

MND Register  
CARE-MND  
University of Edinburgh  
Chancellor's Building  
49 Little France Crescent  
Edinburgh, EH16 4SB  
Tel: 0131-242-7985  
e-mail: [info@care-mnd.org.uk](mailto:info@care-mnd.org.uk)  
web: [care-mnd.org.uk](http://care-mnd.org.uk)

We would like to invite you to join the Scottish MND Register.

The Register offers people living with motor neurone disease (MND) the opportunity to take part in research, including clinical trials to test potential new drugs. It is run by the University of Edinburgh and supported by NHS MND nurses across Scotland.

The register is part of the CARE-MND platform (Clinical, Audit, Research and Evaluation of MND) which sits under Rowling CARE ([www.rowlingcare.org.uk](http://www.rowlingcare.org.uk)). The platform empowers people living with MND in Scotland to directly influence the provision of clinical care and research. It provides data for the audit and evaluation of care across Scotland and for MND research. Findings from CARE-MND have already resulted in changes to practice and have helped local care teams deliver higher standards of care. This includes more timely interventions to improve quality of life and an increase in the number of specialist care team staff.

If you decide to join the Register you can choose if you would like to be contacted about taking part in research studies. These studies may involve tests or trialling new drugs, but it is totally up to you to decide if you want to take part or not when you are contacted. You do not need to give any reasons for your decisions. None of your choices will ever affect your medical care.

If you do agree to be contacted about taking part in research, you may be able to take part in some research projects at your home, without the need to travel.

Please read the MND Register Participant Information Sheet carefully and contact us if you have any questions. If you choose to join the Register, you can sign up online at [www.care-mnd.org.uk/register](http://www.care-mnd.org.uk/register) or complete the paper MND Register Registration form, along with the Consent Form and return it in the enclosed envelope.

If you would like more time to consider if you want to join the register, or to ask further questions, please take your time. If you then do decide to sign up, please complete and return the forms or sign up online. Thank you for your consideration.

Yours faithfully,

Judy Newton  
National Lead MND Nurse

Suvankar Pal  
Senior Clinical Lecturer  
in Neurology

Siddharthan Chandran  
MacDonald Professor of Neurology

## MND Register - Participant information sheet

### What is the purpose of the Register?

The purpose of the Register is to improve the quality of MND care and even out the different standards of care across Scotland. It also provides data to help MND research and clinical trials.

The register was started in response to many patients and health care professionals asking about standards of care and planning for future MND services. Also, importantly, it was because of a strong desire from people with MND to take part in research studies and clinical trials. A national register is an effective method to improve clinical care and encourage and support research.

Scotland is also ideally placed to be a leader in MND care and research due to the linkage of healthcare information within NHS Scotland and the national team of dedicated MND Clinical Specialists.

### Why have I been approached?

The clinical care teams approach everyone who has been diagnosed with MND to join the register. If you require any further information we would be happy to answer your questions. Our contact details are at the end of the document.

### Do I have to take part?

No. And if you choose not to be included in the register this will have no influence on your clinical care. You are also free to withdraw from the Register at any time without providing a reason.

### What do I have to do?

You need to read the MND Register Participant Information Sheet carefully and ask any questions that you feel you need to (our contact details are below). When you are satisfied that your questions have been answered and if you want to join the Register, please sign up online at [www.care-mnd.org.uk/register](http://www.care-mnd.org.uk/register) or complete the paper MND Register Registration Form and the Consent Form and return them in the envelope provided.

You do not need to do anything else, including completing additional paperwork or taking part in additional tests etc. unless you choose to be contacted about other research projects and you choose to take part in them.

### Are there any risks or disadvantages of taking part?

There are no risks or disadvantages to being included in the Register.

### What are the possible benefits of joining the register?

We hope that the results of research that uses data from the register, will help improve the lives of people with MND in the future. We hope that it will allow us learn more about the disease, provide information that will help us give people with MND a more detailed prognosis, and we hope it will develop improved tests for diagnosis.

Also, if you choose to be contacted about taking part in research studies you will receive information about research projects as they start. You can then decide if you would like to take part in any of them or not. Each project will explain any benefits there are to taking part. There are no financial benefits to being on the Register.

### **Will my taking part in the Register be kept confidential?**

Yes. We take your privacy very seriously. All data / records on the Register are anonymised by a unique study number. We will never share your personal or identifiable data with anyone outside the core research team based at the University of Edinburgh. All details will be kept securely on an NHS approved system within The University of Edinburgh. If you agree, your GP will be informed of your consent to being on the Register. If you also agree, we can tell you about future research studies including clinical trials that you may be interested in taking part in.

### **What if a research project using information from the register finds out important medical information about me?**

If any clinically relevant findings become apparent as a result of this research (for example something that can be treated and has so far gone unnoticed, or there are questions about your diagnosis), this will be fed back to your MND clinical care team for them to decide if they need to take action.

### **Do other researchers access my identifiable information?**

We will never share your identifiable information with anyone outside the core research team based at the University of Edinburgh. If you sign up to be contacted about other research studies, the University of Edinburgh core research team will contact you with details of the study. Only when you reply directly to the third party researcher, to show interest in taking part in their study, will you pass on your contact details. To ensure that you are in control at all times of whether you participate in research, we have put in place the following process.

- External researchers will not approach you directly.
- All requests to use the Register to find potential research participants are first evaluated by the Register Management Committee to ensure that the research is appropriate and ethically approved. The Committee members are currently Professor Siddharthan Chandran, Dr Suvankar Pal and Judy Newton.
- If approved by the Committee, study information (project invitation letters and information sheets) will then be sent by the MND research team to people on the Register who may be eligible for the study and who have signed up to receive information about research studies.
- Confidential details are not released by the MND research team to other researchers without your permission.

### **How will I know about the difference the Register makes?**

The results of individual research projects that use the data held on the Register will be presented at academic meetings and published in academic medical journals. This will always be anonymised (see above) so your personal details will never be identifiable. If you are contacted via the Register about a research project, and choose to take part, some projects may contact you with the research results. We will always publish information online about the results of research projects that use the Register at [www.care-mnd.org.uk](http://www.care-mnd.org.uk). We may also include details in the news section of [www.annerowlingclinic.org](http://www.annerowlingclinic.org) and on the Clinic Facebook page @AnneRowlingClinic.

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

The Register is organised by a team of researchers based in Scotland as part of the CARE-MND project. CARE-MND is run by the Anne Rowling Regenerative Neurology Clinic ([www.annerowlingclinic.org](http://www.annerowlingclinic.org)) and the Euan MacDonald Centre ([www.euanmacdonaldcentre.org](http://www.euanmacdonaldcentre.org)) at the University of Edinburgh. CARE-MND is also part of ROWLING-CARE ([www.rowling-care.org.uk](http://www.rowling-care.org.uk)) and operates in partnership with the 14 NHS health boards across Scotland. The research does not

involve medical or pharmaceutical companies. The researchers are not paid to recruit patients to the Register.

### **Who has reviewed the development and management of the Register?**

The creation of the Register and how it is run has been reviewed by the Scotland A Research Ethics Committee. Ethical (Caldicott) approval has also been granted by the 14 Scottish NHS health boards partnering in the Scottish MND Register and CARE-MND.

### **What if there is a problem?**

All core research staff are covered by NHS contracts and the NHS public liability insurance. We do not anticipate any problems with this project but if you do have a complaint, please report this using the standard NHS Lothian Complaints Procedure. Telephone 0131 558 3681 or visit [www.nhsllothian.scot.nhs.uk](http://www.nhsllothian.scot.nhs.uk).

### **Is there anyone I can speak to about this study who can offer me independent advice?**

If you have any questions that you would like to ask of someone not directly involved in the project, please contact: Dr Peter Connick (Consultant Neurologist), tel: 0131-465-9500, email: [pconnick@exseed.ed.ac.uk](mailto:pconnick@exseed.ed.ac.uk)

For further Information, please contact:

Judy Newton  
National Nursing Lead for MND  
Euan MacDonald Centre  
University of Edinburgh  
Chancellor's Building  
49 Little France Crescent  
Edinburgh  
EH16 4SB

Tel: 0131-465-9517

Email: [judith.newton@nhs.net](mailto:judith.newton@nhs.net)

Website: [www.care-mnd.org.uk](http://www.care-mnd.org.uk)