

Latest support and research
news from MND Scotland

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Friend, an update from the
support and research
teams at MND Scotland.



Welcome to the latest edition of the support and research newsletter.

In the spring edition we combined our research and support news and we've received some really positive feedback on this approach. We plan to continue this new format, however, we're always keen to hear your thoughts on any improvements we can make. Please continue to share your feedback by emailing communications@mndscotland.org.uk.

In this edition, we are sharing information on a variety of ways to get involved, including in our upcoming LEARN events taking place across Scotland. We have also been asked to share a range of surveys that are relevant to the MND community. We have included links below and would encourage you to complete these surveys, if you would like to share your personal opinions on any of these topics.

We hope you enjoy this latest edition.

Angela Harris, Director of Support Development, and Jane Haley, Director of Research

LEARN drop-in sessions



The Lived Experience and Researcher Network (LEARN) is designed to improve interactions between people affected by MND and researchers.

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.

We recently hosted a LEARN webinar to provide more information about the upcoming in-person events. The webinar is now available to [watch on our YouTube channel here.](#)

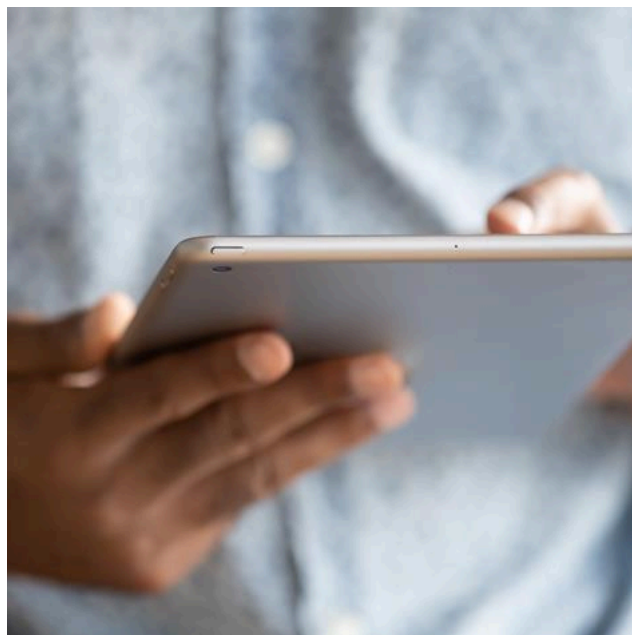
The next stage in LEARN is a series of local events in Glasgow, Edinburgh, Dundee and

Aberdeen, bringing together people affected by MND and local MND Scotland researchers. Here is more detail on the events and a link to register your interest is below.

- [**MND Scotland LEARN Aberdeen**](#), 9 Sep 2024, 2pm, Grub café, Aberdeen Science Centre, 179 Constitution Street, Aberdeen AB24 5TU
- [**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, MND Scotland, 6th Floor, Merchant Exchange, 20 Bell St, Glasgow, G1 1LG
- [**MND Scotland LEARN Dundee**](#), 24 Oct 2024, 2pm, Dundee Science Centre café, 14 Greenmarket, Dundee DD1 4QB

Register your interest for a local LEARN event

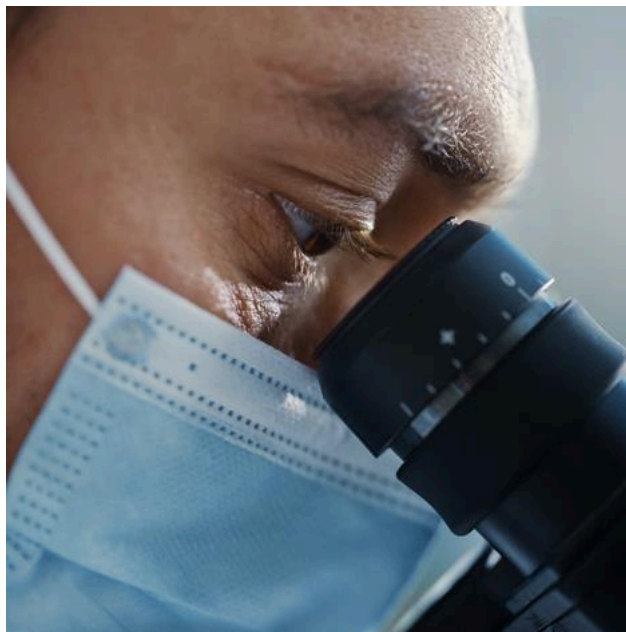
Consultations and surveys - opportunities to have your say



Below is a list of current consultations and surveys relevant to the MND community. These cover a wide range of topics, some of which we understand will be particularly emotive for some people. We present these as opportunities to get involved so it is individual preference whether you participate in any or all of these questionnaires:

- [Scottish Parliament: Assisted Dying for Terminally Ill Adults \(Scotland\) Bill: Short Survey – Call for Views](#)
- [Scottish Government Adult Disability Payment Review: consultation](#)
- [Marie Curie survey on palliative care](#)
- [Carers UK State of Caring survey](#)
- [Neurological Alliance - My Neuro Survey](#)

ACORN – a research study for families where MND has been associated with the C9ORF72 gene



Some people with MND have a change in their genetic code that underlies the disease. These are then potentially heritable forms of MND. Affected families usually have several relatives with the same genetic change, although not all of them will

go on to develop MND in their natural lifetime. The most common genetic code change linked to MND is an abnormal enlargement of a gene called C9ORF72. This accounts for nearly 10% of all cases of MND in the UK and is also linked to a related condition called frontotemporal dementia (FTD).

The University of Oxford MND Centre is running: **A C9ORF72 National study**, known as 'ACORN'. The intention is to provide research opportunities for people affected by MND linked to the C9ORF72 gene change, but also for their healthy close relatives of adult age, who may be at higher risk of MND through an inherited copy of the same genetic change. Importantly, taking part in the study does not require any healthy relatives to know or reveal their own genetic status.

The aim of ACORN is to understand how this genetic change causes MND, the earliest changes and why not everyone with this genetic change goes on to develop MND in their natural lifetime. The hope is to develop specific treatments for people with this type of MND and eventually to find ways of preventing the disease in those family members at higher risk.

If you, or your close relative, has been told they have MND caused by the C9ORF72 gene, you can [find out more about the ACORN study on their website](#) or email acorn@ndcn.ox.ac.uk.

Opportunity to help researchers in Glasgow with new project

A new MRI-based project at the University of Glasgow, funded by MND Scotland, is launching soon and the researchers would like to invite around five people affected by MND to join their patient and public involvement group.

Members will be asked to look at patient-facing information to ensure it can be easily understood, and at the project study outline to make sure it is acceptable for patients. This would start at the end of August and members can receive a voucher payment for their time.

If you would like to help, please contact involvement@mndscotland.org.uk.

Share your feedback on webinar topics

As part of ongoing work to offer enhanced information about MND, the support team is planning a series of virtual information webinars. To help inform topics for these sessions, we would like to know what the MND community is interested in hearing about.

We have [created a short survey](#) and would really appreciate if you could take a few minutes to take part. Thank you for helping to guide our work.

Take part in survey on webinar topics

Allied Mobility vehicles available for holiday lodge transport



We are excited to share a new partnership with Allied Mobility to provide complimentary WAVs

(wheelchair accessible vehicles) for transport to and from our holiday lodges in St Andrews and Oban.

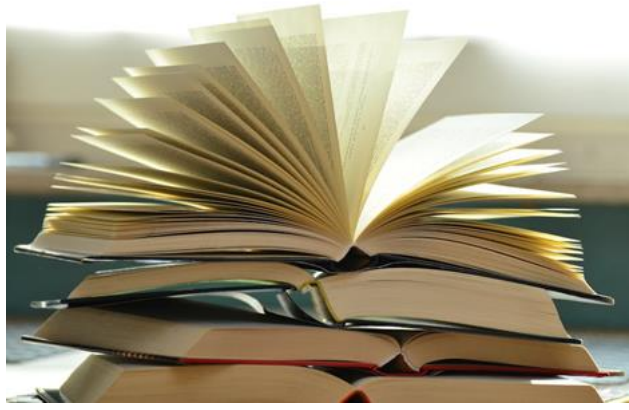
We understand it can be challenging to find accessible holiday accommodation and we want to make it as easy as possible to make memories with your loved ones with a break away. WAVs are available on all new bookings to our holiday lodges, and Allied Mobility will drop off and pick up the vehicle so you can enjoy it for the duration of your stay.

As the UK's leading wheelchair accessible vehicle provider, Allied Mobility knows how important your independence is. Having safe and comfortable transportation to help you get out and about is key. With a wide range of cars available to suit a variety of wheelchairs and powerchairs, Allied will help you pick the best option for you and your needs.

Our website will be updated with more information on this great partnership. When booking, please select 'I would like more information on 'Allied Mobility Partnership' and our team will provide you with more details.

We recently trialled this new service for a person with MND and their family. The feedback has been extremely positive: "***We just wanted to say a huge thank you ... for the hire of the mobility van. It has certainly made a difference and enabled my dad to get out and about in the comfort of his electric chair in St Andrews with MND Scotland. We will be forever thankful to both organisations for helping us to make memories.***"

Calibre Audio



Would you like to try a free audiobook subscription and share your feedback with MND Scotland?

Calibre Audio is a national charity providing audiobooks, book groups, author interviews, access to major literary festivals' content, and a dedicated helpline, for anyone with a disability or learning difference which means they struggle to read print.

Over 16,500 audiobooks across a wide range of genres are available, and over 1,000 more are added every year. Through a partnership with the Accessible Books Consortium, members can borrow 500,000 more from libraries around the world.

A highly subsidised membership is available for £30 per year is available for people with MND. We would like to invite two people to trial Calibre Audio for us. If you're interested, please get in touch with support@mndscotland.org.uk.

**A blog from our Research
Lead on ENCALS**



Our research lead, Paul Jensen, attended the annual ENCALS meeting in Stockholm earlier this summer. ENCALS (European Network for the Cure of ALS (Amyotrophic Lateral Sclerosis)) is a network of universities and hospitals across Europe that work in MND research.

In this blog, Paul shares his thoughts on joining researchers from across the world and how important every MND project being carried out is.

[Read Paul's blog](#)

Perspective of an Early Career Researcher



To mark Global MND Awareness Day in June, an Early Career Research (ECR) member of our Scientific Advisory Panel (SAP), Dr Hannah Smith shared her thoughts on the role.

[Read Hannah's story](#)

MND Scotland Trustee, Professor Richard Ribchester on the progress of MND research



To mark National Research Appreciation Day, our trustee, Professor Richard Ribchester, shared his thoughts on the progress and future of motor neuron disease (MND) research.

[Read Richard's article](#)

Rachel Maitland, MND Scotland's chief executive, is really keen to meet people with MND face to face and listen to your experiences and thoughts about our services and activities. If you would be happy for Rachel to visit for a cup of tea and a chat, please email communications@mndscotland.org.uk and we will be in touch.

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



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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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