

Registration Form

If you prefer, you can email all your responses to terry.mcgrath@dendron.org.uk or you can ask us to post you a copy of this form... Office (020) 7905 2995 or direct (020) 7905 2960

Important note: This form is NOT for people wanting to take part in a research study (e.g. testing a new treatment). In the first instance, always approach your doctor.

We are inviting patients and carers and anyone affected by these conditions to register and have a say in DeNDRoN.

- We want people around the country who are willing to share their thoughts and perspectives, give their views on ideas for research, review study designs, say what they think are the best outcome measures for research, or advise on any aspects of DeNDRoN.
- You must be over 18 to register.
- Giving us your views can be done from home by post or email.
- However, we also ask you if you're potentially interested in involvement activities in your area, or sitting on regional or national research-related committees.

About you

Basic details

Title

First name(s)

Surname

Age range 18-24 25-65 over 65

Methods for contacting you?

Postal address

If you don't want to give us a postal address, we'd still like to know what area you live in:

... ..

Email addresses (please write clearly)

Home telephone

Mobile telephone

Do you have any preferred contact method?

Is it OK for us to leave answerphone messages about DeNDRoN, if there's no answer?

Yes No

Which specific condition or conditions you are interested in?

Include as many as you wish to:

- Alzheimer's Disease and other dementias
- Parkinson's Disease
- Motor Neurone Disease
- Huntington's Disease
- All of the above

Which involvement activities are you interested in?

We don't ask for personal medical details, as the 'Data Protection' section explains.

These activities which can be done from home:

- Receiving newsletters and updates from DeNDRoN
- Suggesting your own ideas for research topics
- Commenting occasionally by post or by email on important questions and issues which come up in DeNDRoN about neurodegenerative disease research
- Commenting by post or by email on the designs of specific clinical studies and research methods
- Other activities which can be done from home, such as commenting on the quality of patient information leaflets

These activities involve travel (travel costs can be reimbursed):

- Attending one-off discussion groups in your area on questions and issues which come up in DeNDRoN
- Travelling to attend one-off discussion groups elsewhere – often in London ...
- Being considered for membership of a range of **regional** advisory committees in your area
- Being considered for membership of a range of **national** advisory committees (usually in London or Newcastle)
- Other activities involving travel, such as visits to research centres for meetings with research staff

Other questions

How you first heard about DeNDRoN involvement

Please tell us how you found out about involvement in DeNDRoN? e.g. a leaflet, medical charity newsletter, a website, etc?

Any other comments?

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**Post this form back to: Terry McGrath,
DeNDRoN, Wolfson Centre, Mecklenburgh Square, London WC1N 2AP**

Alternatively, you may wish to email your full responses to: terry.mcgrath@dendron.org.uk (Please mention which town or county you live in). If you have any questions, you can telephone Terry McGrath on (020) 7905 2995 or direct line (020) 7905 2960.

What happens next

- After you have registered your wish to have a say in various aspects of DeNDRoN, we will send you news updates and let you know about any involvement opportunities that arise which match your interests, by post or email.
- If you've said that you're potentially interested in one-off activities in your area, or sitting on regional or national research committees, we'll let you know about these as they arise.

Thank you very much.

Terry McGrath, Patient and Public Involvement Coordinator, DeNDRoN.

Additional information

Data Protection

All your information will be treated as highly confidential. We will check again with you within a maximum of 18 months of receipt whether you wish to remain on our database. We will not pass on any of your information to anyone outside of DeNDRoN, and we will remove your details at any time at your request. **Personal medical details:** In this form, we have not asked you any personal medical information, such as whether you suffer from any of these conditions yourself, or whether you are a patient, a relative, carer or ex-carer, or are interested for other reasons. If you do choose to inform us, this will not be entered into our DeNDRoN computer database. Terry McGrath.

Your local area

Wherever you are anywhere around the UK, you should be able to have a say in DeNDRoN. However, most of our local involvement work will happen in seven Local Research Network areas and in our supplementary resource areas. Here is a link to various UKCRN research network maps, which includes the DeNDRoN map:

www.ukcrn.org.uk/index/library/literature/mainColumnParagraphs/06/document/All%20LRN%20Maps.pdf