

Every day matters.



Hertfordshire

Hertfordshire Branch Newsletter

Branch Patron Dr. Viv Lucas

May 2026

Printed by the University of Hertfordshire



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The MND association website is: www.mndassociation.org

The National Office Helpline No: 0808 8026262

Motor Neurone Disease Association Registered Charity No. 294354

Making every day matter for people affected by Motor Neurone Disease.



Like many people, I find change challenging and take comfort in familiarity and routine. However, since becoming the **Hertfordshire Branch** covering the whole county, the Committee has been reviewing our meeting locations to ensure we are doing the very best we can to support everyone living with, or **affected by MND across Hertfordshire** and feel that some changes are needed.

After much discussion, we have decided to move our regular meetings **from Box Moor Trust Centre to Burston Garden Centre** and to change the meeting date to the second Thursday of each month. We hope this change will make it easier for more people to attend, as well as allowing **the Committee** to better support **Lesley and Jenny**, who have so kindly hosted the **Box Moor meetings**.

The final meeting at **Box Moor** took place at the beginning of May, and our first meeting at **Burston Garden Centre** will be on **Thursday 11 June at 2.00pm**.

We very much hope you can join us there.

We also hope to see as many of you as possible at our Annual Walk at Stanborough Lakes on Saturday 11th July.



*** Finance Report - March - April ***

March was a fairly quiet month but we were very pleased to receive **£2,000** from the **Herts Keep Fit Association** who nominated our branch as their charity over the last 2 years. In April we received **£600** from a fundraising dinner at **Letchworth Rugby Union FC**, **£260** from a **70th Birthday Fundraiser** and **£240** from a fundraising evening at the **Pear Tree Pub in Stevenage**. **The Holy Trinity Charity Café in Bengeo** raised **£1,662.15** in memoriam donations and one of our wonderful members raised **£760** for us through a collection at his **Mother's funeral**.

Over the 2 month period we have been able to contribute **£5,122.50** towards **Support Funds** granted through **National Office** and have also funded **£638.00** for **WAV Taxis** to appointments and meetings. I would like to thank everyone whose donations, either large or small, have made these payments possible.

Thank You

Heather

--- Branch News ---

Hertfordshire branch 5th Annual Walk - Saturday 11th July - Hetty will be happy to give details of registration etc. - hetty.smith@mndassociation.org



Hertfordshire Branch 5th Annual Walk

Saturday 11th July at 11.00am (registration from 10.30am) - join us for a lovely walk around the North Side lake.

At Stanborough Lakes, North Side, Stanborough Road, Welwyn Garden City, AL8 6DF

Suitable for walkers with dogs and those in wheelchairs.

Donation of £10 per person or £20 for a family of four.



For more information please email:



hetty.smith@mndassociation.org



Hertfordshire Keep Fit Association

On Saturday 21st March, Lindsey and Heather attended the Annual General Meeting of the Hertfordshire Keep Fit Association (KFA), where they were formally presented with a cheque for £2,000 by Molly Steventon, President of Herts Keep Fit. We are sincerely grateful to the Hertfordshire KFA for selecting Hertfordshire MND as their chosen charity over the past two years and for their outstanding support.



Cycle ride

Phil Adams set off on the 13th April to cycle from **Stevenage in Herts to Pinoso, a village near Alicante, in Spain** to raise funds for **MND research**. This is a cycle of about 1,300 miles and as if that isn't hard enough, he is doing it on a Brompton folding bike.

Phil is doing this as the wife of his ex-colleague and long-time friend, **Rob**, was diagnosed with **MND** in May 2025. There was an enthusiastic crowd attending, including **Stuart and Grant from Herts MNDA**, as **Phil** departed from **Rob's** workplace in Stevenage in bright sunshine.

The trip will last about four weeks and **Phil** has already raised in excess of **£14,000** for **MND** research at the time of writing.

His JG page is <https://www.justgiving.com/page/phil-adams->





We hope the good weather lasts for Phil and that he has a safe and enjoyable journey south. **Grant**



Folk Festival

Baldock and Letchworth Folk Festival will take place at **Letchworth Rugby Club** from **Thursday 23rd until Sunday 26th July**. It will feature many local acts and some from further afield. Organised by **Brian Burke**, one of our dedicated supporters, this event will be raising money for **our Branch**.



So do come along and enjoy some great music.



* National Office News *

New Voice Cloning

The MND Association offers financial support for communication aids and environmental controls, including voice cloning services. They provide grants towards the cost of a headset microphone to enable voice banking, which can be applied for using the Wellbeing Support fund application form.

The Association also offers comparison charts of voice banking services to help users understand the options available. They can assist with funding for items such as text to speech devices and voice cloning services.



Voice cloning for Motor Neuron Disease (MND) involves creating a synthetic voice that mimics an individual's natural speech patterns and tone. This technology allows individuals to retain their unique vocal identity, even after losing their ability to speak.

Users typically record short phrases or text while their voice is clear, which is then processed to create a synthetic version of their voice.

AI Technology: Eleven Labs offers free voice cloning services for individuals diagnosed with **ALS and MND**, capturing the natural prosody of the user's voice. Cloned voices can be used in communication devices, allowing users to communicate in their own voice which can be emotionally significant for many.

Contact the Association helpline for more information - 0808 802 6262
mndconnect@mndassociation.org



Supporting the continuation of the **MND-SMART** platform trial in the UK.

MND-SMART
Clinical trials for MND

About the project

This project supports the continuation of the **MND SMART** clinical trial through helping to maintain the infrastructure surrounding the trial. **MND-SMART**, the UK's first platform trial in **MND**, is a long-term study that is designed to test more than one potential treatment at a time. It is testing drugs that are already known to be safe and are approved for use to treat other conditions to see if they may be of benefit for people with **MND**.

Researchers can change the drugs being tested throughout the trial, allowing new ones to be added and drugs that are found to have no benefit to be quickly removed.

Trial participants taking one of the treatments will be compared with a group who receive **a placebo (a dummy drug)**. Platform trials, like **MND-SMART**, that provide lasting infrastructure for trials and test several possible treatments at once may play a key role in finding effective therapies.

What could this mean for **MND** research?

This funding is helping to maintain the infrastructure of the trial so that it can continue for years to come and new drugs can be added for testing. This will give more people with **MND** the opportunity to take part in the trial now and in the future.

This research study is currently recruiting participants - for information go to -
MND Smart - Clinical trials for MND

Principal Investigator: Dr Suvankar Pal

Lead Institution: University of Edinburgh

MND Association Funding: £1,500,000 - in partnership with **MND Scotland**

Funding dates: November 2023 - October 2028





Get togethers for those living with **MND**, family, carers and friends are held on the last Monday of the month at 11am at the **Three Horseshoes pub, Hooks Cross, Watton at Stone SG14 3RY** and the first Wednesday of the month at 2pm at the **Box Moor Trust Centre, London Road, Hemel Hempstead HP 2RE**. **Last meeting 6th May.**

Moving to a new venue on the second Thursday of each month at 2pm at **Burston Garden Centre, North Orbital Road, Chiswell Green, St Albans, AL2 2DS**. **1st meeting 11th June**

*** Both venues provide disabled parking and level access. All are welcome.***

Dates for the Three Horseshoes: - Last Monday of each month
Monday - 25th May - 29th June - 27th July - (**August NO Meeting**) - 28th September



For more information contact Chris Carter - christine.carter@mndassociation.org

Dates for Burston Garden Centre - Second Thursday of each month
At 2pm - 11th June - 9th July - 13th August - 10th September



For more information contact - Hetty Smith - hetty.smith@mndassociation.org

**** ZOOM's ****

Daytime Group - Zoom - 3rd Tuesday of every month - 11am to 12.30pm
- 19th May - 16th June - 21st July - 18th August - 15th September

For more information contact - Dawn.Pond@mndassociation.org

South East Carers Coffee & Chat - Zoom - Carers only - First Tuesday of each month
- 11am - 2nd June - 7th July - 4th August - 1st September



For more information contact - lisa.burnard@mndassociation.org

Evening Carers Group - Zoom - Carers only - Last Wednesday of each month-
6.30pm - 27th May - 24th June - 29th July - 26th August - 30th September

For more information contact - charlotte.stanford-gibbs@mndassociation.org or
abigall.igbokwe@mndassociation.org

The following website gives information for all our online support groups at:
www.mndassociation.org/support-and-information/local-support/online-support-groups.

Making every day matter for people affected by Motor Neurone Disease.



~ BRANCH MANAGEMENT COMMITTEE ~ 2026 OFFICERS ~

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WEBSITE

f FACEBOOK

MNDA Hertfordshire Branch www.facebook.com/mndahertfordshire/

MND Connect Helpline: 0808 802 6262

2026

mndconnect@mndassociation.org

2026

Our MND Connect Helpline offers advice, practical and Emotional support and directing to other services and agencies.
Monday-Friday 9.00am - 4.00pm



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