

Your quarterly update from
MND Scotland

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from MND Scotland.

A word from our CEO



Welcome to our Autumn 2024 newsletter.

As many of you will be aware, the MND community is awaiting publication of data from the MIROCALS trial. Earlier this month, we wrote to both the EU Clinical Trials Register and the Ethics Committee at Centre Hospitalier Universitaire de Nîmes, the MIROCALS trial sponsor, informing them of the

delays to publication and expressing our disappointment at the time it has taken to make the data available. [You can read our statement online.](#) It has now been more than three years since the trial officially closed and we do not think the delay publishing results is acceptable.

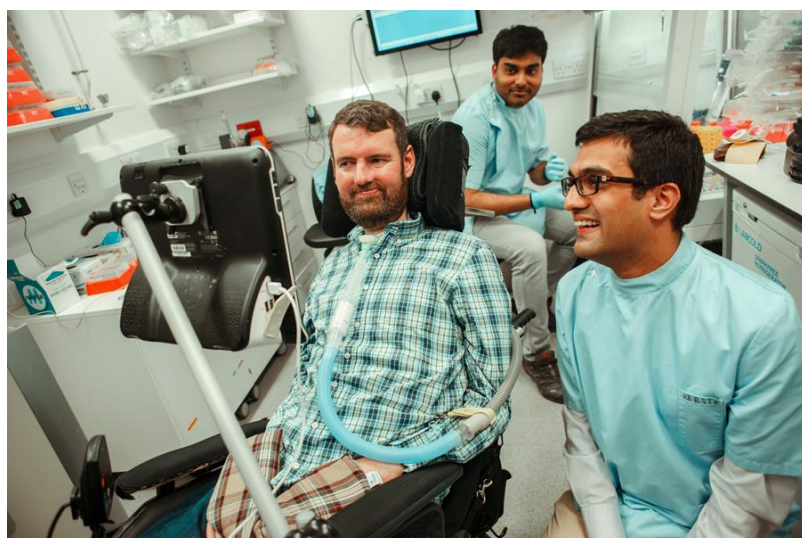
In our summer newsletter, we celebrated the 10 year anniversary of the global phenomenon that was the Ice Bucket Challenge. We've had a great response from supporters, old and new, who have shared videos and taken on new ice buckets to raise awareness and vital funds. Thank you to everyone who took on the cold water challenge.

I received such a great response to my recent request to meet face to face and listen to your experiences and thoughts about our services and activities, and I'm working my way through all your generous invitations. I find it incredibly valuable to meet and hear the first-hand views of as many people as possible impacted by MND. If you would be happy for me to visit for a cup of tea and a chat, please email communications@mndscotland.org.uk and I will be in touch as soon as possible.

Rachel Maitland

Chief Executive Officer

Remembering Euan MacDonald MBE



We were deeply saddened to hear that former trustee of MND Scotland, **Euan MacDonald**

MBE passed away in August.

Euan and his father, Donald MacDonald CBE, committed to doing whatever they could to ensure MND research was brought to the forefront of everyone's mind, following Euan's diagnosis in 2003. Having both come from an investment background, they approached a group of key MND researchers at the University of Edinburgh and began discussions to establish [The Euan MacDonald Centre for MND Research](#). MND Scotland worked closely with Euan and Donald from the inception of the centre and funded research projects based there, including the innovative [MND-SMART](#) trial, which is the largest-ever clinical MND drug trial in the UK.

In 2013, Euan, his sister Kiki and Donald launched [Euan's Guide](#), a disabled access review website that is helping to open up towns and cities to disabled people everywhere by removing the fear of the unknown, and inspiring people to try new places.

Euan's legacy will live on through his incredible work to raise awareness, improve accessibility for all and help drive our shared vision of world without MND.

Our thoughts remain with Euan's family and friends at this difficult time.

Scottish Housing Day



Wednesday, 18 September marked Scottish Housing Day. This year, the focus was on 'Homes for Life', recognising that many people face a wait of several months for home adaptations to be put in place.

At MND Scotland, we know from our 2022 report, [**No time to lose: Addressing the housing needs of people with MND**](#), that the reality is even more stark with local authorities reporting average waiting times of 15 months for a simple ramp and up to four years for an accessible home. For anyone, that's unacceptable. But for someone with MND, when average life expectancy post diagnosis is just 18 months, that is simply unthinkable. People with MND do not have time to wait.

That's why we're proud to be working alongside organisations such as Wheatley and Thenue, who have already changed their processes to enable people with MND who require rehousing to be fast tracked. This is exactly the type of action that helps make time count.

We continue to work with the Scottish Government and other agencies on this but were disappointed that a commitment to accessible housing was missing from the Scottish Government's Programme for Government. On Scottish Housing Day, we therefore renewed our call for a system which is fast enough, and flexible enough, to respond to the rapidly changing adaptation and accessibility needs of people with MND. To help enable this: a minimum of 10% of the affordable homes the government has committed to being built to wheelchair accessible standards; increased investment for adaptations; and clear and publicly available information on the Scheme of Assistance are urgently required.

Without those in place, a home for life will continue to be delayed for many and for people with MND will likely never come.

[**READ OUR 'NO TIME TO LOSE' REPORT**](#)

LEARN events



The Lived Experience and Researcher Network (LEARN) is designed to improve interactions between people affected by MND and researchers. We recently hosted our first LEARN in-person event in Aberdeen with presentations from three local researchers. The event was well attended and we are looking forward to meeting more people in Edinburgh, Glasgow and Dundee.

Our LEARN drop-in sessions offer people with MND and supporters the opportunity to meet and engage with local MND researchers. Building relationships between those with lived experience and researchers can help to make sure that research reflects the needs of people with or affected by MND.

The series of local events continue over the next few months, bringing together people affected by MND and local MND researchers. Here is more detail on the events and a link to register your interest is below.

- [**MND Scotland LEARN Edinburgh**](#): 26 Sep 2024, 2pm, Bonnie and Wild Marketplace, St James' Quarter Level 4, St James Cres, Edinburgh EH1 3AD
- [**MND Scotland LEARN Glasgow**](#): 3 Oct 2024, 2pm, The Social Hub Cafe, 15 Candleriggs, Glasgow, G1 1TQ

- [MND Scotland LEARN Dundee](#): 24 Oct 2024, 2pm, Dundee Science Centre café, 14 Greenmarket, Dundee DD1 4QB

MORE INFORMATION ON LEARN

Gordon Aikman Scholarship develops MND-specific Future Care Plan

Funding that honours the late motor neuron disease (MND) campaigner Gordon Aikman has delivered an MND-specific future care plan.

The [Gordon Aikman Scholarship](#) was set up in 2017, in honour of late MND campaigner Gordon Aikman, to fund research and developments into improving care and support for people living with MND. The £50,000 scholarship scheme is jointly funded by MND Scotland and the Scottish Government.

The [Aikman Future Care Plan](#) was developed by Louise Gardiner, an MND clinical nurse specialist working for NHS Fife, who now hopes the care plan will be rolled out across the other Health Boards in Scotland.

READ MORE ABOUT LOUISE'S WORK
[HERE](#)

Help us shape the future of MND research

As a person affected by MND, whether you live with, support someone with, or have helped care for someone with MND, you can play an important role in ensuring that the research we fund makes

the biggest possible difference by **becoming a lay reviewer**.

Lay review is a process where you tell us whether you think a research project tackles an issue that is important to people affected by MND. We will send you summaries of applications submitted to us for you to read and answer some questions on. Don't worry - no scientific knowledge is required! The summaries will be written in plain English and jargon-free.

We expect to be sending applications out for review in November, so if this sounds like something you would like to get involved with, please contact the research team on involvement@mndscotland.org.uk.

Spotlight on ... MND Scotland Fun Run



It's been a busy summer, including the recent return of our annual in person **MND Scotland Fun Run**. Thank you to everyone that joined us at Lochore Meadow Country Park in Fife for a great event. As you can see from our pictures of the day, the weather was kind to our walkers and runners and the atmosphere was fantastic.

The **MND Scotland Fun Run** will return in 2025 so keep an eye on our website and socials for more information.

Sign up and get involved

If our Fun Run has inspired you to take on a fundraising challenge, there is still time to sign up for the [Great Scottish Run](#) on Sunday, 6 October. Whether you take on the 10K or half marathon, it's always a fantastic day with a brilliant atmosphere as thousands of participants race through the centre of Glasgow.

That's just one of a great range of fundraising events coming up. One of our long-term supporters is holding a Golf Day on Tuesday, 22 October at King Robert the Bruce Course, Turnberry. If you would like to get involved, please contact the fundraising team by emailing fundraising@mndscotland.org.uk.

You can visit our website for the latest events, including our 2025 calendar. Upcoming events include:

March: Falkirk Wheel Abseil (15th) & Supernova Kelpies (14th & 15th)

April: London Landmarks Half Marathon (6th), Kilomathon (6th) & the Glasgow Kiltwalk (date TBC)

May: Rob Burrow Leeds Marathon (11th) & Edinburgh Marathon Festival (24th & 25th)

June: Aberdeen Kiltwalk (date TBC) & Glasgow Men & Women's 10k (15th)

We will also be promoting Facebook challenges in the new year so [keep an eye on our website](#) and social media for more information on all of these soon.

If abseiling or running is not for you and you want to support in a different way. We have [a range of MND Scotland merchandise available in our online shop](#), including our newly designed Christmas cards coming soon. Sorry ... we know it's too early to mention Christmas!



Be part of something great



Volunteers play a vital role in helping us raise awareness and funds; driving our vision of a world without MND. We are so grateful to everyone that gives us their valuable time, including the team that joined us for the Fun Run and LEARN event in Aberdeen recently.

We have a variety of volunteering opportunities available - the more volunteers we have, the more people we can support with MND in Scotland. Please [visit our website](#) to learn more about our upcoming opportunities and how you can get involved.

SIGN UP TO VOLUNTEER

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

We also share a quarterly newsletter on support and research. If you would like to be added to this mailing list, please email communications@mndscotland.org.uk.



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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.

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