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

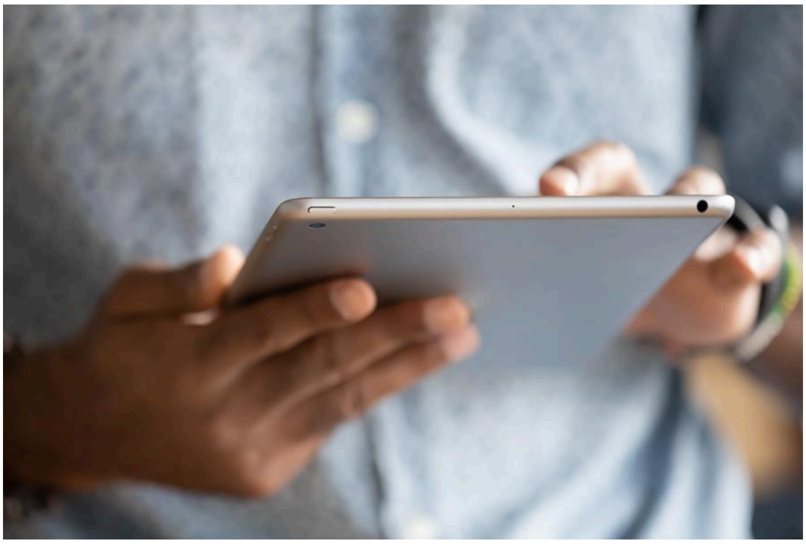
Welcome to the latest edition of the support and research newsletter.

We hope you are having a positive start to 2025. We know that, especially at this time of year, it can help to talk to someone other than your own family and friends if you need emotional support. To access our Counselling Service, please contact **support@mndscotland.org.uk**. This service is for people living with MND and their families and offers the opportunity to access up to 12 free one-to-one counselling sessions. These sessions are led by a qualified therapist and could help you understand and manage difficult feelings you may be experiencing.

There is lots to update you on below and we hope you find the information below helpful. We would love to hear more of your views this year. Please continue to share your thoughts by emailing **communications@mndscotland.org.uk**.

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

What Matters Survey coming soon

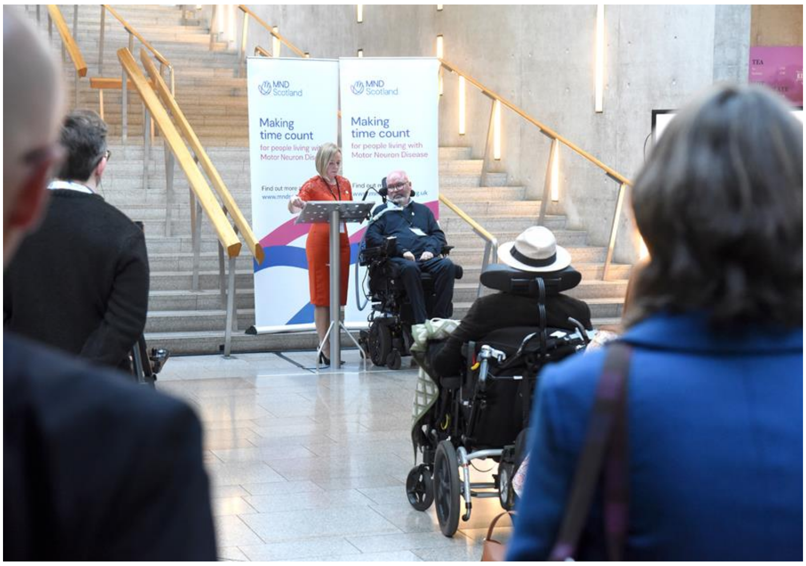


In the last support and research newsletter, we mentioned that we will be inviting people affected by MND to share their views in an online survey.

The follow-up to our **What Matters Survey** will be issued later this month so please keep an eye out for it. We want to understand how our focus as an organisation can best meet your needs so we are encouraging as many of you as possible to take the opportunity to share your views.

As it is being sent by email, we also want to ensure we have up-to-date contact details for you. The survey will be sent by email, and shared on social media. If you have made any changes to your contact details, please let us know by emailing **info@mndscotland.org.uk** or calling us on 0141 332 3903.

Save the date for our Parliamentary reception



Last April, many of you joined us at the Scottish Parliament to hear from the Minister for Social Care, Mental Wellbeing and Sport, Maree Todd, and Brian Murphy, who was diagnosed with MND in 2019. The event highlighted the need for better social care for people with MND.

The MND Scotland Parliamentary reception returns this year on **Tuesday, 20 May, 6 - 8pm,** and we hope you will keep the date free to join us.

Invitations will be sent out in April but ahead of that, and following a recent Scottish Government announcement on the National Care Service, we plan to host an online 'roundtable' meeting with MSPs in March to discuss social care. If you are interested in attending this roundtable, please let us know by Friday 21st February by getting in touch with susan.webster@mndscotland.org.uk.

Clinical trial and regulatory updates

Ellorarxine

Last week we shared a statement on this new drug compound following UK-wide media coverage.

Working in collaboration with the other main MND charities, we remain committed to funding research in a manner which is safe and appropriate for the community. This research is still at an early stage and before ellorarxine, which is a newly created compound, can be tested in people with MND it needs to be shown to be safe. **You can read the statement in full here.**

Amantadine

In December, we shared the news that, following a review of stage 1 interim analysis data, amantadine will continue to be evaluated as part of the MND-SMART trial. **Read more about amantadine** and how the MND-SMART trial is speeding up the progress of drug testing by allowing multiple drug treatments to be tested at the same time.

Tofersen

In November, we shared the positive news that NICE will now appraise the drug tofersen via the Highly Specialised Technologies (HST) route, following a successful campaign driven by the MND Association, supported by MND Scotland and My Name'5 Doddie Foundation. Tofersen, developed by Biogen, is targeted to treat people living with motor neuron disease (MND) who have alterations in the SOD1 gene. **Read more about the NICE decision here**.

Bereavement support

We are here for everyone affected by an MND diagnosis, including those of you who have lost someone you love.

Early last year, we piloted a bereavement workshop to provide individuals with an opportunity to share their experience and find support.

Some of the women who took part in that initial workshop have kindly, and bravely, shared their stories with us in the video above to highlight what they got out of coming together and sharing their stories.

If this resonates with you, you are struggling with your grief and would like more support with a future group, please email **support@mndscotland.org.uk** for more information.

Update on funded research projects

Telehealth in MND

Telehealth in MND (TiM) is a new tool developed to support care for people with MND. This MND Scotland funded project, which began in 2019, focused on understanding the feasibility and acceptability of using remote monitoring for people with MND, with the aim of developing a telehealth approach to improving access to specialist MND care.

Thanks to the success of this feasibility study, the researchers secured further substantial funding from NIHR (National Institute for Health and Care Research) which means that TiM can be implemented and tested in more centres across England. **Read more about this project**.

Individualised support needed for carers

A project by Professor Eneida Mioshi and Dr Polly Trucco, carried out at the University of East Anglia, has found a need for targeted and individualised support for carers of people living with MND.

The MND Scotland funded PhD Studentship project aimed to identify key factors influencing anticipatory grief to better support unpaid family carers and inform future interventions and research. **Read more about the findings here.**

Anatomical Society awards three-year PhD studentship

The findings of a new project could help push motor neuron regrowth research towards finding a novel way to help retain motor neurons and muscle function for longer and slow the progression of MND.

Dr Lyndsay Murray, Lecturer in Anatomy at the University of Edinburgh, is investigating whether the use of drugs can help encourage regrowth of damaged motor neurons. The three-year PhD studentship was awarded by MND Scotland and the Anatomical Society. **Read more about Dr Murray's work**.

We are recruiting new trustees to join the MND Scotland board

We are currently recruiting for up to five new Trustees to join our Board. To complement the skills of our current Board members, we are especially interested to hear from people with expertise in the areas of income generation, finance / risk, governance, health & social care / local authority and early career individuals from any discipline looking to gain Board experience.

If this sounds like something you would like to get involved with, a full recruitment pack is available on our website.

Board of Trustees recruitment pack

Join us online at CORE in March

In partnership with **My Name’5 Doddie Foundation**, we are looking forward to hosting our inaugural **Community Of Research and Lived Experience (CORE)** event on **03 March 2025.**

The main aim of our CORE event is to create a community of people who are passionate about and invested in MND research. To ensure **CORE** is accessible to as many people as possible, we will be hosting **two virtual sessions** on the day of the event via **Zoom**. Between **14:15 – 15:15 and 15:45 – 16:15** on **03 March 2025**, we are inviting people to join us for our virtual round-table discussion sessions.

If you are interested in taking part in the virtual sessions, please use **this form** to provide us with your name and email address so we can send the Zoom link. If you would like more information, or would like to get in touch, please email **involvement@mndscotland.org.uk**.

Help to shape our virtual webinars

As part of ongoing work to offer more helpful information about MND, we are planning a series of virtual information webinars. People affected by MND are at the heart of everything we do, so to help inform the subjects, structure and timing for these sessions, we are looking for volunteers to join a webinar focus group. If you would be interested in sharing your thoughts to help us shape this new activity, please email **involvement@mndscotland.org.uk** and a member of the team will be in touch.

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**.

MND Scotland

Share

Tweet

Share

Forward

MND Scotland is the only motor neuron disease (MND) charity providing direct support to people living with MND in Scotland. We campaign to create lasting change and invest in pioneering MND research to find a cure.