Getting involved in MND research

MND research doesn’t just revolve around scientists shut away in high-tech labs performing experiments in plastic dishes and test tubes. Many important areas of research rely heavily on the involvement of people affected by the disease.

Individuals with MND can find that taking part in a research project is a positive experience, providing an opportunity to contribute to the effort to improve treatment and care for future generations. By 2015 we want everyone with MND to have the opportunity to take part in clinical and healthcare research if they so wish and we’re promoting this message throughout the research community.

Here we take a look at two very different but groundbreaking Association-funded projects that would be impossible without the input of people living with MND.

Research to improve healthcare

At present, little is known about the long-term psychological consequences of non-invasive ventilation (NIV) use. Prof Carolyn Young from the Walton Centre in Liverpool aims to examine the impact of NIV on both patients and carers. She’s investigating how their attitudes towards NIV can change over time. An understanding of these issues is essential if people with MND and healthcare professionals are to make the best decisions about using NIV. The results of this research are important as they could be used by the Association in the development of new healthcare guidelines and policies.

Bill Newton from Southport found out at a routine clinic appointment that patients were needed and didn’t

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hesitate to sign up.

“I decided to take part because I wanted to help others and get involved in research. I don’t have to travel as the researchers visit me at home every three months or so to carry out an interview and perform some tests on my breathing. I’m glad I’ve contributed to the project.”

Projects we’re funding involving people with MND

- DNA Bank
- Evaluating the psychosocial influences upon quality of life in MND
- Is there a blood biomarker for MND?
- Lithium clinical trial
- Impact of NIV on people with MND and carers – see article
- Finding biomarkers in MND – see article
- Relationship between MND and cognitive impairment
- The benefits of a mechanical ‘cough assist’ device
- The effect of physical activity on the development of MND
- Understanding choice for NIV and PEG in MND

Participation opportunities we are helping to promote:

- PhD project looking into the views of people living with MND in the UK
- Donation of brain and spinal cord tissue
- Sheffield Research Advisory Group

To find out how to get involved in MND research, please visit the research pages of our website www.mndassociation.org/research and click on ‘participate in research’, or call our research development team on 01604 611880.

Research into diagnosis

The diagnosis of MND can be a long and gruelling process. Dr Martin Turner from the John Radcliffe Hospital in Oxford is looking for an MND specific ‘fingerprint’ or biomarker that can speed up the diagnosis of the disease and enable us to develop more accurate ways of measuring its progression. Although in its early days, this study is already producing potentially exciting results.

Working with Dr Turner is Mel Lord, a research assistant whose role is to explain to prospective participants what the project involves and ensure they and their carers are comfortable when they attend the research clinic.

Mel says: “Patients often report that taking part in research is a positive action they are keen to take, even it does not help them personally, to help other people with MND in the future.”

Dr Brian Dickie, our director of research development, explains: “Taking part in a research project is a chance for people to make a difference to our understanding of MND and to be involved in the improvement of care and treatment. Whether it’s completing a questionnaire or committing to a clinical trial for 18 months, the contributions of people affected by MND are invaluable.”

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Ten out of the 38 research projects we currently fund have some element of direct patient participation - a figure we’re very proud of but which we are keen to increase.

Taking part in MND research has different levels of patient involvement. For example over 2,500 people have already donated a blood sample, a simple procedure, to our DNA Bank project. These samples are now being used by researchers across the globe to provide valuable insight into the genetic factors underlying MND. We’re also funding our first clinical trial to test the drug lithium carbonate as a treatment for MND. This requires a greater level of patient involvement as individuals take the drug or a placebo every day and regularly visit their local care centre for close monitoring.

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