Your quarterly update from MND Scotland

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Friend, here is your latest news from MND Scotland.

A word from our CEO

Welcome to our Spring 2025 newsletter, the first of the year. We are already nearly three months into the new year and it's been a busy time here at MND Scotland.

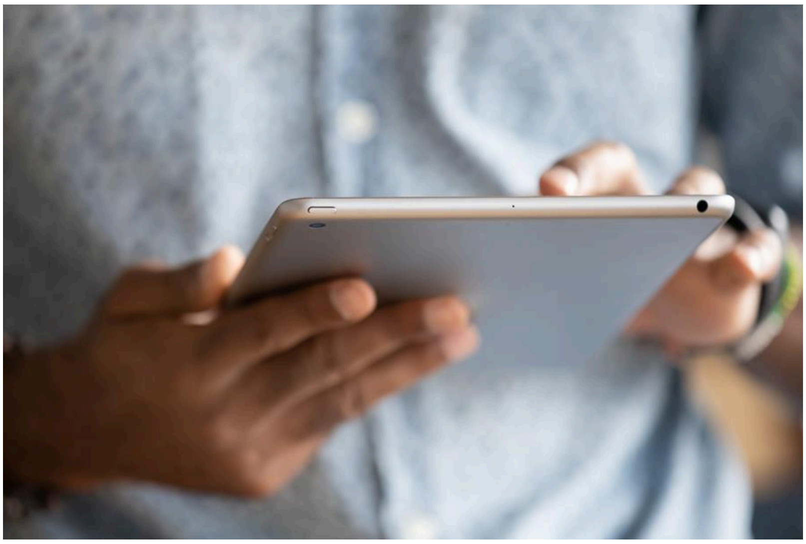
Last month, we launched our What Matters Survey 2025. Listening to the views of everyone impacted by MND Scotland is incredibly important to us and we want your views to shape our work. Whether you are living with MND, are a friend or family member supporting someone, or have lost someone you love, we want to hear from you. Please access the link below to complete the survey.

Its Mother's Day at the end of March, which can be a time of reflection for anyone that's lost a mum, gran, or mother figure to MND. In remembrance, **we have created a dedication page for Mother's Day** for anyone that wishes to leave a message or photo as a tribute to loved ones.

I continue to find it incredibly valuable to meet and hear the first-hand experience of as many of you as possible, to hear your experiences and thoughts about our services and activities. If you would be happy for me to visit for a cup of tea and a chat, please email **communications@mndscotland.org.uk**

Rachel Maitland
Chief Executive Officer

What Matters Survey 2025



In 2022, we undertook an in-depth survey to understand how MND Scotland can best meet the needs of everyone affected by MND across the country. The findings from the 2022 survey have helped shape our work over the last three years.

Last month, we launched the follow-up survey. There are three different surveys, one for people diagnosed with MND, one for family members that have been impacted by a diagnosis and one for bereaved carers. Your responses will help us better understand how we can support everyone affected by the disease. If you have been affected by MND, please take the time to share your thoughts and experiences by completing the survey via this link: **https://revealingreality.welcomesyourfeedback.net/gpttl7**

Following completion of the survey, we are committed to sharing our findings with the MND community in Scotland.

Take part in our What Matters Survey

Free Wills Month 2025

March is **Free Wills Month.** You may have seen our campaign highlighting the opportunity to write a Will for free across social media channels. We've partnered with the **National Free Wills Network** to give you the chance to make your Will for free.

If you're thinking about creating or updating your Will this month, please consider leaving a gift to support our future work too. Every gift, big or small, helps to make time count for families across Scotland when they need us most.

You can download our Gifts in Will pack here, or visit our website using the button below for more information.

Visit our website for more information

Celebrating our supporters

Our supporters never cease to amaze us with their wonderful fundraising endeavours. Here are some of the stories we have had the privilege to share over the last few months:

- Abbi Noone, a 21-year-old from Renfrewshire, will take on the TCS London Marathon next month to honour the memory of her father, Mark. Abbi and her family have been dedicated supporters of MND Scotland over the years and we really appreciate their continued support. **Read more about Abbi's story.**
- Supporter, Gemma Catton **'socked it to motor neuron disease'** in 2024 with her innovative fundraiser. Over the years, Gemma has raised £25,000 for MND Scotland in honour of her mother.
- Aberdeen couple, Leah and Ryan, have raised over £5,000 in their inspiring fundraising journey in memory of loved ones affected by MND by running a total of 100.4 miles in 2024. **Learn more here**.
- Long-term supporter, Calum Scoular is heading to Paris next month to take on the marathon in memory of his teacher and friend. **Good luck Calum!**
- Also participating in the Paris Marathon is Alan Arnott, an optician from Milngavie, who is raising money in memory of his brother, Michael. Alan said: *"Mike and his family*

received a lot of support from MND Scotland while they were in Aberdeen. He was very passionate about raising funds for MND research". **Read more about Alan's marathon efforts here**.
- Twenty-three-year-old, Connor Whitelaw from Kirkintilloch, will take on the West Highland Way this year to honour the memory of his beloved aunt Gwen. **Read more about why Connor wants to support MND Scotland.**
- Andy Huxtable from Ayr has raised a phenomenal £222,000 for MND Scotland helping us to fund vital research and support families across Scotland. **Learn what inspired Andy to start his fundraising journey over 15 years ago.**

Inspired to support us?

If our supporter stories have inspired you, there are many ways you can get involved and fundraise this year, including the return of **A Dip A Day in May!** Sign-up for an ice bath or cold water dip every day in the month of May and you will be supporting families across Scotland living with MND, and funding vital research. **Register your interest here**.

Our **Fun Run** will also return this year, with not just one but two events to get involved with! Save the dates - **21 June in Fife** and **6 September in Glasgow**.

We also have a range of third-party events to get involved with:

- **2025 Kiltwalks** in **Glasgow** on 26 & 27 April, **Aberdeen** on 1 June, **Dundee** on 17 August and **Edinburgh** on 14 September
- **Rob Burrow Leeds marathon** on 11 May - just one final MND Scotland charity place is available for this event
- **Great Scottish Run** in Glasgow on Sunday, 5 October

For more information on our 2025 fundraising events, **please visit the events page on our**

website and sign-up for your next challenge.

CORE success

Earlier this month, we hosted our first **C**ommunity **O**f **R**esearch and lived **E**xperience, **CORE** event in Edinburgh, in partnership with My Name'5 Doddie Foundation.

The inaugural **CORE** was a great event so thank you to everyone who attended online and in person and our contributors, including **Professor Tom Gillingwater**, **Professor Gareth Miles**, and **Alan Ogg** for their insightful presentations.

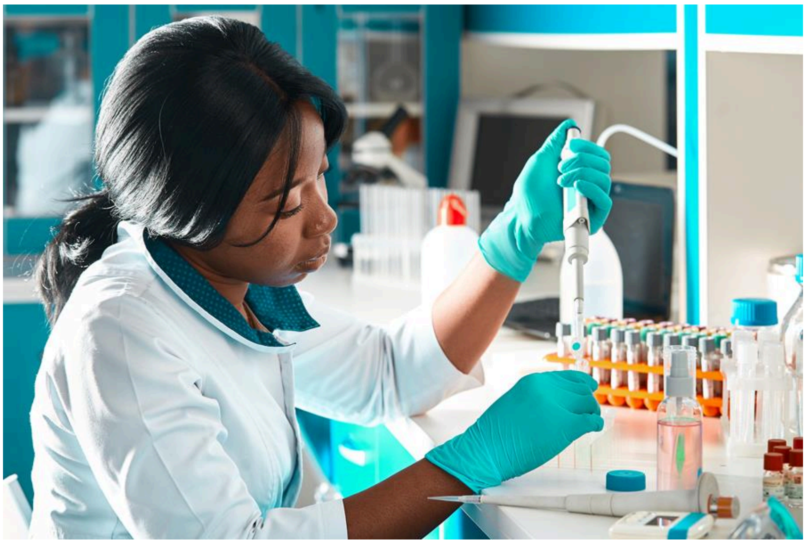
CORE brought together people affected by MND in Scotland and researchers to provide the opportunity to build a community of people who all have a stake in MND research, and share the same goal of finding meaningful treatments for MND through research.

It was an inspiring day which included a panel of people with lived experience sharing their personal insights and opinions. Their input was very much appreciated and valued by everyone that attended. If you attended and haven't yet completed the feedback form, we would really appreciate if you have time to do so.

The voice of people with MND is at the heart of everything we do, and we believe that we will only make progress by working collaboratively.

Click here for more information on the research we fund

Spotlight on ... ellorarxine



We are committed to spending the money our supporters generously raise to fund the very best and most promising research. We have robust review processes in place to ensure we are funding research in a manner which is safe and appropriate for the MND community. One early-stage compound, ellorarxine, has attracted some interest since the start of this year. **You can read our statement here**.

Following the media coverage about ellorarxine, the UK Motor Neuron Disease Research Institute - a national network of MND centres all working together to understand how and why MND happens and testing possible treatments in clinical trials - issued a statement on the compound. The UK MND Research Institute say there is currently no evidence that ellorarxine is safe in humans. However, if this evidence becomes available, they would be delighted to work with the company involved to advise on the fastest way to assess it in clinical trials. **You can read their statement here.**

To help everyone understand the drug approval process, and the associated timescales, we partnered with the MND Association and My Name'5 Doddie Foundation to create infographics that explain the pathway a new drug needs to navigate before it can become a treatment. You can view these infographics on **this page of our website**.

Read our statement on ellorarxine in full

We welcome feedback on our quarterly newsletter. If you have any comments or suggestions, we would love to hear from you. We also share a quarterly newsletter on support and research. If you would like to get in touch or be added to our support and research newsletter mailing list, please email: **communications@mndscotland.org.uk.**

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.