

A quarterly update from MND  
Scotland

No images? [Click here](#)



**Friend**, your latest news  
from MND Scotland.

## **A word from our CEO**



**Rachel Maitland**  
Chief Executive Officer

Welcome to our Spring 2024 newsletter.

It's hard to believe we're already in March, but thanks to our incredible supporters this year is already off to a great start.

A big thank you to all our guests who joined us at the first-ever MND Scotland Shindig earlier this month. It was fantastic to see so many of you enjoying yourselves, and I think we can all agree that the Shindig delivered on its promise of a fun-filled evening with great company, superb music, and most importantly, lots of funds raised. To everyone who came out and supported us, you made it a night to remember. Thank you!

The evening would not have been so successful if not for Mark Ferguson and his family, who bravely shared their story in a special video - please watch below - that debuted on the night. We are very grateful to both Mark and his family for highlighting why we all came together at the MND Scotland Shindig and for inspiring people to donate, so that we can continue to support people like Mark.

If you haven't had the chance to get involved yet, seize the opportunity on our [events page](#). There are plenty of fundraising events waiting for you to make time count.

## Fundraising



# Mark Ferguson's Story

Mark received his diagnosis of MND in January 2023, prompted by a persistent arm spasm he had been struggling with since June 2022.

His story, originally shared [on our website](#) last year, has been profoundly impactful and we are very grateful to Mark for dedicating his time to help create a video that left a lasting impression at the MND Scotland Shindig.



## Self-proclaimed 'non-athlete' training hard to represent MND Scotland at TCS London Marathon

Inspired by her neighbour, Jo Knowlton, who is living with MND, on April 21st, Louise Burns, 40, will take on the prestigious TCS London Marathon in support of MND Scotland.

Louise has already raised over £4,000 and is well on her way to reaching her goal of £5,000. You can help to propel her across the 5k mark by [making a donation](#).

**READ MORE**



## Ice Bucket Challenge

Some of you will be aware that this year marks the 10 year anniversary since the ice bucket challenge. We have a series of activities planned, the first one is in May, so keep an eye on our [social channels in April](#) to hear more.

In the meantime, supporter Greg Proctor is taking on an ice bucket every day this year to raise funds. [Watch Greg's highlights from the year so far and support his fundraising.](#)

If you would like to get involved with the ice bucket challenge 10 year anniversary, please get in touch with [fundraising@mndscotland.org.uk](mailto:fundraising@mndscotland.org.uk).



Become a corporate partner in 2024

Do you work for an organisation with a charity partner? Could your business pair with an organisation making a real difference in the lives of people affected by MND?

As the new financial year approaches, we are looking for Scottish businesses to partner with for the year ahead. Partnering with MND Scotland offers the chance to make a real impact on the lives of people affected by motor neuron disease.

To find out more, please contact our Partnerships and Philanthropy Lead, Odette Landsburgh on [odette.landsburgh@mndscotland.org.uk](mailto:odette.landsburgh@mndscotland.org.uk).

## Research

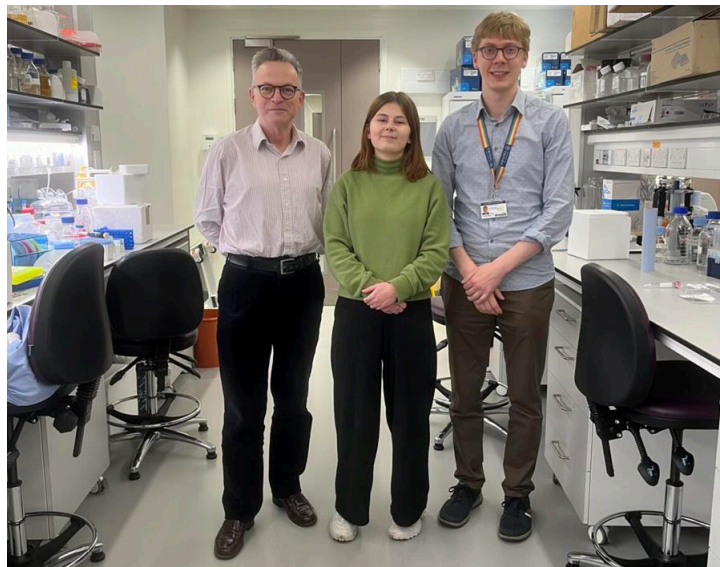


## NICE confirms tofersen drug appraisal via STA route

Last week, we heard the disappointing news that the National Institute for Health & Care Excellence (NICE) has confirmed its decision to appraise tofersen through the Single Technology Appraisal. We joined the main MND charities to respond on what this means for people living with SOD1 MND.

**READ THE FULL STATEMENT**





## MND Scotland welcomes new PhD student to explore role of microglia

We are pleased to welcome Professor Kevin Talbot, Dr Björn Vahsen, and Ms Lara Nickel (University of Oxford) to our community of funded researchers as they begin a new PhD project examining the role of microglia, the immune cells of the brain, in MND.

[READ MORE](#)

## Our support services



## MND Scotland Partners with Housing Association to Address Housing Needs for MND Patients

MND Scotland has been working with the Wheatley Group to highlight the very specific housing needs of existing tenants or waiting list applicants diagnosed with MND. A key outcome has been an agreement that an early detailed housing needs assessment is undertaken to identify and understand what individuals and their family need to ensure that appropriate housing is identified as a priority.

Through our commitment to partnership working with the Wheatley Group, we have identified a named liaison person for MND Scotland to contact on behalf of people with a diagnosis of MND. We have also undertaken a joint awareness and development day to share knowledge and greater awareness of the more immediate needs of people with MND and the impact on them and their families.

Wheatley Group works across 19 of the 32 local authorities in Scotland. MND Scotland is looking to explore opportunities to replicate the arrangement we have with Wheatley, with other housing

providers. In addition, we have also been meeting regularly with the Housing Minister, Paul McLennan and other partners to explore how we can implement the recommendations of our housing report 'No time to lose: addressing the needs of people with MND'

MND Scotland is working with other housing associations, Scottish Government, local authority bodies and other networks to try to secure priority access to accessible housing and adaptations for all people with MND across Scotland.



## Update on Holiday Lodges

We're pleased to announce that after undergoing some fantastic upgrades, our holiday lodges are now ready for you to enjoy. To make your booking, please contact us at [holidays@mndscotland.org.uk](mailto:holidays@mndscotland.org.uk).

In your email, please let us know which accommodation you're interested in and your preferred dates. We'll do the rest! Expect to hear back from one of our friendly team members within five working days to chat about your stay.

Our lodges are available for weekly stays (Friday to Friday) or for shorter breaks (Monday to Friday, or Friday to Monday). At MND Scotland, we believe in making sure our accommodation is accessible to those who need it most. That's why we give priority to booking requests from individuals living with MND in Scotland. However, you can still reserve your spot up to four weeks before your desired stay if you don't meet this criteria.



# Spotlight on ... volunteering



## Volunteering with MND Scotland

MND Scotland is currently developing an exciting new volunteer programme, aiming to provide our committed supporters with opportunities for more hands-on involvement in our work. Under the guidance of our Volunteer Coordinator, Roisin O'Donovan, we're eagerly anticipating the launch of this initiative.

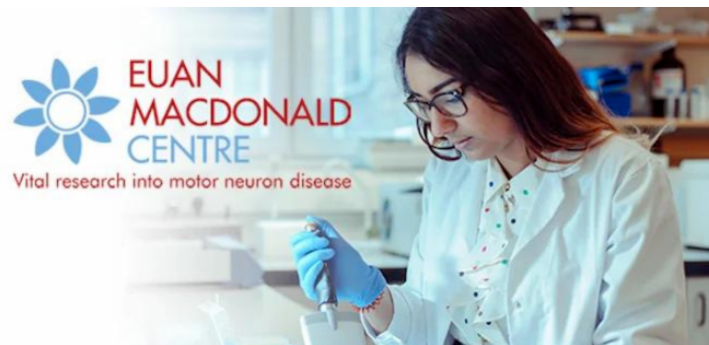
Discussing the programme, Roisin highlighted its potential. She said, *"The impact of volunteers in MND Scotland is enormous. Whether contributing to fundraising events, offering support to families, or raising awareness in local communities, volunteers play a crucial role in assisting those affected by MND. Throughout the year, various volunteering opportunities will be available for individuals to engage with. The more volunteers we have, the greater our capacity to support people with MND and make their time truly count."*

Roisin, who joined MND Scotland in January, discovered her passion for volunteering during her college years, finding immense satisfaction in helping others and building new connections.

Underlining the significance of volunteers, Roisin emphasized, *"Volunteers will play a vital role in achieving a world without MND. Their efforts will raise funds for this incredible cause, increase awareness of MND, and promote the support that MND Scotland provides to those affected by the disease and their families and carers."*

For anyone interested in committing some free time to become a volunteer, please get in touch with Roisin at [volunteers@mndscotland.org.uk](mailto:volunteers@mndscotland.org.uk).

## Other news



## Spring Research Open Evening at Euan Macdonald Centre

To learn more about MND, join researchers on Monday 27th May 2024 from 6pm to 7.30pm, for the popular research open evening hosted by the Euan MacDonald Centre for Motor Neuron Disease Research and the Anne Rowling Regenerative Neurology Clinic.

This drop-in evening is designed to allow you to meet the centre's scientists and learn more about the current research into motor neuron disease. In addition, you can learn more about the UK's largest clinical drugs trial for MND, MND-SMART.

No registration is required. Simply pop along to the Anne Rowling Regenerative Neurology Clinic, 49, Little France Crescent, BioQuarter, Edinburgh, EH16 4SB between 6pm and 7:30pm to meet researchers and ask those questions you'd like to ask.

FIND OUT MORE



## Your donations matter

Your donations support people affected by motor neuron disease across Scotland, and fund vital research which is taking us a step closer to finding a cure.

You can make a single gift, set-up or increase your regular monthly donation. Thank you for making time count.

**DONATE NOW**

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

 Share

 Tweet

 Share

 Forward

Company limited by guarantee, registered in Scotland. Company number SC217735. Scottish Charity number SC002662.

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.

You're receiving this email because you told us you wanted to hear more about MND Scotland's news, events, support and campaigns. If you no longer wish to receive these emails unsubscribe below.

[Preferences](#) | [Unsubscribe](#)