



## **Patient Information Sheet**

### **Liverpool Neuroscience Biobank at the Walton Centre (LNBW)** **(Formerly: Walton Research Tissue Bank WRTB)**

Nervous System Tissue and/or Blood Collections for Research

**Name of Researchers:** Mr A Brodbelt, Prof M Jenkinson, Ms C Gilkes, Mr M Wilby other Walton Centre Consultant Neurosurgeons, Dr N Rathi, Dr P Pal, Dr D Husband, Dr S Mehta, Dr B Haylock, Dr A Shenoy.

*We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 30 minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.*

*Thank you for reading this.*

#### **What is the purpose of this project?**

We wish to collect and store ("bank") bloods, tissue samples and in some cases urine samples from patients with brain and spinal disorders. This will help future research into the cause, diagnosis and treatment of these disorders. Some studies may include genetic research to understand the way in which genes (molecules instructing cell division and growth) influence disease. Researchers in Liverpool and elsewhere will be able to access the tissue and blood collection subject to ethical approval. Some of the research will be carried out in collaboration by researchers other than at The Walton Centre NHS, including researchers working nationally like Brain Tumour North West (BTNW) and International level and also working for commercial companies.

#### **Why have I been invited?**

You are being asked to take part in this project because you are being investigated for a disorder of the nervous system (brain, spinal cord, nerves, or pituitary gland). Your management includes surgery. During surgery tissue is removed routinely for access, diagnosis or treatment. We would like to ask you to allow us to include this tissue and any blood and/or urine samples in the research collection (Biobank).

#### **Do I have to take part?**

NO, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Your management and treatment will not be influenced in any way whether you wish to take part or not.

### **What will happen to me if I take part?**

- Participating in this study by donating samples to the Biobank will not affect your treatment in any way. The length of your operation and stay in hospital will not be affected. No additional surgery will be performed.
- We will ask you to give us permission (signed consent) to include samples removed as part of your surgery in our studies. It will not involve taking any tissue other than that routinely removed during essential surgery.
- Tissue will only be stored for research use once all diagnostic needs have been met.
- You will be asked to give blood and/or urine samples at various times during your treatment to check how your treatment is affecting you. If you give permission for blood and/or urine samples to be stored for research, extra samples may be taken on some of these occasions.
- The laboratory studies could include analysis of DNA and RNA (material inside cells that carries genetic information) or proteins to help us understand how cells function. We may wish to grow cells from your tumour or tissue sample in the laboratory or compare laboratory information with scans taken during your treatment.
- We will ask you for permission to consult your medical records at *The Walton Centre, Clatterbridge Cancer Centre* (or other relevant medical records elsewhere) for some information relevant to your illness.
- This information will include details such as your age, gender, surgery, pathology diagnosis, epilepsy history, radiological (X-ray/CT/MR) scans, your medical treatment and the response to treatment.
- You may already have had brain surgery or surgery elsewhere in the body for this disorder at *The Walton Centre* or other hospital. If so, we ask your permission to have access to previous pathology specimens held in hospital pathology archives for comparison.
- In some instances samples from LNBW can be used in animal models to observe the direct effects in laboratory mice or rats or in chicken embryos. This will be carried out only by qualified personnel and within Home office licenced premises in the collaborating institutes.

If you agree to take part in this study, your samples will be treated as gifts to research. Samples will be held under the care of the LNBW within the usual diagnostic archive, in accordance with Human Tissue Authority regulations.

### **What are the possible disadvantages and risks of taking part?**

There are no disadvantages or risks to taking part.

### **What are the possible benefits of taking part?**

There are no specific benefits to you directly, but the results of investigations using this tissue may help others with similar disorders.

### **What happens to samples in the Biobank?**

Samples will be securely stored until allocated to an ethically approved project where it will be used for laboratory research. During analysis some will be “used up”. This allocation will go on until the supply is exhausted.

### **Will my taking part in this study be kept confidential?**

YES. If you agree to take part in this study, only your name, address, NHS number, date of birth and relevant clinical details will be extracted from your records. Any information about you released by LNBW will have personal details such as your name and address removed from it. The same will apply to the samples used in any laboratory studies. The information and samples will only be known by a research number, which will prevent researchers from knowing your identity.

### **What will happen if I don't want to carry on with the study?**

Any unused samples stored in LNBW will be transferred to the diagnostic archive and stored or disposed of according to departmental diagnostic protocols. No further samples will be used for research. Data from samples that has already been used in research projects will remain associated with those projects, but in an anonymous form.

### **Will any genetic tests be done?**

DNA derived from samples may be examined for abnormalities, which may give information on the cause of a disorder. It is unlikely to produce results with a direct influence on you or your relatives.

### **What happens if something goes wrong?**

The planned research will have no influence on your treatment. The banking of your samples for research carries no risk. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated, you may use Patient Experience Team service (0151 556 3090/3091) at the Walton Centre. Also National Health Service complaints mechanisms will be available to you.

### **What will happen to the results of the research study?**

Results will be analysed and presented at conferences and published as scientific papers, but you will not be identifiable in any report or publication. Results obtained from your samples are unlikely to include information of immediate clinical relevance, but should anything helpful be found, this will be conveyed to your treatment team

### **Who is organising and funding the research?**

The LNBW will be managed and organised by Biobank manager and HTA Designated individual along with the team of Consultants neurosurgeons, neuropathologists, oncologists and scientific researchers at The Walton Centre and Clatterbridge Cancer Centre, with the day-to-day curating of the samples performed by a team of Biomedical scientist and Lab assistants from Neuropathology.

LNBW is funded by the Walton Centre Trust. However, to partially recover the running cost of the Biobank which includes Biobank staff time and various

consumables used; we will be charging for providing the samples and clinical data for research projects. But the patients participating will not be entitled to any financial gain.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by Wales REC 4, Research Ethics Committee.

### **Where can I get independent advice about taking part in the study?**

Independent general advice about taking part in research may be obtained from your Clinicians or Specialist nurses, who will be able to advise. Alternatively he/she will pass your query to independent clinicians or help you contact relevant patient support groups and support charities for further advice.

Also please note that The Walton Centre NHS FT is the sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The Walton Centre NH FT will keep identifiable information about you for 20 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at <http://www.thewaltoncentre.nhs.uk> or by contacting the Neuroscience Research Centre 0151 529 5666.

You will be given a copy of the information sheet and a copy of signed consent form to keep.

### **Contacts for Further Information:**

Liverpool Neuroscience Biobank at the Walton Centre (LNBW)

The Neuroscience Laboratories

The Walton Centre NHS Foundation Trust

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Email: [neurolabs@thewaltoncentre.nhs.uk](mailto:neurolabs@thewaltoncentre.nhs.uk)

Websites: [www.waltoncentre.nhs.uk](http://www.waltoncentre.nhs.uk) & [www.btnw.org.uk](http://www.btnw.org.uk)

**Thank you very much for reading this information sheet.**