



Movement Disorders Centre

UCL Institute of Neurology

Movement Disorders Research Registry (MDRR)

Thank you for expressing your interest in learning about current and future opportunities to participate in clinical research by registering your details on the Movement Disorders Research Registry, held at the Institute of Neurology, University College London (UCL). Before you decide whether or not you would like your personal details included on the registry, it is important for you to understand the purpose of the registry, what registration will involve and how your personal information will be protected. Please take the time to carefully read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information – our contact information can be found at the end of this document.

What is the purpose of the registry?

The primary purpose of the registry is to allow us to identify research studies which might be relevant to you so that we can then contact you with details and offer you to take part.

To better understand the causes and effects of movement disorders such as Parkinson's and other conditions, and how they may be treated, we carry out a variety of research projects at the Movement Disorders Centre (Institute of Neurology, University College London), often in collaboration with other teams in the UK and abroad. For these projects to succeed, we need the help of people like you who are willing to take part in research. The registry will allow us to contact people who are interested in participating in research and let them know about available studies. The data collected in the registry would enable us to match potential participants to each research study and contact you only for studies for which you are potentially suited.

What information will be held about me?

We will collect some of your personal details and contact information (such as your name and date of birth, address and telephone number), clinical information about your medical condition (e.g., what movement disorder you were diagnosed with, when your symptoms started, whether you take any medications, etc.) and the types of research in which you are interested. All of this information will be treated as confidential and will only be used to find a best match between research projects and potential participants. We will also seek your consent to view your medical records for the purpose of confirming details you have provided or completing details required to identify research opportunities that might be relevant for you.

Who is responsible for the registry?

The registry is the responsibility of the Movement Disorders Centre at the Institute of Neurology, University College London. Access to the registry is restricted to the centre's research team, as well

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as the hospitals' authorities involved in regulating it. The Institute of Neurology undertakes much of its research work in close cooperation with the National Hospital for Neurology and Neurosurgery and The Royal Free Hospital.

Should I join the registry?

It is up to you to decide whether or not to add your personal information to the registry and your participation is entirely voluntary. By joining the registry you consent to being contacted about research projects, but this **does not** mean that you agree to take part in any of these projects. Your decision whether or not to join the registry will in no way affect your medical care. If you decide to join the registry, you will be free to withdraw your details at any time, without having to give a reason.

How do I join the registry?

If you are if you are treated at the Royal Free Hospital or University College London Hospital (UCLH) please ask your doctor or specialist nurse for the registration form. Alternatively, you can contact us directly (at movementdisorders@ucl.ac.uk) and enquire about signing-up to the registry. Secure on-line registration will be available soon.

What will happen next?

If you decide to join the registry, your information will be recorded on a highly secured computerised database and kept in accordance with Data Protection Regulations. Further relevant information about your health may be obtained from your medical records. As new research opportunities open up, we will review the registry to identify patients who might be suitable for each individual research study. You may be contacted and invited to participate in studies that may be relevant to you as judged based on the information you provided in your registration form or obtained from your medical records. If you are contacted you will be provided with full information regarding each study and will be free to decide whether or not to participate.

How will my privacy and personal information be protected?

Because the registry contains sensitive information about you and your health, we will adhere to best ethical and legal practices to ensure that your privacy is protected. Registry information will be kept on a secure database compliant with NHS standards for secured storage of medical and personal information. Access to the database will be protected and restricted to members of the Movement Disorders Centre research team. The registry's online consent and registration website uses a highly secure encrypted web connection. Alternatively, you can complete your registration in hand written paper format, which will be processed by the registry administration team and securely stored in locked filing cabinets.

Your personal information will not be used or made available for any purpose other than for research, and you will not be identified personally in any report or publication. We will only pass on your name and contact details to researchers wishing to contact you about participation in research projects you

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may be interested in, and only after ensuring that research projects and personnel were carefully reviewed and formally endorsed and approved by the relevant research authorities.

How long will my information be kept?

Your details will be held on the registry for 10 years in the first instance, unless you ask them to be removed or the whole database is disbanded.

What if I no longer want to be included on the registry?

You are free to withdraw from the registry at any time without giving a reason, and this will not affect your current or future medical care in any way. You can inform us by phone, e-mail or in writing at the contact information given at the end of this document. If you choose to withdraw, and your identifying and contact information will be removed from the registry from the moment the registry team has confirmed your withdrawal.

Who funds and sponsors the registry?

The registry is managed by The Movement Disorders Centre at UCL which is currently funded by the National Institute for Health Research University College London Hospitals Biomedical Research Centre. The Movement Disorders centre's mission is to carry out high quality research, teaching and training in basic and clinical aspects of movement disorders and promote improved patient care through the translation of relevant research into routine clinical practice together with its affiliated hospitals.

What do I do if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff due to your inclusion in the registry, please contact the registry's administrator or chief investigator who will do their best to address any problem or concern (contact information given below).

What if I still have questions?

If you want more information or have any questions regarding the registry please contact the registry administrator:

Registry Administrator

Maya Bronfeld
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Queen Square, London WC1N 3BG
Email: movementdisorders@ucl.ac.uk

Registry Chief Investigator

Prof. Huw Morris
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Thank you for considering joining the Movement Disorders Research Registry!