

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 Winter 2024 newsletter and best
wishes of the season to you.

It's been a busy year for MND Scotland and I would like to thank you for your continued support. In the last three months, we have had the privilege of a visit from our patron, HRH The Princess Royal, and the opportunity to support Kevin Sinfield on his phenomenal Running Home for Christmas - 7 in 7 in 7 Challenge when it came to Glasgow. We end the year with these positive events but we know this can be a difficult time of year for many of the families we support.

Our thoughts are very much with you if you have lost a loved one to MND. We have been really touched by the beautiful messages left on our new dedication page. We know that the festive season can be a particularly challenging time when you are missing a loved one. If you want to celebrate the life of someone you love this Christmas, you can [leave a personal message or picture on our dedication page.](#)

In early December we held our annual AGM. However, despite quite a few members signing up in advance, we did not achieve quorum at the meeting. As a result, we have rescheduled the AGM for Tuesday, 14 January on Zoom. [More information is available on the website, if you would like to join the meeting.](#)

This week, I shared an update on the charity's position on assisted dying. [The statement can be read here.](#) We understand this is a subject that is currently receiving a lot of media attention, and touches the MND community, so we want to be clear on our position.

I continue to find it incredibly valuable to meet and hear the first-hand experience of as many of you as possible. I received a great response to my recent request to meet face-to-face and listen to 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. If you have already been in touch, I am working my way through all your generous invitations, and I will be in touch as soon as possible.

Please continue to look after each other and have a very Merry Christmas.

Rachel Maitland

Chief Executive Officer

2024 Christmas campaign



Thank you to everyone who has donated to our Christmas campaign.

In a series of videos, Mark Ferguson bravely shares his story of living with MND. Mark is 45 and lives in Aberdeen with his wife Lucy. Mark has four children and was diagnosed two years ago.

The above video is part of the series on what Christmas means to Mark and his family. Please share and engage with the videos to help us raise awareness of this brutal disease and raise vital funds this festive season.

Watch Mark's videos in full

Kevin Sinfield in Glasgow



We were incredibly proud to support Kevin Sinfield on the Scottish leg of his **Running Home for Christmas - 7 in 7 in 7 Challenge** earlier this month.

It was a fantastic day with a great atmosphere and an abundance of camaraderie amongst the MND community as Kevin took to the streets of Glasgow. Thank you to everyone who joined us at a cheer point, shouted encouragement from the sidelines, donated or ran the Extra Mile. You are all amazing!

There is still time to donate to Kevin's challenge

Get involved in 2025



If you want to **Make Time Count** for people affected by MND, there's a number of ways to get involved and support MND Scotland.

This January, we are encouraging people to start 2025 with a bang and **Do It, Ditch It!** January is the perfect time to take up something new and ditch a bad habit. You could take on a 'Couch to 5K' challenge and ditch chocolate or sweets for a full month, or craft every day while taking a break from alcohol in January. Whatever you choose as your personal challenge for January, remember to set up your fundraising page and share it with everyone - you never know it might spur someone on to join you in your challenge!

[Visit the Do It, Ditch It! page to find out more.](#)

There are also a number of third-party events to get involved in, including:

- **[Falkirk Wheel Abseil, March 2025](#)**
- **[Glasgow Kiltwalk, April 2025](#)**
- **[Edinburgh Marathon Festival, May 2025](#)**

For more information on our 2025 fundraising events, **[please visit the events page on our website](#)** and sign up for your next challenge.

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.](#)

Alternatively, have you thought about nominating MND Scotland as a charity partner of the year? Whether through your employer, local golf club or Rotary Club, it's a great way to raise awareness and vital funds. We recently announced our partnership with Glasgow Airport for 2025, which we are extremely proud of. Get in touch with lynne.wiseman@mndscotland.org.uk if you know any organisations seeking a charity partner.

[Visit our events page](#)

Stories from our supporters

It's always a privilege to share the stories of people we support and something we're keen to do more of. Over the last few months, we have been proud to share the stories of some fantastic fundraisers.

- In a remarkable display of strength and solidarity, Mert Zorlu, a courageous man battling motor neuron disease (MND), participated in the AJ Bell Great Scottish Run. [Read Mert's story here.](#)
- ["The Proclaimers walked 500 miles – we walked 500 more!"](#) The Skills Development Scotland team from Alloa got active for MND Scotland to support much-loved friend and colleague, David Irvine.
- Kelly Huxtable from South Ayrshire recently completed an extraordinary journey to Everest Base Camp. [Read more about the challenge here.](#)
- Inspired by rugby legend Kevin Sinfield CBE, supporter [Jeff Dobson completed the incredible challenge of running seven half marathons in seven days](#), in support of his father who is living with MND.
- Sharon Watson from Dumfries and Galloway organised a charity afternoon tea with the support of family and friends in memory of her

mum, Phyllis Shaw. [Read more about the event here.](#)

- Marie Millar from Cumbernauld successfully took part in this year's Edinburgh Kiltwalk to raise funds in memory of her late husband, Ian. [Marie shares her story on our website.](#)
- Dundee-born and raised drag queen, Raspberry will take on the prestigious TCS London Marathon in April 2025 for MND Scotland. [Raspberry tells us about the motivation to take on the marathon challenge.](#)
- Last month, we received a £25,000 boost from Apache North Sea. [Read more about this generous donation.](#)

Bereavement support



We're here to support everyone affected by MND, including those bereaved by this brutal disease. Earlier this year, we worked with ALS Canada to create a Bereavement Workshop to support those who have lost a loved one.

In this deeply moving video, we hear from Beverley, Sandra, and Marina, who bravely share their stories, and experiences of the workshop, to help others who have lost someone they love.

If you or someone you know needs support, please reach out to find out how we can help by emailing support@mndscotland.org.uk or [visiting the support pages on our website](#) for more information.

Updates on research



In October, we announced the award of a three-year PhD studentship in partnership with the [Anatomical Society](#). Dr Lyndsay Murray, Lecturer in Anatomy, at the University of Edinburgh and her PhD student, Ernie Ho, are testing the theory that, if motor neurons can be stimulated to regrow, it could help slow the progression of MND. [Read more about their project here.](#)

In November, we received the welcome news that NICE will now appraise the drug tofersen via the Highly Specialised Technologies (HST) route, rather than conduct a standard appraisal. This followed a campaign by the MND Association, supported by MND Scotland and My Name's Doddie Foundation. While there is still some way to go, this is an important step in making tofersen available to people with SOD1 MND in the UK. [Read more about the decision here.](#)

This month, we shared a round-up of feedback on our recent [Lived Experience and Researcher Network \(LEARN\)](#) events. In September and October, we hosted in-person LEARN events in Aberdeen, Edinburgh, Glasgow and Dundee attended by members of the MND community with presentations from local researchers. [Read more about the feedback we received here.](#)

Spotlight on ... A visit from HRH, The Princess Royal



Her Royal Highness, The Princess Royal, visited us on Tuesday, 12 November, to meet supporters and people with MND. Thank you to everyone who came along and made the event a great success.

Guests included Bea Burns, 7, who presented The Princess Royal with a posy of flowers at the end of the visit. Bea (pictured at the top of this email) took part in MND Scotland's fun run in September, and her mum, Louise, ran the London marathon earlier this year.

Louise Burns said: *"It was fantastic to be surrounded by so many other MND Scotland supporters who have gone above and beyond to raise money and given their time to help the charity. To be recognised by Her Royal Highness at this event was an honour, and Bea was so excited to present The Princess Royal with flowers. It's a memory we will both remember for a long time."*

[Read more about the Royal visit here](#)

Sharing your feedback

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.

Some of you may remember that in 2022, we invited people affected by MND to share their views in our [What Matters Survey](#). Early next year we will invite you to share your opinions again as we revisit the research, and refine it to help us understand how our focus as an organisation can best meet your needs. We will share the survey once it's available, so please watch this space.

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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