

Hertfordshire Branch Newsletter

Branch Patron Dr. Viv Lucas

September 2024

Printed by the University of Hertfordshire



St Paul's Walden Bury, an English Country House Grade 11 listed.

The Home of the Bowes-Lyon family.

**The Childhood Home of the late Queen Elizabeth the Queen Mother.
Spectacular formal Woodland Gardens Grade 1 listed, laid out in 1720.**

St Paul's Walden Bury, Hitchin SG4 8BP

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,

How is your appetite these days? Mine is really bad. I seem to have lost all interest in most food – surprisingly, even favourites I have loved for years and years.

Also, the portions I want are much smaller than before **MND**, and I always need to be prompted to care about ‘meal time now’ or even some snacks.

I’m not happy about this situation, but I haven’t yet found the magic elixir or incentive that will drive me to eat/drink the proper amounts for almost every meal.

I do have **Aymes protein drinks** regularly, as a supplement, however regardless of the stated ‘flavour’ they all taste the same to me. Everyone that supports me is always very encouraging and I want to follow their suggestions and help.

My wife and I have the gift that we can still go out most days to a coffee shop / restaurant / pub and enjoy the experience – mostly people watching and having a coffee/cake treat! However, at home I am not so incentivised.

So, what else can I do, to get my nourishment/enthusiasm higher?

I have just discovered the updated **MNDA** publication, **Eating and Drinking with MND**, 142 pages of colourful, detailed and delicious suggestions, recipes and advice about the nutrition feelings/comments I have shared with you. It is certainly worth getting your own copy, to assist with ideas, motivation and alternatives available to regain a desire to maintain this fundamental health need.

As a start, I’m going to highlight various examples/recipes to my wife and try some new snacks/meals suggested in the book.

If my situation resonates with you, just call **MND Connect** and they will send you a copy, for your own exploring and experimenting, and hopefully you will regain some more fun and/or satisfaction with enjoying mealtimes again. **Bon appetite, - Kent -**

* Finance Report – July and August 2024 *

The summer as usual has been a quiet period but we have received several generous donations. Our Annual **Walk to D’Feet MND** at Stanborough Lakes raised a total of **£440**, a pleasing total considering the horrendous weather that day! We also raised **£258** at the **Classics on the Common Event**, with a further donation expected from the organisers. We received **£270** from a **Cup Cake sale** in July followed by a further **£100** in August. We have also received **£1,900** from **WoolyFest**, **£1,000** in memoriam donation, **£438.50** from **Headstone Lawn Tennis Club**, **£250** from **St Stephen’s Freemason’s Lodge** and **£100** from the **Tilehouse Rotary Club of Hitchin**.

Over the last 2 months we have been able to fund many requests for Grants including, Stair lifts, Riser Recliner Chairs, Wet Room adaptations, Air Conditioning unit, specialist hairdryer, cleaning service, Carer’s Grants, Young Peoples Grants and Wheelchair Adapted Taxi’s to meetings, events and appointments. We are very grateful for the fundraising and donations that have made all this possible. **Heather** **Thank You**

Our **ASC, Justine** has now left the **Association**, she will be keeping in touch and hopes to attend some of our meetings. It was a very sad goodbye at our meeting in July, **Kent** thanked her for all she had done for the branch, her support to us all, and wished her well for the future.

Christmas
2024



Christmas
2024



The Branch will be doing a **Christmas Card Order** again this year, if you would like to order cards **Lindsey** will be collecting orders. You can see the **Cards** on the **Association website**, we will also have Catalogues available at our next meeting on 30th September. **Lindsey** would like all orders to her by the end of October, thank you.

Contact her on 079055157764 - lindsey.lucas@mndassociation.org.

The branch receives 15% back if cards are ordered through the branch.



**The Branch Christmas Lunch at the Three Horseshoes
will be on Monday 2nd December 12am.**



Menus will be available at our meeting on the 30th September and are available on line

3 courses - £36.50 plus 10% service charge - £40.15

2 courses - £32.50 plus 10% service charge - £35.75

I will be collecting names and choices again - christine.carter@mndassociation.org

Thanks Chris.



- Fundraising -



"Walking for Mary: John's 135km Journey to Raise Awareness and Hope for MND"

John undertook an incredible challenge to support both the **MND Association and Petals, a Baby Loss Counselling Charity** (both charities close to his heart), by **Walking the Entire Length of Hadrian's Wall—a demanding 135km journey.**

John wanted to support the **MND Association** in honour of his sister, **Mary**, who was diagnosed with **Motor Neurone Disease (MND)** last year. **John** shares how "**Mary** faces the future with both determination and considerable courage. Our family is extremely proud of her and I feel strongly that this walk is the least I can do"

The journey not only tested **John's** physical endurance but also served as a powerful tribute to his sister and all those affected by the condition.

Reflecting on the experience, **John** shared one of the best parts about the challenge was "meeting people on the way who instantly recognised the **MND logo**. They would offer to donate on the spot which happened numerous times." **John** was joined by friends and family for parts of his challenge and the support has been tremendous.



Mary, when talking about **John's challenge**, shares how "at the beginning of this year he told me that he wanted to take up this challenge of the **Hadrian's Wall Path 135kms walk**. The months leading up to this he trained to reach a good fitness level. Others helped him and the achievement has been a joint effort in many ways. Most of all though I feel very lucky to have a brother who was prepared to do this."

John has raised over **£3000** for the **MND Association** and we are truly grateful for his amazing support. [John Liberty is fundraising for Motor Neurone Disease Association \(justgiving.com\)](http://justgiving.com)

Carmen Brown – Community Fundraiser



Jenny Fellas, Association Visitor in South Herts, Grant Cameron and Hetty Smith, committee members, spent the day at the annual **Classics on the Common** event in **Harpenden** on 24th July. **Thanks to Jenny's contacts at the Harpenden Rotary Club**, who hold this event annually, we were nominated as one of three charities chosen this year to receive a share of the proceeds from the day. **Over 855 classic cars and 100 motorbikes** came on to the common - it was quite a spectacle. We will know in a few weeks how much we will receive.

We are extremely grateful to the Harpenden Rotary Club for their support. Hetty



Hetty, Jenny and Grant with the High Sheriff of Hertfordshire



Woollyfest Music Festival

Jackie Castle and Phil Corke started the **Woollyfest Music Festival at the Red Lion in Woolmer Green** some years ago and this year have donated **£1,900** to our branch, raised in memory of **Aaron Starkey**. The cheque was presented to Aaron's wife, **Claire** and our **Committee Member, Grant**. The funds were raised at the annual festival held in July where **MND** was one of the three supported charities. An amazing fund raiser from what was, by all accounts, a fantastic community event. **Grant** **Thank You**



Wellbeing Coffee morning



On Saturday 28th September from 10am to 12am, **Debbie Newbound** and **Helen Ruggles** will be holding a **Wellbeing Coffee Morning at St Thomas Church 585a Hitchin Road Stopsley LU2 7UL** kindly raising funds for the branch. An opportunity to try some of the lovely cupcakes made by **Helen**.

Debbie is the parish nurse and will be happy to take your blood pressure and have a general health chat with you.

Variety Express



Variety Express have again chosen our branch as one of their charities for this year. **The Scary Fairy Tale** will be performed at **St Francis Theatre Letchworth**, 31st October - 3rd November - 7.30pm and 2.00pm - adults £12.00 - concessions £10.00. Following on from their Pirates show last year this terrifyingly hilarious tale is a must see. Tickets online at VARIETYEXPRESS.ORG.UK

Box Office – 0333 6663366



The Association has information leaflets that you can request from the Helpline - 0808 8026262

[10A - Benefits and entitlements](#)

Information on relevant benefits and entitlements, whether you may qualify and how to apply.

[10B - What is social care?](#)

Guidance on social care and how it works, including how to get your needs assessed for care support, who pays for any care services agreed and how to use direct payments if you want to control the care services you receive.

[10C - Disabled Facilities Grants and home accessibility](#)

Guidance on how and when to apply for a Disabled Facilities Grant (DFG) and other benefits regarding housing.

[10D - NHS continuing healthcare](#)

Details about NHS continuing healthcare and how to apply.

[10E - Work and motor neurone disease](#)

Information about available options if you are living with MND and considering whether to continue or leave employment.

[10F - Personal health budgets](#)

Information on personal health budgets for people living with MND or Kennedy's disease in England.

[10G - Support for families with children](#)

Information on the different types of support that may be available for families affected by MND

[11C - Equipment and wheelchairs](#)

This information sheet looks at ways to make daily life easier by using a range of equipment, including wheelchairs, and how to access this support.

[11E - Environmental controls](#)

Detail on environmental controls and how they may be helpful if you're living with MND.

See also our booklet on **[Personal care with MND](#)** and our booklet **[Getting around](#)**.



Future Meetings & Events for Your Diary



Branch meeting -Monday 30th September - Held at The Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY- 11am.



Branch meeting -Monday 28th October - Held at The Three Horseshoes, Hooks Cross, Watton at Stone. SG14 3RY- 11am.

*** 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.



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** - 2nd October - 6th November - 4th December.

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 September - 15th October - 19th November - 17th December.

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

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

On First Tuesday of each month at **11am**

- 1st October - 5th November - 3rd December.

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



Evening Carers Group - Zoom - Carers only -

On Last Wednesday of each month at **6.30pm.**

- 25th September - 30th October - 27th November.

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

or abigall.igbokwe@mndassociation.org





Contact Details



~ BRANCH MANAGEMENT COMMITTEE ~ 2024 OFFICERS ~

- CHAIRMAN:** Kent Allen 51 London Road Hitchin, Herts. SG4 9EW
kent@latimers51.com Tel: 07771876562
- TREASURER:** Heather Hurley 8 The Dale Letchworth Garden City, Herts. SG6 3SG
heather.hurley@mndassociation.org Tel: 01462 627025
- SECRETARY:** Lindsey Lucas 4 Woolston Avenue Letchworth Herts. SG6 2ED
lindsey.lucas@mndassociation.org Tel: 07905157764

-- BRANCH CONTACTS --

- Christine Carter** North and East Herts Area
christine.carter@mndassociation.org Tel:01462 338450
- Hetty Smith** South Herts Area
hetty.smith@mndassociation.org Tel:01462 630195

-- REGIONAL FUNDRAISER --



ROGER WIDDECOMBE



roger.widdecombe@mndassociation.org

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



To be appointed at the end of September



WEBSITE

MNDA Hertfordshire Branch

FACEBOOK

www.facebook.com/mndahertfordshire/

OUR EMAILS

mndaneherts@gmail.com

mndassoc.southherts@gmail.com

2024

Twitter

twitter.com/MndaHerts

*** * 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

