



BEAUMONT HOSPITAL

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DNA Bank Privacy Policy

Study Title: A Study of Multiple Effects of Genes Associated with MND

Principal investigator's name	Professor Orla Hardiman
Principal investigator's title	Consultant Neurologist
Telephone number of principal investigator	01 896 4497
Data Controller's/Joint Controller's identity	Beaumont Hospital (Prof. Orla Hardiman)
Data Controller's/Joint Controller's Contact Details	01 896 4497
Data Protection Officer's Identity	Mr Mark Graham
Data Protection Officer's Contact Details	dpo@beaumont.ie

Confidentiality

All of the information collected from participating individuals will be kept strictly confidential. However, some of the questions you will be asked as part of this research are of a sensitive nature. Given the nature of this information, there are some limits to confidentiality. This means that if, either through speaking to the researchers, or completing questionnaires, you express that there is a risk to your safety or the safety, health or welfare of others, the researchers are obliged to take appropriate action and report this to the relevant persons or bodies in accordance with professional guidelines. We will endeavour to include you in this process as much as possible, if appropriate, should it arise. This is ultimately to ensure your safety and the safety of others.

The investigators may request information on your condition from your GP and your medical records will be reviewed. Data will be stored in password-protected encrypted files in Trinity College and will only be accessed by Prof. Hardiman and approved members of her team. The data will be codified (each individual will be assigned a unique code) so that those analysing

the data will not be able to identify you and no personal information will be included in publications in the scientific literature or at scientific conferences.

Data Protection

1. We will be using your personal information in our research to help us to understand the cause of ALS, and to develop new and more effective treatments. The essential data being collected include demographics, neuropsychological and MRI and EEG data, and blood samples.
2. Your data is being processed in accordance with Article 6(1)(e) Public Interest; and Article (9)(2)(j) Scientific Research Purposes of the General Data Protection Regulation 2016.
3. Members of the project research team, under the approval and supervision of Prof. Orla Hardiman, Principal Investigator, will have access to your information. Your data in coded form will be shared with other European Motor Neurone Disease research groups who are carrying out similar projects and are collecting similar information.
4. Your personal data will be coded using your unique identification number. Paper data will be retained for 5 years, until the study has concluded and then destroyed. Electronic data will be transferred to the Academic Unit of Neurology for analysis. Following completion of the study anonymised electronic data will be stored on a secure server in the Academic Unit of Neurology in Trinity College Dublin.
5. As your data will be coded at the time of testing with a unique identification number we do not foresee any situation where a data breach could cause harm. The electronic data on computers will also be coded and the key to link your name with the number will be kept separately. After completion of the study this key will be destroyed. In the unlikely event of a data breach, it will only be possible for someone to see your raw test scores which will not be meaningful to an untrained third party.
6. You have a right to withdraw your consent at any stage during the research study without giving a reason and without penalty. You can inform any member of the research team of your decision to withdraw at any time and they will accommodate your request.
7. You have the 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 their 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. If automated decision making or profiling were to occur, you have the right to object to this 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 an international organisation and will be advised on the safeguards you have in place to protect your data. We do not foresee any situation where we will be transferring data outside the EU.