Bank collecting and storing donated tissue and fluids for their respectful and ethical use in research, including genetic analysis.
- Have read the information sheet on the donation of tissue.
- Understand that I have the right to withdraw my consent at a later date.
- I would like to receive the following information regarding the neuropathological findings  
A short report YES  NO  or A full report YES  NO  or No information YES  NO

Signed: ..... Date: .....

Please give details of another person (next-of-kin or close friend) who is aware of the bequest to the Parkinson's UK Brain Bank:

..... (print name)

of ..... (print full address)

..... (telephone number)

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## Information about your health

It is vital that we have a full medical history for each person who donates tissue to the Parkinson's UK Brain Bank. Please help us collect this information by answering all the questions on this form that apply to you.

### 1. About you

Full name (print) .....

Date of birth .....

Person with Parkinson's       Person without Parkinson's       NHS number .....

### 2. General Practitioner

Name .....

Address .....

Telephone number .....

### 3. Parkinson's nurse

Name .....

Address .....

Telephone number .....

### 4. Neurologist Name .....

Address .....

Telephone number .....

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**5. Assessment of your Parkinson's**

Date of initial diagnosis of Parkinson's? .....

What were the first symptoms of Parkinson's you experienced? .....

What medications are you taking at the moment?  
.....  
.....

Brief past medical history. Please tell us about any major illnesses or chronic conditions you've experienced e.g. high blood pressure, head injury etc.  
.....  
.....

Family history. Do any of your immediate family have Parkinson's or any other neurological condition?  
If yes - what condition and what is your relationship (e.g. sister)?  
.....

Do you smoke? YES  NO  Ethnic group .....

Working life. What have been your main jobs throughout your life (e.g. teacher)?  
.....

**6. Any other information that you think we should consider**

.....  
.....  
.....  
.....  
.....

(please continue on a separate sheet of paper if required)