Quarterly update from research and support at MND Scotland

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MND Scotland
Making time count

Friend, here is an update from the support and research teams at MND Scotland.

A warm welcome to our latest support and research newsletter. We want these updates to be shaped by you, so please continue to share your thoughts by emailing communications@mndscotland.org.uk with feedback and ideas.

Earlier this week, the Scottish Parliament voted on the Assisted Dying for Terminally Ill Adults Bill. MSPs voted in favour of the bill, which means it will move onto a second stage. We take a neutral stance on assisted dying. Our statement can be read on our website here. The bill passing the first stage means that the topic of assisted dying will continue to receive a high level of attention. As this bill progresses, we will continue to engage with MSPs on the considerations for people with motor neuron disease. We know this can be a challenging topic and we are here to support everyone affected by MND. For support, please get in touch with support@mndscotland.org.uk.

We hope you find the information below informative and useful, whether you have MND, are caring for someone living with the disease or have lost a loved one.

Angela Harris, Director of Support Development, and Jane Haley, Director of Research

MIROCALS data published

The long-awaited data from the MIROCALS trial, testing low dose interleukin 2 (IL-2) on survival of people with MND, was published in The Lancet last Friday, 9 May. We appreciate that it has been a very frustrating time for the MND community waiting for the publication of these results.

Following the publication of the data, the Clinical Studies Group (CSG), incorporating the leading neurologists in the UK, met to discuss the results. We appreciate that this happened promptly, and following this meeting the CSG agreed a statement on Thursday, 15 May in response to the trial data.

We have included everything you need to know, including a link to The Lancet publication and the CSG statement, on our website. The CSG has concluded that more data is needed to determine whether this treatment is effective in a sub-group of people with a particular biomarker on the trial. There are several ways to gather more evidence, and we are committed to working with all stakeholders to progress making proven new treatments available to people living with MND.

Read more about MIROCALS

Opportunities to get involved in research

Researchers at Newcastle University are conducting a study to better understand how motor neuron disease (MND) affects muscles, aiming to improve diagnosis and monitoring. The study involves four MRI scans over 18 months, where participants will tap their foot in time with audio cues. Each visit lasts around two hours and takes place at the Newcastle Magnetic Resonance Centre, with travel costs covered. Adults aged 20–80 with an MND diagnosis who are eligible for MRI scans are invited to take part. For more information, contact **Dr. Ao Wang** by email **Ao.Wang@Newcastle.ac.uk** or call 07835 146 031.

Researchers at the University of Sheffield are running the iDeliver MND study to understand the experiences and preferences of people living with MND, and their unpaid carers, regarding psychological care services. Participants are invited to complete a short online survey (15–30 minutes), with paper or phone options available. The aim of this research is to help shape how psychological care is delivered, with opportunities to get involved in the wider study upcoming. To learn more or take part, contact **Dr. Sarah Creer** by email s.creer@sheffield.ac.uk, or follow this link to the survey – bit.ly/iDeliver-survey.

The Motor Neuron Disease Research Data Catalyst study aims to accelerate MND research by making it easier for researchers to access relevant data. People living with MND and their carers are invited to join three online group meetings (via Teams) between June 2025 and June 2026 to share their perspectives and help guide the project. Additional optional opportunities include reviewing materials and sharing personal experiences, with participants reimbursed for their time (HDR UK's Expense and Honoraria Policy). The study is designed to be accessible and inclusive, with one-to-one support available. To learn more, email MNDinvolvement@hdruk.ac.uk.

Find all research involvement opportunities on our website

Working in partnership with Marie Curie on a respite pilot

Thank you to everyone that took part in our recent **What Matters** survey. While we await the results, one of the themes that is coming through, and came through powerfully from the previous survey, was an acute need for respite care.

In the period since we collected the initial data, we have been working on ways to better support the MND community with respite. Short term and regular respite is needed and wanted by both people living with MND and their carers, who are under enormous pressures as the key or often sole unpaid carer for their family member. MND nurses have repeatedly championed an approach that will support people within their own homes whilst providing safe support in an often complex family environment.

Following a period of focus on respite, we are pleased to announce that we are collaborating with **Marie Curie** on an innovative pilot project in Glasgow.

We will be working in partnership with the **Marie Curie Hospice Network** to provide a tiered community respite support in people's homes. The 18-month pilot will run in Greater Glasgow and Clyde. We would then look to expand accessibility across Scotland using a phased approach.

We are keen to involve lived experience in the design and delivery of the pilot. If this sounds like something you would like to get involved with, we are looking to fill two main roles:

1. **Bereaved carer or person with MND to be part of the steering group for the project.**
2. **Volunteers.**

Here is some more information on what is involved in volunteering for this project:

- People who live within Greater Glasgow and Clyde to work closely with MND Scotland and Marie Curie to deliver the volunteer element of the service.
- This will involve supporting people in their homes with their practical and emotional needs in regular four hour shifts.
- We appreciate this is a significant commitment and will provide training and support.
- We are looking for volunteers to commit for the duration of the pilot, 18 months.

- Role description, clear boundaries, training and regular support will be provided following successful induction as a volunteer.

To express an interest in getting involved, please email support@mndscotland.org.uk with the subject line **'Respite pilot'**. We will be interviewing potential volunteers over the Summer with a view to the service starting around Autumn.

Changes to grants

You will have received an email or letter from us earlier this month explaining changes to our grants that will come into effect on 1 June.

Following a financial review of our grants, we have taken the decision to combine our previous grants into one simplified wellbeing grant – **Making Time Count Grant** – to help us continue supporting **people with MND, their carers and family members** in a sustainable and consistent way.

The **Making Time Count Grant** will come into effect on 1 June 2025 and will be funded by MND Scotland and My Name'5 Doddie Foundation.

Read more about the changes to grants on our website

British Neuroscience Association Festival

2025

At the **British Neuroscience Association (BNA) Festival 2025**, MND Scotland was proud to partner with the MND Association and My Name'5 Doddie Foundation to deliver a symposium titled 'New approaches to diagnostics, biomarkers, and trial drug selection in MND – highlighting UK MND translational research'.

This session talked about the innovative research that is happening across the UK, shared the latest findings and discussed what the next steps are. This was a collaboration between MND researchers and funding bodies and showcased how working together can lead to leaps and bounds in MND research and care, and how we can aim for a shared goal – A world without MND.

Read more about the event here

Bringing together lived experience and research

In March, MND Scotland hosted our Community Of Research and lived Experience (CORE) event, in partnership with the My Name'5 Doddie Foundation. This rounded off a series of engagement events we announced in June 2024, beginning with our Lived Experience And Researcher Network (LEARN) local events in Aberdeen, Dundee, Edinburgh and Glasgow. We were thrilled that our events brought over 150 people affected by MND in Scotland and MND researchers together to share knowledge, experiences and opinions.

Following the success of our 2024 events, we are excited to announce that our LEARN local events will be returning in the Autumn of 2025. We will be hosting events in Aberdeen, Dundee, Edinburgh and Glasgow again. But, this year, we will be expanding the network to include an event in the Highlands. Our research team is currently planning the events. Keep an eye on our social media channels and website for our **LEARN** announcement.

To view the researcher talks from the 2024 LEARN events, please visit our YouTube channel.

Parliamentary reception cancellation

If you were planning to attend our Parliamentary Reception on 20th May, you should have received an email or phone call to let you know it has unfortunately been cancelled. This is due to unexpected parliamentary business that is anticipated to run late on the evening of the event.

We understand that this news may be disappointing. The decision to cancel was not taken lightly, but unexpected parliamentary business would have significantly reduced our event's duration, compromising on the quality and impact of our planned gathering. In addition, the ability for MSPs and guests to network, which we recognise is an integral part of the event, would have been impacted too.

Although the event has been cancelled, we remain determined to influence the Care Reform Bill over the coming weeks. We are working with the Scottish Government and MSPs to ensure this Bill delivers for people affected by MND. If you would still like an opportunity to meet with your local MSP, we will happily try to arrange that for you. Please contact colette.mcdiarmid@mndscotland.org.uk who will help facilitate a meeting.

Radio Teleswitch Service (RTS)

The Radio Teleswitch Service (RTS) is going to switch off on Monday, 30th June 2025. RTS meters use radio signals to switch between ‘peak and off-peak rates’ in some homes with electrical heating and hot water. These radio waves are no longer going to be used, meaning that your heater won’t switch between rates.

Have you received a smart meter upgrade yet? Get in touch with your energy supplier to book an appointment. If you don’t have an upgrade, your heating and hot water may not work properly and the costs can increase.

Click here for further guidance if you have an RTS meter

Rachel Maitland, MND Scotland's chief executive, is keen to meet people with MND face to face and listen to your experiences and thoughts about our services and activities. If you would be happy for Rachel to visit for a cup of tea and a chat, please email **communications@mndscotland.org.uk** and we will be in touch.

We welcome feedback on our quarterly newsletter. If you have any comments or suggestions, please get in touch by emailing **communications@mndscotland.org.uk**.

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