

Your quarterly update from  
MND Scotland

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from MND Scotland.

## **A word from our CEO**



Welcome to our Summer 2024 newsletter.

Today, 21 June is Global MND Awareness Day. While this is a day for the international MND community to come together and collectively maximize awareness, and as an organisation we will be supporting that, we understand that MND affects people each and every day. That's why the MND Scotland team are committed on a daily basis to raising awareness and fundraising, so we can continue to support people with motor neuron disease and fund vital research throughout the year.

This afternoon, an ice bucket challenge video will be shared by the International Alliance of ALS/MND Associations to highlight the 10 year anniversary of the global phenomenon that was the ice bucket challenge. Called "Spreading Hope One Bucket at a Time," this video captures the collaboration of the International Alliance, with each bucket symbolising a commitment to standing in solidarity with people affected by MND, and the Alliance's collective commitment to a world free from ALS/MND.

This week we have been highlighting the 10 year anniversary and are extremely grateful to Jim Maxwell for sharing his story, and helping to raise awareness. You can watch Jim's story below.

As part of our campaigning over the next few months, we will be asking everyone to share their videos from 10 years ago, take on another ice bucket and donate to support the MND community and fund much-needed research. We hope you will join us.

Earlier this month, we were deeply saddened to hear of the death of Rob Burrow CBE. Rob raised an incredible amount of awareness of MND and how the disease can progress, inspiring thousands of people across the UK to donate and fundraise for new treatments and better support services. We know Rob will have a lasting legacy on the MND community and our thoughts remain with his family and friends.

It's really important to me that the work the MND Scotland team does, and the way in which we do it, is informed by as many of you as possible. I find it incredibly valuable to meet face to face and listen

to your experiences and thoughts about our services and activities. I'm really keen to do as much of that as I can 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](mailto:communications@mndscotland.org.uk) and I will be in touch.

On a final note, this weekend marks our 43rd birthday. We have been providing help and hope for 43 years, only made possible by your ongoing support, and will continue to do so until a cure is found for this brutal disease.

Thank you for your continued support of MND Scotland and we hope everyone enjoys the summer months.

**Rachel Maitland**  
Chief Executive Officer

## Jim's story



To support our activity to raise awareness ahead of **Global MND Awareness Day**, Jim Maxwell shared his story about taking part in the Ice Bucket Challenge 10 years ago.

Thank you so much to everyone who took part in the Ice Bucket Challenge, and to Jim for sharing his story. You can read more about what's happening 10 years on from the Ice Bucket Challenge on our website.

READ MORE

## Alison's story for Carer's Week

Earlier this month, with a theme of 'Putting Carers on the Map', Carer's Week highlighted the invaluable contributions of carers across the UK.

Thank you to Alison Barry for sharing her personal story of caring for her partner John, and helping to make people aware of the significant impact that a diagnosis of MND has not just on the person with the disease, but on the people around them.

READ ALISON'S STORY ON OUR WEBSITE

## Support for children & young people

We have been working closely with organisations to gather best practice and the most appropriate way to help our children and young people. We are here to support everyone affected by a diagnosis of MND and research shows that children and young people need more support.

This week, we've launched new resources on our website, including a graphic novel, **Real Kids Talk About MND** by Dr Melinda S. Kavanaugh and the team at [Global Neuro Ycare](#).

We hope you find these resources helpful and welcome any feedback you would like to share with [support@mndscotland.org.uk](mailto:support@mndscotland.org.uk).

VISIT OUR CHILDREN AND YOUNG  
PEOPLE PAGE

# Launch of LEARN events

MND Scotland has launched a network of events to bring together researchers and people with, and affected by, MND to help drive research through shared knowledge, ideas and lived experience.



The **Lived Experience and Researcher Network (LEARN)** is a series of events offering people with MND and their supporters the opportunity to meet and engage with local MND researchers, and learn more about their work.

To provide more details on the events and the aims of LEARN, the MND Scotland research team will host an online webinar at **12.30pm on Friday, 26 July 2024**. To sign-up for the webinar, or to find out more information, please visit our website:

**SIGN-UP TO OUR ONLINE WEBINAR**

## Clinical Academic Fellow Announced



We have joined forces with the Scottish Government's Chief Scientist Office to fund a three-year Clinical Academic Fellow to investigate potential causes of, and therapies for, motor neuron disease (MND), with the aim of building research capacity in the area of MND in the Scottish NHS.

Kristine Roberts, from NHS Grampian and the University of Aberdeen, will undertake a PhD focused on seeking new biomarkers of MND which could be used to detect the disease early, ideally before symptoms present.

**READ MORE ABOUT KRISTINE'S WORK  
HERE**

## **Working with housing officials**



Earlier this month, MND Scotland's policy and advocacy teams joined forces with ALACHO (Association of Local Authority Chief Housing Officers) to hold an MND Masterclass with senior housing officials from different local authority areas across Scotland.

With them, we discussed the local authority recommendations from our report '[No time to lose: Addressing the housing needs of people with MND](#)' which include fast-tracking people with MND for adaptations and bypassing waiting lists for accessible homes.

Engagement from the officials was very positive and the policy team aims to follow up with them individually over the summer to establish what can be done in their areas to implement the changes needed to make sure people with MND have an accessible home that meets their needs.

This is part of wider work we are doing with housing associations to ensure that support is fast enough, and flexible enough, for people living with MND.

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

**Feedback on  
Parliamentary  
Reception in April**



Thank you to those who attended the parliamentary reception on 16th April. We hope you enjoyed the event and found it worthwhile.

As we start planning for next year, we need your input to make it even better.

Included below is a link to a short survey so we can hear about your experience or the reasons you couldn't be there. Your views will help us understand what went well, what didn't, and how we can improve for next year. The survey should take no more than **5-7 minutes** to complete, and all your responses will be kept confidential.

Please click the link below to access the survey **before 30th June**.

Thank you in advance.

**COMPLETE SURVEY**

## Update your will for free

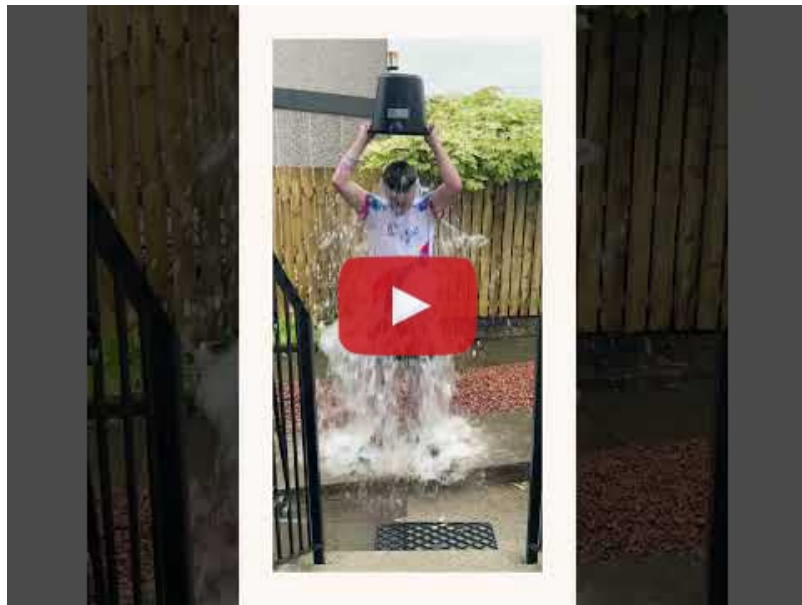
We've partnered with the national free Wills network to give you the chance to make your Will for free. All we ask is that once you've looked after those close to you, you consider including a gift in your Will to support our future work too.

A gift to MND Scotland in your Will is the most powerful way to support our work long term.

**FIND OUT MORE AND REQUEST YOUR  
FREE WILL PACK**

## Spotlight on ... A Dip A Day In May





Throughout May our amazing fundraisers raised over £19,000 taking on daily cold water challenges for ***A Dip a Day in May***.

A massive thank you to everyone who participated and supported us in our cold water challenge. Your efforts and donations will make a significant difference for MND Scotland and those living with the disease.

There is still time to donate by texting **ICED to 70085** to donate £10.

**READ MORE ABOUT OUR COLD WATER  
CHALLENGE**

## **MND Scotland Fun Run is back!**

We are thrilled to announce that MND Scotland's in-person Fun Run is back on **Saturday 7th September**, with a brand new location in central Scotland.



The Fun Run isn't just for seasoned runners, it's for everyone who believes in the power of giving back and wants to support people affected by MND. So, whether you decide to run, walk, or roll, there are lots of ways to get involved and support MND Scotland.

Registration will open in mid-July, so if you would like to be added to our waiting list for more information, [please email the Fundraising team](#) to be kept updated.

## Celebrating our three year partnership with Hearts FC

We want to say a huge thank you to **Heart of Midlothian F.C.** and the club's loyal fans for really getting behind our partnership and helping to raise awareness of MND over the last three years.

This special video highlights the amazing collaboration between MND Scotland and Hearts, showcasing the powerful impact we've made together in the fight against MND.

We want to thank each and every supporter for taking us to their hearts and we know many of you have become supporters of the charity. Our dedicated fundraising team is available to support anyone that wants to take part in an event. Please visit [our website](#) to get involved.



## 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 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.

### VOLUNTEER WITH US

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).

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](mailto: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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