Our Vision is a
World Free of MND

Hertfordshire Branch Newsletter

Branch Patron Dr. Viv Lucas

November 2024

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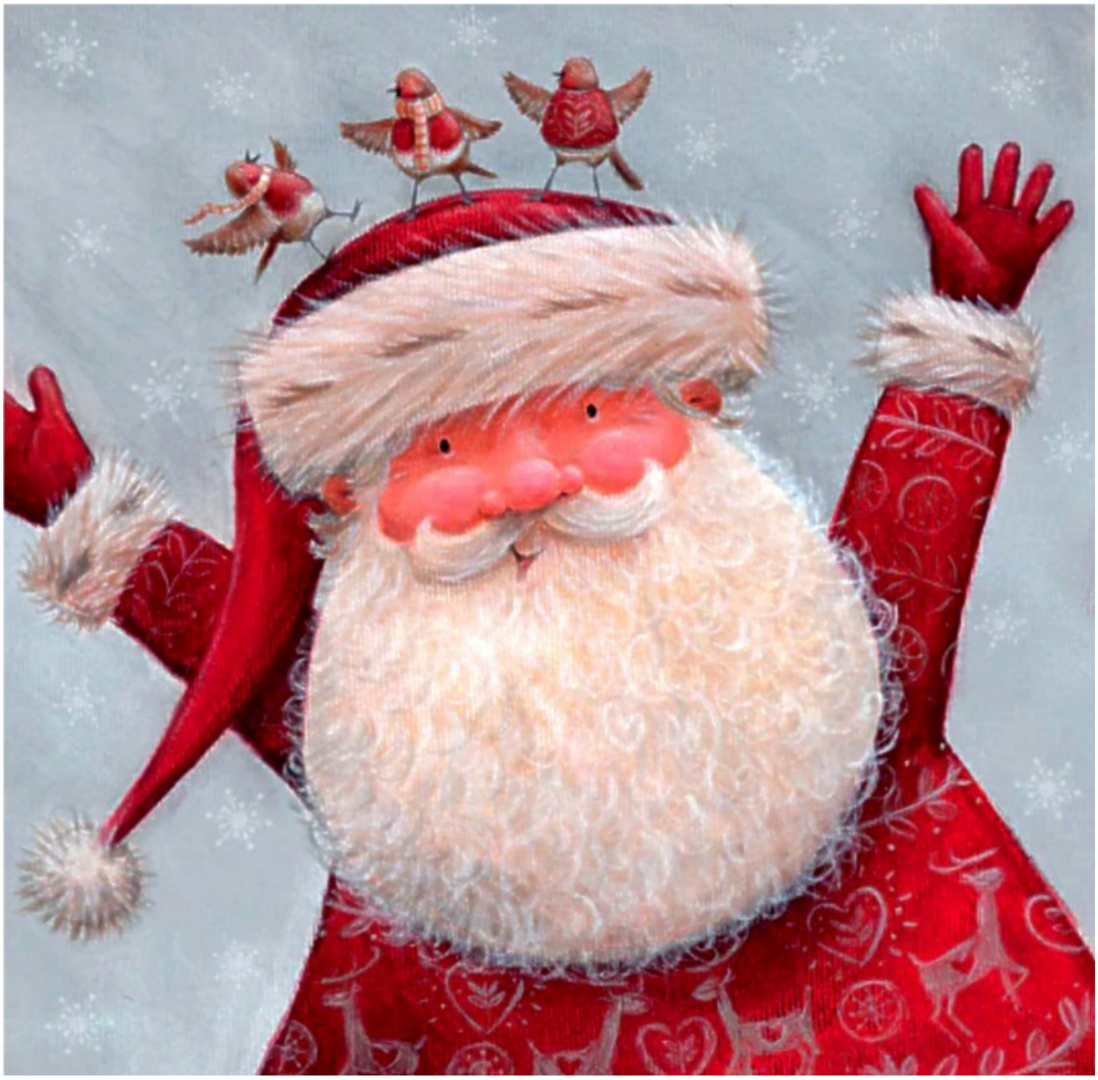


Wishing you all a very Merry Christmas and a Healthy and Happy 2025

The MND association website is: www.mndassociation.org

The National Office New Helpline No: 0808 8026262

Motor Neurone Disease Association Registered Charity No. 294354

FIGHTING MOTOR NEURONE DISEASE

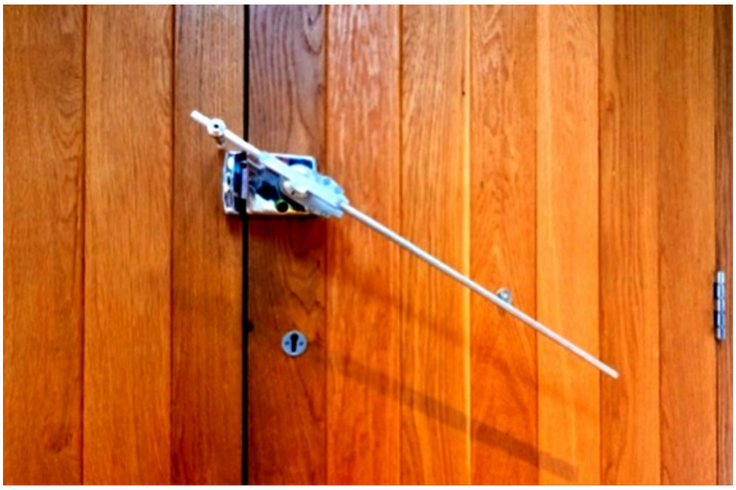
- A Message from the Chair -

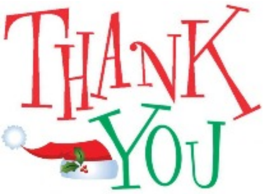
From Frustration to Empowerment

Hi everyone,

This month I want to share a personal story and give a plug for a wonderful charity.

As we know, MND is a progressive disease that gradually takes away our physical abilities to attend to the smallest tasks. My recent frustration has been my new inability to open our front door – my hands just don't work! We contacted the charity Remap https://remap.org.uk/solutions and a wonderful chap called Steve came and designed a bespoke and clever engineered solution that now enables me to open the door, even in my wheelchair. I no longer feel trapped – I can let in visitors and just go out, whenever I want to – ***Yippee !***





Thank you Remap, this was an early Christmas gift for me.

As the year comes to an end, may I take this opportunity to thank everyone on the Committee and all our volunteers and supporters across Herts, who continue to work so hard on our behalf.

We send our warmest wishes to everyone for the festive season and beyond!

- Kent -

* Finance Report – September and October 2024 *

We have received a number of donations over the last 2 months; namely **Helen Ruggles** Cup Cake sales have raised a further **£188** and **St Mary the Virgin in Welwyn** donated **£115** following a talk by **Kent & Hetty**. We also received several smaller, but very gratefully received, donations. We were especially pleased to receive an amazing **£7,800** from the Classics on the Common fundraiser in Harpenden.

These continuing donations have enabled us to fund many grant requests from across the county. These have included Riser Recliner Chairs, Stair Lifts, Mobility Scooters, Short Breaks, Treatments and Wheelchair Adapted Taxi's to appointments and meetings.

Heather Thank You Thank You

* Ground-Breaking Drug *

On October 17th the MND Association launched a national campaign focused on creating a route for people with the **SOD1 gene Motor Neurone disease (MND)** to access a ground-breaking drug.

The charity's Prescribe Life campaign is urging the **National Institute for Health and Care Excellence (NICE)** to use its discretionary powers to evaluate **Tofersen** in the way that gives it the best chance possible of being prescribed in the future.

People with MND have been at the heart of the Association's project from the very start.

The charity is now urging people to sign its petition asking people to support the call to NICE to make an exception for Tofersen.

It is the first step in the campaign and is aimed directly at **NICE. Tofersen** has been shown in clinical trials to slow the progression of symptoms in people living with MND who have alterations in the **SOD1 gene.**

This is about two per cent of the MND population, estimated to be between 60-100 people in the UK, but some people taking **Tofersen** have reported their symptoms have actually improved.

Leading MND clinical and research experts have called for the drug to be appraised through NICE's Highly Specialised Technology (HST) route, designed for treatments for serious rare diseases where only a small number of patients would benefit.

NICE has refused and in March 2024, confirmed it would assess Tofersen through the Single Technology Appraisal (STA) route instead, to which Biogen, the pharmaceutical company which developed Tofersen, has responded by not progressing its application.

NICE has decided Tofersen should not be assessed using the HST route because MND is not rare enough to qualify. But NICE's own guidance states that it can make an exception for treatments that can make a big difference to people with conditions with a poor prognosis.

Currently Biogen is keeping its early access program open, so people with SOD1 MND can get the treatment if they wish to. However, at any point, that program could be closed to new patients.

To sign the petition please go to the MNDA website and search for Tofersen.

- - - Branch News - - -

Chloe Rich – Area Support Coordinator Hertfordshire and Essex

We were very happy to welcome Chloe to our branch meeting on the 28th October. Chloe previously worked as a Project Manager in the Hospice sector. She is excited to join the team and connect with the local MNDA community. Her role is to ensure people with or affected by MND are supported and empowered in accordance with their needs.

She will be leading the provision of all Association services and support, delivered primarily through volunteers and working directly to support people with or affected by MND. She will also lead and coordinate all aspects of volunteer activity, specifically branches, groups and support volunteers.

Chloe Rich – ASC

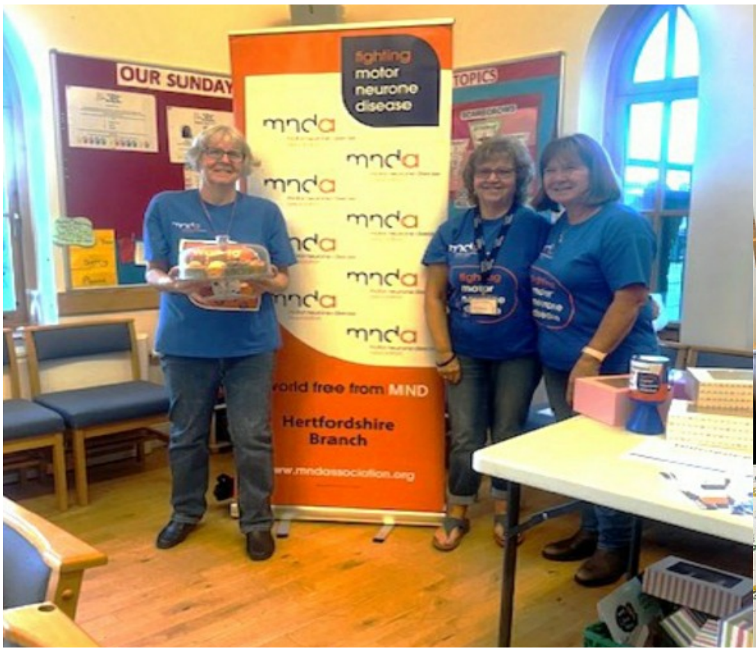
She is a passionate volunteer supporting a local Autism charity in her hometown of Harlow Essex.

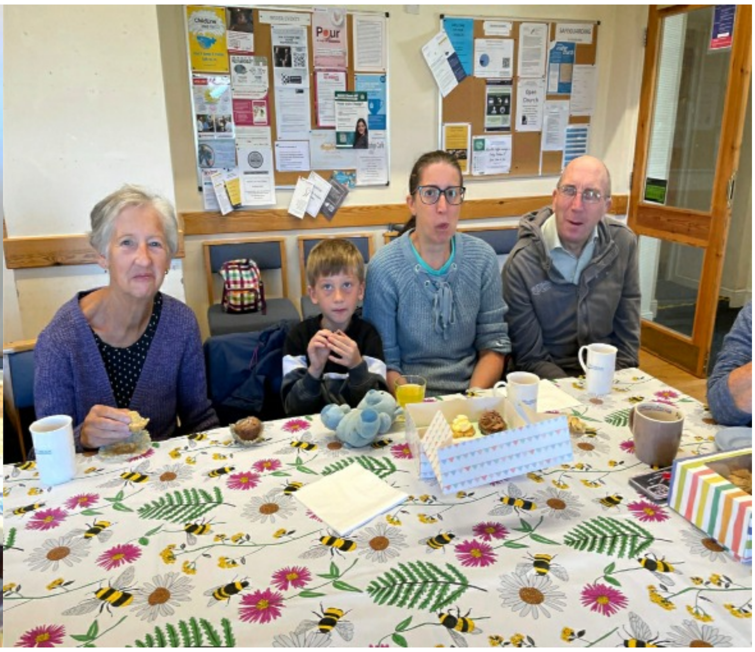
- -- Fundraising - - -

Wellbeing Coffee Morning

On Saturday 28th September, **Derek and I** attended the **Wellbeing Coffee Morning** kindly organised by **Debbie and Helen, at St Thomas's church, Stopsley**. Helen had made 96 beautiful cupcakes with different flavours, Lemon Meringue, Biscoff, Chocolate Marble and Coffee Fudge. The morning was well attended, with a visit from the new **Luton North MP Sarah Owen**. It was lovely to meet friends of **Debbie and Helen** and to catch up with **Chris and Martin with their daughter Melanie and grandson Ronnie**, who all came to support the Hertfordshire Branch. A good awareness meeting as well as raising **£188.00.**

*** Well Done Debbie and Helen ***





Thank You

Thank You

Molly Sykes running the Brighton Marathon

In 2022 Molly's dad, was diagnosed with MND, she has decided to run the Brighton Marathon in April next year to raise funds for those affected by MND and help families to access the vital equipment and care needed to support loved ones through this journey. The first **£500.00** of donations received will go to ***National Office***, monies raised above **£500.00** will be split 50/50 between ***National Office*** and the Hertfordshire branch. Molly is raising funds for the Hertfordshire branch as her dad, Mike lives in South Hertfordshire. Every donation, no matter the size can make a huge difference. Your support means the world to her and could give her dad, as well as others facing this disease, a chance to live a longer, more comfortable life. If you would like to support Molly this is her just giving page.**www.justgiving.com/page/molly-sykes**

Classics on the Common – Harpenden 24th July

The event raised over £28,000 of which £7,800 has been donated to us. Kent Allen - Chair, Hetty Smith - Fundraising Coordinator and Jenny Fellas - Association Visitor attended a presentation evening on 23rd October where we outlined how the money will be spent.

Rotary in Harpenden

Classics on the Common

Variety Express - Fairy Scary Tale

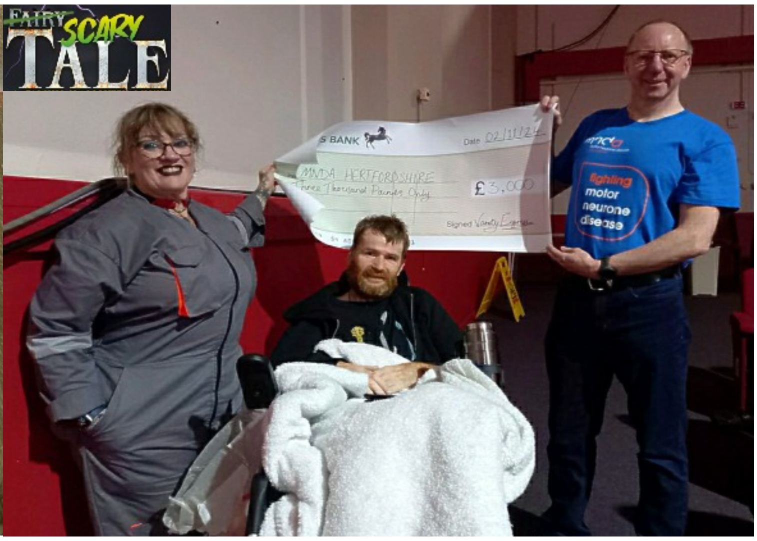
The branch has been very lucky to have been chosen for the second year running by Variety Express as their charity, along with Young Carers Crew charity based in Stevenage.

The Fairy Scary Tale, a family Halloween musical, was very entertaining, good songs to sing along too, great dancing, especially from the Style Dance School Street Crew and the Varity Express dancers. The Ghostbusters and performing skeltons during the scene changes were funny and clever. Elvis was in the building performing Devil in Disguise, wearing his famous white sequined suit and famous black quiff. Magic Jack was also there with his mind reading act ably helped by a member of the audience.

Variety Express - Fairy Scary Tale

The whole cast and behind the scenes crew worked really hard, thank you so much to them all for supporting the Hertfordshire branch and donating the amazing amount of **£3000.00.**

2024 Cast of Variety Express



Michelle Darren and Grant

In Memory of Iain Rutherford

The Stotfold Good Neighbours Groups, Friends on Friday, and the Exercise class Groups had a collection in memory of Iain at their recent meetings on what would have been his birthday, raising an amazing **£120.00**. Many thanks to them all for remembering one of our past members.

Inspiring Fundraiser for the London Marathon 2025

Lauren Petchell, the daughter of one of our people living with MND, has an MND place to run the London Marathon in April 2025. After witnessing the devestating effects of MND on her father, she is looking to raise money for both the Hertfordshire branch of the MNDA, and also the national association.

Lauren has already undertaken two major fundraising event to raise money for the MND Association, the **first being a sky dive in 2017** which raised over **£4,700**, the second being the Brighton Marathon in April of this year which raised **£3,600**, so when she was offered a charity place for the London Marathon she knew she couldn't rely on donations alone, so set about planning some fundraising events.

Her dad has sadly been living with the condition since 2015, and before he was diagnosed was a keen golfer so a charity golf day made perfect sense as her first event. With the help of her family, she ran the golf day on Friday October 25th at Stocks Golf Club, and hosted 64 golfers! The day was a huge success massively helped by the generosity of a few people / companies she would like to thank:

Star Platforms and Richard Miller for their generous sponsorship.
Stocks Golf Club for allowing the use the course and discounting their green fees.
The Old Town Golf Shop in Hemel for giving a discount on all competition prizes
The Golf Clubs who donated an auction prize which made **£1725** on the day
!Plus all the golfers who supported the event.

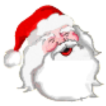
In total the day raised a staggering **£5,771** which is amazing and is going towards her Just giving page.

Thank You Thank You

Future Meetings & Events for Your Diary

(* NO BRANCH MEETING IN NOVEMBER *)

Branch Christmas Lunch - Monday 2nd December - Held at The Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY- 12 noon.



Branch Meeting - Monday 27th January - Held at the Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY - 11am

Branch Meeting - Monday 24th February - Held at the Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY - 11am

Branch Meeting - Monday 31st March - Held at the Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY - 11am

For More Information Contact Chris Carter christine.carter@mndassociation.org

Get Togethers - Box Moor Trust Centre, London Road, Hemel Hempstead HP1 2RE
For those living with MND their family and carers - **on First Wednesday** of each month **at 2pm** - 4th December - 15th January - 12th February - 5th March

For more information contact - Lesley Ralston - leshenhouse@gmail.com

* * ZOOM's * *

***Daytime Group* - *Zoom* - 3rd Tuesday** of every month at **11am to 12.30pm** - 17th December - 21st January - 18th February - 18th March

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

South East Carers Coffee & Chat - Zoom - Carers only - On First Tuesday of each month at 11am - 3rd December - 7th January - 4th February - 4th March

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

Evening Carers Group - Zoom - Carers only - On Last Wednesday of each month at 6.30pm. - 27th November - 29th January - 26th February - 26th March

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

Christmas 2024 Christmas 2024

Contact Details

~ BRANCH MANAGEMENT COMMITTEE ~ 2024 OFFICERS ~

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- - BRANCH CONTACTS - -

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- - REGIONAL FUNDRAISER - -

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- - - AREA SUPPORT COORDINATOR (ASC) - - -

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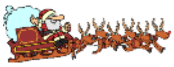
WEBSITE	**FACEBOOK**
MNDA Hertfordshire Branch	**www.facebook.com/mndahertfordshire/**



* THE MND HELPLINE – Tel 0808 8026262 *

mndconnect@mndassociation.org

Our MND Connect Helpline offers advice, practical and Emotional support and directing to other services and agencies.

Monday-Friday 10.00am - 4.00pm

Editors : Derek Dunn & Christine Carter
Newsletter Booklet Coordinated by Alan J Lockett