



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

#### A word from our CEO



Welcome to our Summer 2025 newsletter.

Tomorrow is Global MND Awareness Day. While this is an opportunity to raise awareness about MND, we appreciate that MND affects people each and every day. We're here throughout the year to support people following an MND diagnosis and are committed to providing practical, emotional

and financial support to everyone affected. This year, to mark Global MND Awareness Day we are sharing inspirational stories from people living with MND and fundraisers. Read more below.

Last month, we launched an Urgent Appeal. MND is a descent into the unknown. No one in Scotland should face the unknown alone. We are currently supporting more people with MND than ever before, including Mert who courageously shared his story for the campaign. You can read more about the Appeal on our website and, if you are able to, please consider donating today.

Last week, the Care Reform (Scotland) bill passed in the Scottish Parliament. To ensure people with MND were considered in the bill, we worked with Scottish Labour MSP, Paul Sweeney, to influence two amendments. Thanks to these amends, everyone living with a terminal illness is now entitled to a priority care assessment and care packages are 'portable', meaning an individual's care and support will follow them if they relocate to another local authority area due to their need for an accessible home. We are incredibly grateful to Paul Sweeney for bringing forward these amends. MND Scotland remains committed to seeing the amends progress and we look forward to continued engagement with the Scottish Government around the setting of timescales. Read more about our campaigning work here.

Next week is MND Scotland's 44th birthday. I am proud to lead an organisation with a long-standing legacy but it is a stark reminder that we still haven't found meaningful treatments and a cure. We are committed to a world without MND and will continue to fund cutting edge research until we make that breakthrough.

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

### **Global MND Awareness Day**





This Global MND Awareness Day, we're sharing the inspirational story of **Alan Budge**, who was diagnosed with MND in April 2024.

Alan, known as 'Budgie' to his friends and family, said: "It's very difficult for people to grasp how variable MND is, so I've made my own saying that seems to work: 'nobody can tell you what's next, and nobody can tell you when next is'."

#### Read more about Alan's MND journey here.

This week, we have also shared a piece from long-term supporter **Cllr Lorraine Cameron**, Provost of Renfrewshire. Lorraine lost her mum to MND and shares her story and memories of her mum in a blog on our website.

Read Lorraine's blog here.

### **LEARN kicks off soon**



Following a successful series of **Lived Experience** and **Researcher Network (LEARN)** events in 2024, we're pleased to confirm they will return this year, with the addition of a new location.

This year, we will be hosting our **LEARN** events at local football stadiums, to make the events accessible for as many people affected by MND as possible. This year's events will take place in September and October and be held at the following locations:

- Glasgow Celtic Park (Celtic FC)
- Aberdeen Pittodrie Stadium (Aberdeen FC)
- Edinburgh Tynecastle Park (Heart of Midlothian FC)
- Dundee Tannadice Stadium (Dundee United FC)
- Dingwall Global Energy Stadium (Ross County)

The dates of this year's LEARN events will be confirmed as soon as the football fixtures for the upcoming season are available, so please keep an eye on our social media channels for more information in the coming weeks.

Read more about our 2024 LEARN events

### **Supporting Carers Week**



Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face, and recognise the contribution they make to families and communities throughout the UK. We know this is an area of significant impact for those caring for someone with MND, so we take the opportunity to mark the occasion.

This year, we attended a roundtable with MSPs and an event at the Scottish Parliament, alongside other caring organisations, to raise awareness of the value of unpaid carers. We also shared Stuart's story following his wife, Claire's MND diagnosis in 2024. The two spoke about how Stuart's involvement has changed over time and the effect this can have on those supporting a person living with MND. Thank you to Stuart and Claire for sharing their story.

# Celebrating our supporters



We've had some incredible people take on amazing challenges to raise money for MND Scotland in the last few months. We would like to celebrate their hard work and determination, and share their stories:

- Michael Cole and his son Andrew completed the Edinburgh marathon. Michael, who is living with MND, was pushed round the 26.2 mile route by Andrew. The Dumfries pair have even exceeded their fundraising goal, an incredible achievement for the marathoners. Read more about Michael and Andrew here.
- Kenney Collins, friend of the late MND
   campaigner Gordon Aikman, raised money by
   taking part in the Rob Burrow Leeds Marathon
   in May. A great achievement and a lasting
   tribute to their friendship. Kenney shared his
   story with us here.
- Two brothers from Glasgow, Steven and Alan Lindsay, took on a variety of fundraising challenges in memory of their mother who passed away recently from MND, including the Leeds marathon and Etape Caledonia, followed by the 5 Ferries cycle route. Read more about the brothers' fundraising efforts.
- Michael Hopkins has taken on a 5k-a-day in 2025 challenge in support of a family friend currently living with MND. <u>Almost half way</u> there Michael - keep up the great work!
- Good luck to Andrew Wonnacott who is taking on the Gazley Volkswagen Wellington Marathon in New Zealand next week. Andrew is running in memory of his dad, Allan, who passed away from MND earlier this year. Andrew shared his family memories and fundraising ambitions.

Over the past couple of months, our corporate fundraisers have also been busy with events to help raise money for MND Scotland.

- Barrhead housing will raise vital funds across our year-long charity partnership. The cause holds personal significance for many colleagues at Barrhead Housing and their support is invaluable. Read more about what they are up to on our website.
- A local SSE depot held a charity rugby day on 31
  May to raise funds for MND Scotland in honour
  of their friend and colleague Donald Graham.

  Thanks to everyone that came along and
  supported the cause.
- The Glasgow Airport team, led by Chaplain Ian Hudson, completed the Glasgow Kiltwalk's 'Big Stroll' in support of MND Scotland. We are thrilled to be the chosen charity for Glasgow Airport and the team will be taking part in more fundraising efforts throughout the year. Read more here.

Finally, thank you to everyone that took part in **A Dip a Day in May!** Taking a cold dip every day for 31 days in support of MND Scotland - together they managed to raise a fantastic £7000!

Thank you to all these groups, individuals and organisations who have taken on fundraising challenges. Your support is invaluable and very much appreciated by everyone affected by MND in Scotland.

### Inspired to support us?

If our supporter stories have inspired you, there are many ways to get involved and fundraise this year, including two **Fun Run events** in September. We would love for you to tie up your laces, join us at an event and hit the ground running!

Join us for a 5k walk, run, wheel or stroll at this years Fun Runs. We'll be returning to Lochore Meadow Country Park on 20 September for Fun Run Fife and this year we're adding in Fun Run Glasgow – Taking place in Kelvingrove Park on 6

September. Everyone is welcome to join the funfamilies, adults, children, mums, dads, colleagues, friends, and, of course, furry companions are all invited.

This year's <u>Great Scottish Run</u> takes place on 5 October. By running as part of Team MND Scotland, every step you take and every penny you raise will bring us closer to our vision of a world without motor neuron disease. You can <u>sign up</u> <u>directly to secure your place.</u>

The final two **Kiltwalks** of 2025, in Dundee and Edinburgh, are taking place in August and September. Take on the tartan walk in support of MND Scotland and help us make sure no one in Scotland faces the unknown alone.

Whether you want to take a Mighty Stride (20 miles), Big Stroll (11 miles, Edinburgh only) or go for a Wee Wander (4 miles) your support brings us closer to a world without MND. Sign up for:

- The Dundee Kiltwalk on 17 August.
- The Edinburgh Kiltwalk on 14 September.

For more information on our 2025 fundraising events, <u>please visit the events page on our</u> website and sign-up for your next challenge.

Click here for more information on all upcoming events

## Get involved by volunteering

**Volunteers Week** (2 - 8 June) was the perfect opportunity to acknowledge all the work our amazing volunteers do - from fundraising to support, the time they give is always appreciated.

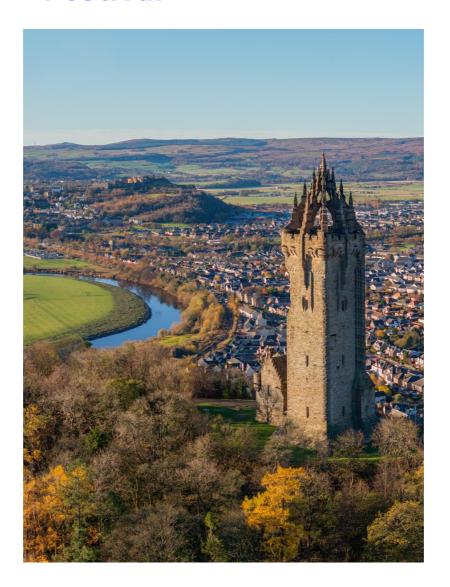
We asked some of our current volunteers why they choose to volunteer with MND Scotland, and they **shared their responses here**.

Our volunteers are valued and appreciated, but we need more support! As each of our volunteers have told us - "Just do it!"

Alongside fundraising volunteers, we have opportunities to join Steering Groups and share personal experiences of MND. We also have opportunities to work directly with families affected by the disease. If you want to learn more about the benefits of volunteering with MND Scotland, please visit our website, or contact volunteer@mndscotland.org.uk and get involved with work that matters.

**Volunteer with MND Scotland today** 

# Spotlight on ... William Wallace Running Festival



Last month, we were very excited to announce a partnership with a brand new running event, **The William Wallace Running Festival**.

The inaugural **William Wallace Running Festival** is set to take place on Saturday, 11 October and will feature a variety of races for anyone to take part in and help raise vital funds. The day will include the Ultra 70km, the Ultra 50km - both with team relay options - and the Braveheart 10km. There is even a **Wallace Warriors** challenge - a 1 mile, traffic-free, flat route designed for young warriors, those with accessibility needs, or those who use wheelchairs.

**Jonathan Mitchell**, our Head of Fundraising, said: "We are thrilled to partner with the new William Wallace Running Festival.

"The partnership will allow us to raise important awareness of motor neuron disease, whilst generating vital funds to support those affected by this devastating condition across Scotland.

"The festival's spirit of determination and resilience perfectly mirrors the bravery shown by those living with MND every day.

"Thank you to Gregg, Craig and Graham Coull from You Can Sport, and Peter Ness from Scurry Events for organising the running festival and for their support and collaboration."

For more information and to claim your discounted charity place with MND Scotland, contact <a href="mailto:fundraising@mndscotland.org.uk">fundraising@mndscotland.org.uk</a>

Image by: The Kilted Photographer

Read more about this exciting partnership

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.



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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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