Protocol for Promoting Studies from Researchers through the MND Association

Progress in research would not be possible without people volunteering to take part in research studies. The MND Association can help researchers to recruit participants for their research studies. We are open to promoting studies from all types of MND research, and can help recruit people living with MND, carers, family, healthy participants and healthcare professionals.

The MND Association has a centralised process for requests to promote research studies. This is to check the researchers has appropriate ethical approval, relevant information and consent literature as some studies could be distressing or fraudulent.

The centralised process

 Any requests for the promotion of research studies must come through research@mndassociation.org. If you receive a request from a researcher, please forward the email to us and we will reply to the researcher as soon as possible.

Please feel free to send a holding email to the researcher stating that you have passed on the information to the research team who will be in touch soon.

We **do not** promote studies from market research companies.

2. Researchers will then be required to complete a <u>'Help with recruitment'</u> <u>proforma</u> from our website. We also ask them to send a copy of ethical approval, participant information sheet and consent form.

These documents are stored in a centralised location which can be accessed by any member of the research team.

- 3. Once a member of the research team has checked these documents, the study can be promoted throughout the Association. As part of the process, we ask researchers which of the following promotion methods they would like:
 - a. Email to our research participation list
 - b. Post on the MND Association Forum
 - c. Take part in research page on the MND Association website
 - d. Tweets through our <u>@mndresearch</u> Twitter account
 - e. Email newsletters (Education/Volunteer News)

We are also more than happy to get them in touch with local Branches and Groups as appropriate.

To stay up to date on research studies which have been approved for promotion by the research team please:

- Go to our <u>Take part in research page</u> on the MND Association website
- Sign up to the <u>research participation list</u> where you will receive no more than 2 emails a month about recent research opportunities