

Hertfordshire Branch Newsletter

Motor Neurone Disease Association

2024

Branch Patron Dr. Viv Lucas

January 2024

2024

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ALL GOOD WISHES FOR A VERY HAPPY 2024

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



Hi everyone,

SAVE THE DATE – on THURSDAY 23rd MAY we are having a special get together and we'd love you to join in.

Our special guest is Tanya Curry, the Chief Executive of our UK MND Association.

It's our opportunity to hear about all the key initiatives, progress and plans for **2024** and beyond. It will be a great forum to ask questions, interact with her in person – and meet up with others in **Hertfordshire** who are part of our community - current friends and possibly new ones.

The Meeting will be held at THE RED LION, 88 GREAT NORTH ROAD, HATFIELD AL9 5EU - from 2pm. We're planning the get together for the afternoon and we will have refreshments for everyone.

In the next Newsletter we will have more details about the agenda – if you have any suggestions or ideas to make this a valuable time together, please get in touch with me, your **AV** or **Chris Carter**. We would welcome your input, to make this event a memorable, positive day out for everyone.

Best wishes for 2024 and we so look forward to seeing you there.

- Kent -

* Finance Report – November and December 2023 *

As 2023 drew to a close it was time to reflect on what was definitely an unusual year. Merging the 2 branches brought with it several problems financially but these were finally ironed out by the end of July and with a few ups and downs, the processes have now become straight forward again. Obviously having one large branch has brought with it a much higher demand for grants but equally a great deal more generous donations and fundraising.

November and December were no exception, another **£1,600** was donated to **Paul Gilbert's Golf Day** and a further **£3,376** came to us from **Mark O'Brien's Open Water Swim**. We have received a further **£455** from **Letchworth RUFC**, Our Committee Member **Grant Cameron** has raised over **£800** by **Walking 25 miles** in December and **Stotfold Town Council** donated **£230** collected when they turned on their **Christmas Lights**. Just before Christmas, **London Building Control** in **Welwyn Garden City** donated **£1,000**.

All of these generous donations mean we have a very comfortable financial position and have been able to meet all grant requests. **During November and December We funded Riser Recliner Chairs, Stairlifts, House Adaptations, Taxi's to Meetings and Appointments, Holidays, several different types of Therapy and a Dog Walker, plus both Carers Grants and Young Peoples Grants.**

We look forward to continuing to support everyone during 2024.



Thank You Heather Thank You



MNDA Research update

On 3rd November 2023 the New UK MND Research Institute (UK MND RI) was Launched. This is a Virtual Institute bringing together a Network of Labs working on MND to better coordinate a wide range of activities to accelerate drug discovery and development. **The Institute is co-directed by Professors Ammar Al-Chalabi at King's College London and Chris McDermott at the University of Sheffield.**

Clinical Trials update



<https://ukmndri.org/>

Clene Nanomedicine (USA) have reported two key updates from their ongoing trial of their investigational **CNM-Au8® treatment in ALS/MND** participants. They have stated that there was a 60% decrease in long term mortality events between a group given the active treatment versus a group given a placebo (dummy drug).

The second important report was that the measurement of a protein in the blood called **Neurofilament Light Chain (NfL)** appears to correlate well with disease progression and the goal would be to use the **NfL levels** and changes as a biomarker for disease progression. Having a proven **biomarker** can be a significant step forward in monitoring and carrying out diagnosis and clinical trials as the results can be seen more quickly than current methods.

NeuroSense (USA) have reported 6-month data from a small, **phase 2b study** with their therapy **Prime C**. The potential treatment was stated to be safe and well tolerated by people with **ALS**. **Prime C** was also found to slow disease progression and slow decline in lung function compared to a placebo (dummy drug). **Prime C** is a novel formulation composed of two **FDA-approved drugs, Ciprofloxacin and Celecoxib**.

It should be noted that all these results above are from small, early stage clinical trials. However they are encouraging updates and will allow continued trials and additional larger trials where true clinical significance will be investigated in the coming years.

Grant



- The Hertfordshire Branch -

2023 has been an interesting year for the Branch.

After forming the new **North Hertfordshire Branch in May 1994**, it soon became the **North and East Hertfordshire Branch** to cover a wider area, it was then decided in April 2023 that the **South Herts Branch** would join us to become the **New Hertfordshire Branch**. It has been a learning curve for us all getting used to a **New Larger Hertfordshire Area**, with **New Systems, New Committee Members and Association Visitors**, all of which are **Now Up and Running**.





- The Hertfordshire Branch -



Our first venture was the second **Herts County Walk in July**, which was well supported, and enjoyed by all even though it ended in a downpour.



We have been extremely lucky with some wonderful people fundraising and supporting us. A big thank you to them all.

Thank You

Welwyn Golf Club - Stotfold Town Council - Penny Briggs at the Craft Fair - St.Albans 41 Club – Two runners in the London Marathon - Katelyn and Annie having their hair cut to donate to The Little Princess Trust - The amazing West End Charity Gala at the Gordon Craig - Emily, the niece of one of our members, holding a bake stall at her school - Vernon and Hilary celebrating their 25th Wedding Anniversary - Marks World Record Open Water Swim - Pauls Birthday fundraiser and Golf day with Adrian - Folk by the Tree with Viv and Brian - Variety Express Pirates Show - Stotfold Mayor and my Granddaughter Lara collecting at the Stotfold Christmas Lights Switch On.

PIRATES!



Thank You

To finish, our **Christmas Lunch at the Three Horseshoes** was a well-attended event, where 33 members and friends enjoyed a varied Christmas meal. **Santa, aka Alan**, joined us with his **Sack full of Chocolate goodies**, Elaine made a beautiful **Christmas Cake** for the Raffle. **Many thanks to them both and to everyone who kindly donated a Raffle Prize.**

Raffle

Thank You



Not quite, **Grant took on the MNDA challenge of running 25 miles in December**, In total He Ran 36 Miles in the month and raised a total of **£840** through the **MNDA GoFundMe Page** and through local activities by various groups during the month. **Grant would like to thank all the amazing individuals who donated and the following groups for rallying together to really make a difference; Hitchin Floral Art Club, Letchworth Arts & Leisure Group (LALG) Ukulele Group & LALG Malt Whisky Appreciation group.**

Emily and her Friends at School **Thank You** Lara with Steve Buck – Stotfold Mayor





Vernon and Hilary Docwra on their Wedding Day and 25th Wedding Anniversary



**A big thank you to our wonderful Committee Member Grant
The 'Run 25 miles in December' Challenge raised a total of £111,178.**



Raffle

* Christmas lunch at the Three Horseshoes *

Raffle



*** The Three Horseshoes is Closed for Refurbishment during January & February ***

Branch meeting - Monday January 29th - ZOOM MEETING at 11 am
ID - 841 789 6055 - PASSWORD 515616

Branch meeting - Monday February 26th - ZOOM MEETING at 11 am
ID - 841 789 6055 - PASSWORD 515616

Branch meeting - Monday March 25th - Face to face meeting
The Three Horseshoe Hooks Cross Watton at Stone - 11am

Branch meeting - Monday April 29th - Face to face meeting
The Three Horseshoes Hooks Cross Watton at Stone - 11am



**Branch meeting - Thursday 23rd May - MEET TANYA CURRY - THE NEW
CHIEF EXECUTIVE**

From 2pm - The Red Lion, 88 Great North Road, Hatfield AL9 5EU.

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 -
- 7th February - 6th March - 3rd April**

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

**** ZOOM's ****

Daytime Group - Zoom - 3rd Tuesday of every month at 11am to 12.30pm
- 20th February - 19th March - 16th April

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

South East Carers Coffee & Chat - Zoom - Carers only -

On First Tuesday of each month at 11am

- 6th February - 5th March - 2nd April

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



Evening Carers Group - Zoom - Carers only -

On Last Wednesday of each month at 6.30pm

- 31st January - 28th February - 27th March - 24th April

For more information contact - justine.cox@mndassociation.org





Contact Details



~ BRANCH MANAGEMENT COMMITTEE ~ 2024 OFFICERS ~

- CHAIRMAN:** Kent Allen 51 London Road Hitchin, Herts. SG4 9EW
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- SECRETARY:** Lindsey Lucas 4 Woolston Avenue Letchworth Herts. SG6 2ED
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-- REGIONAL FUNDRAISER --



ROGER WIDDECOMBE



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



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MNDA HERTFORDSHIRE BRANCH WEBSITE

<http://www.mnd.n-herts.freeuk.com>

2024

Twitter X

twitter.com/MndaHerts

OUR EMAILS

mndaneherts@gmail.com

mndassoc.southherts@gmail.com

* * **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 9.00am - 5.00pm & 7.00pm -10.30pm.



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

