



BEAUMONT HOSPITAL

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Fibroblast Biobank Privacy Policy

Project Title: Development of a Bioresource for FutureNeuro Targeted Neurological Disorders

Principal investigator's name	Professor Orla Hardiman
Principal investigator's title	Consultant Neurologist
Telephone number of principal investigator	01 896 4497
Consultant co-investigator's name	Margaret O'Brien
Consultant co-investigator's title	Consultant Neurologist
Data Controller's/Joint Controller's identity	Beaumont Hospital and Academic Unit of Neurology, Trinity College Dublin (Prof. Orla Hardiman)
Data Controller's/Joint Controller's Contact Details	01 896 4497
Data Protection Officer's Identity	Mr Mark Graham (Beaumont Hospital) / Ms Evelyn Fox (TCD)
Data Protection Officer's Contact Details	dpo@beaumont.ie / evelyn.fox@tcd.ie

Confidentiality

All the information collected from participating individuals will be kept strictly confidential. The investigators may request information on your condition from your GP and your medical records will be reviewed.

The biological samples will be linked with clinical information that you provide under a separate consent. It will be stored in a secure laboratory in Trinity College Dublin. Each sample will be "coded", meaning that personal identifiers are removed and replaced with numbers under multiple layers of password-protection to ensure that your personal details are screened from unauthorised viewing. Medical records will be only accessed by the clinical team in Beaumont Hospital.

Samples taken during this study will be retained indefinitely in a biobank as to allow further analysis. They will be used in related studies in the future, subject to approval by the Beaumont Hospital Ethics (Medical Research) Committee.

Data Protection

1. We will be using your skin fibroblasts in our research to generate neural cell lines and establish a biobank for the use of future research projects involved in the understanding and treatment of the disease. Blood samples will be taken and processed to look for proteins and other constituents that may provide clues about the disease.
2. Your data is being processed under the following General Data Protection Regulation 2016 legal basis.
Article 6(1)(e) processing is necessary for the performance of a task carried out in the public interest.
Article 9(2)(j) processing is necessary for archiving purposes in scientific research purposes in accordance with Article 89.
3. The recipients of the data are Prof. Orla Hardiman (Principal Investigator and Consultant Neurologist), Dr. Margaret O'Brien (Consultant Neurologist) and the research team in Trinity College Dublin under the supervision of Prof. Hardiman.
4. This study involves the establishment of a biobank therefore biospecimens will be retained indefinitely (subject to approval from the Research Ethics Committee).
5. As your biospecimens will be pseudonymised (coded) at the time of biopsy, it is unlikely that any data breach could cause harm. Biospecimens will be coded using your unique identification number and codes will be stored on a passcode protected encrypted computer in a secure facility in Trinity College Dublin.
6. You have the right to withdraw consent to your personal data being used in the research project at any stage by contacting Prof. Orla Hardiman on 01 896-4497. On withdrawal of consent, the relevant samples will be permanently destroyed. This will not affect your future treatments.
7. You have a right to lodge a complaint with the Data Protection Commissioner about this research study if you feel your personal data is being mishandled.
8. You have a right to request access to your data and a copy of it, unless your request would make it impossible or make it very difficult to conduct the research.

9. You have a right to restrict or object to processing, unless your request would make it impossible or make it very difficult to conduct the research.
10. You have a right to have any inaccurate information about you corrected or deleted, unless your request would make it impossible or make it very difficult to conduct the research.
11. You have a right to have your personal data deleted, unless your request would make it impossible or make it very difficult to conduct the research.
12. You have a right to data portability, meaning you have a right to move your data from one controller to another in a readable format.
13. There will be no automated decision making or profiling using your data.
14. You have a right to object to automated processing including profiling if you wish.
15. You will be informed if we intend to further process your personal data and you will be provided with information on that other purpose.
16. You will be informed if we wish to transfer your data to a country outside of the EU or to an international organisation for both primary purposes within the remit of the study and secondary purposes not outlined in the immediate study and you will be advised on the safeguards we have in place to protect your data. Memorandums of understanding (contracts) will be put in place if data and/or samples are transferred outside of the EU, and these will include standard contractual clauses.

