

# Our Vision is a World Free of MND

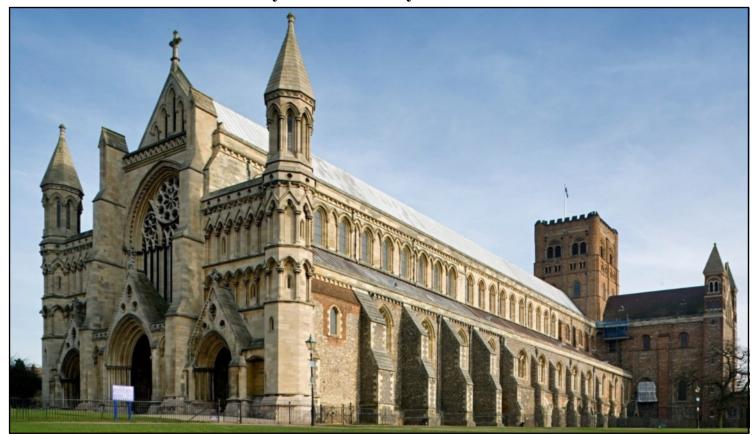


# **Hertfordshire Branch Newsletter**

Branch Patron Dr. Viv Lucas

May 2024

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St Albans Cathedral is a Church of England Cathedral in St Albans, England, built on the site of the Martyrdom of St Alban, the first British Saint. It was founded as a Benedictine Abbey by King Offa in 793, using Roman bricks from the nearby ruins of Verulamium. It was a place of Learning and a Meeting Place for Churchmen and Nobles who contributed to the Magna Carta in 1215. It became a Cathedral in 1877, after the Dissolution of the Abbey in the 16th century.

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 -





#### Hi everyone,

Are you noticing and enjoying all of the 'fleeting moments' that surround us every day? Sometimes they are just simple events, surroundings or other life that we take for granted, possibly don't really pay attention to... or miss entirely because we're too busy, distracted or not looking. However, when we are alert and curious, there is so much more to see, and enjoy.







Photography is my window into aspects of the world we miss, take for granted or can see differently. I have always enjoyed capturing some of these moments as I see them, to remember them and be able to share them over and over again.

On days when I'm energetic I stretch my awareness and curiosity to notice new things. On days when I'm more housebound and stationary, I can look at past examples and smile at the images I've captured and collected before.

As examples, nature is a vast source of fleeting moments; gardens, creatures, sky...how marvellous, when we just choose to relax and have a look. Of course, people and pets also provide us with daily examples of fleeting moments.







Every day we have, presents constant ways to capture the fleeting moments that give us comfort, wonder, appreciation and joy.

The world around us is happening so quickly, and every day we can only catch and absorb relatively few moments. These are very similar to *microjoys*, which I've written about before, however fleeting moments may not be as predictable, repetitive or from our influence.

As a closing thought, here is a very fleeting moment we have just created for you – the opportunity to meet with **Tanya Curry**, **CEO** of the MNDA. Just sign up for our *May* 23 Special Event, and who knows what support, insights or friendships you may create!

I hope to see you there and hear about some of your fleeting moments.

- Kent -



## \* Finance Report – March and April 2024



March and April have been fairly quiet months for donations. £2,850.58 was donated by the Rickmansworth Townswomen's Guild, £500 of which has been transferred to Research at their request, £200 was received from St Albans 41 Club, £500 via JJK Fitness, from the London Metric Property PLC and a further £215 in respect of Grant Cameron's December Run.

Over the 2 months we have been able to fund a variety of different items and services - Stair lifts, Wet Room adaptations, Riser Recliner Chairs, a Tumble Dryer, Wireless Headphones, Holidays, Massages, Pilates and Reflexology, Care at Home, Transportation and even a Dog Walker. We have also funded Carers' Grants for Holidays, a Yoga Retreat, Massage and Driving Lessons. We are very grateful for the fundraising and donations that have made all this possible.

We would also like to thank **Daniel Bourke** for the years of regular support given by him and his family, we wish them well with their new ventures. **Heather** Thank You









## Hertfordshire Branch Annual Walk to d'feet MND



Saturday 6th 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

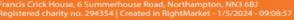


Walkers of all levels very welcome.
Walkers in wheel chairs very welcome.
Walkers with dogs very welcome.
Donation of £10 per person or £20 for a family of four.
Register in advance for concessionary parking.

Bring a picnic to enjoy after the lake walk.

For more information and registration form please email: hetty.smith@mndassociation.org















## - Fundraising -







The Rickmansworth Townswomen's Guild chose the Hertfordshire branch as their charity for the year. Lesley was invited along to their recent A G M to receive a cheque for £2850.58 for the branch, £500.00 of which will be going to research. The cheque was presented to Lesley by the Chairman, Margaret West, on the left and Almoner Frances McMurray. Many thanks to them for choosing The Hertfordshire branch as the charity of the year.

## \* Looking forward to getting out and about \*

## Sociability - Let's go out

Do you ever want to go out to a venue such as a cafe, restaurant, or entertainment venue but you are nervous because you have no idea what it's going to be like when you get there as far as accessibility goes? Well, Sociability can make that process easier for you. These venues are mapped primarily by disabled people, so it is seen through our eyes and include the elements of a venue that you are interested in. It doesn't just include the things that as a wheelchair user you need to know. It includes tags for people who have mobility-related access needs, as well as encompassing those with hearing, visual, and sensory access needs too. Knowing what to expect before you arrive at a venue is really helpful.





## Let's go out ..





As well as Sociability having a team of trained mappers based in the capital, you can also map venues yourself, anywhere in the world! You can map the indoor and outdoor areas of a venue, as well as any lifts or upstairs spaces including the toilets and other essential areas. It is an easy user interface, and you will get the hang of it after a few goes! It doesn't take much time to map the venue and just think of the person who wants to go where you have been but is anxious about what the facilities are like; only to find that all the information is there for them!

Empower others by adding tags and photos while you are out. Create lists of venues to save your favourites or plan ahead. Share your favourite venues and lists with friends and family.

Sociability is an app and is available for free on iOS, Android & on the web.

Email - hello@sociability.app



### \* Maison Des Landes – Jersey - as recommended by one of our members \*

Maison des Landes combines the relaxing atmosphere of a modern hotel with the very latest facilities for people with disabilities and their carers'. Each of the 23 rooms is different, which means that they can select the accommodation that will best suit your needs. Whether that's inter-connecting rooms or specific facilities, they will tailor your experience.

The spacious lounge and adjacent orangery form a welcoming place for visitors to be able to relax, have a chat or read a book. The floor to ceiling doors have a wonderful view out over **St Ouen's bay**, and on those sunny days, the doors open right up to allow easy access onto a patio with tables and chairs and shelter from any wind, so that you can relax without worry.







All bedrooms have been totally refurbished. 15 ground floor rooms are fully accessible with ceiling hoists to aid transfers. The 5 premium rooms have continuous tracking from the beds to the wet room. These also benefit from easy access to their own private patio.

All rooms are equipped with tea-making facilities and safes, whilst small fridges can be provided for storing medical items.





#### MAISON DES LANDES

ACCESSIBLE HOTEL & COMMUNITY HUB





As well as accommodating 48 diners, the dining room has a modern bar where guests can order a wide range of drinks. During the summer, guests can dine outside on the patio where staff can also prepare food on the BBQ. The dining room is easily accessible and we can cater for a variety of dietary requirements.

#### There is an Accessible Pool and Minibus.



Contact - 01534 481683 - email - reservations@maisondeslandes.co.uk

Website - <a href="https://maisondeslandes.co.uk/">https://maisondeslandes.co.uk/</a>

MAISON DES LANDES

MAISON DES LANDES



## - MND EnCouRage UK - MND COMMUNITY -

Just to let you know that the MND EnCouRage UK 2024 event is now open for registration. The event's aimed at bringing the Latest Research News and Updates, and the opportunity to talk to MND Researchers.

## On Wednesday 10th July 2024

More information and the registration link can be found at:

<u>MND EnCouRage UK - MND Community | MND Association</u>



Hear more about the latest MND research – find out more about the ins and outs of clinical trials.

Take part in discussions about research topics that are relevant to you.

News about research that is taking place now, presented in non-technical terms, bringing you up-to-date with what's happening in the research community.

If persons living with MND and their Carers attend, and need to arrange transport, we could fund this via a **QOL Grant.** 





# Future Meetings & Events for Your Diary





\* Branch Meeting - Thursday 23rd May - MEET TANYA CURRY -

THE NEW CHIEF EXECUTIVE \* - From 2pm -

The Red Lion, 88 Great North Road, Hatfield AL9 5EU.



**Branch meeting - Monday 24th June -** Face to face meeting The Three Horseshoes Hooks Cross Watton at Stone - 11am

Hertfordshire Branch Annual Walk to d'feet MND -

- Saturday 6th July - 11am - Stanborough Lakes.





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

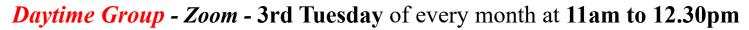


**Get Togethers - Box Moor Trust Centre,** 

London Road, Hemel Hempstead HP1 2RE - For those living with MND their family and carers - on First Wednesday of each month at 2pm -

- 1st May 5th June 3rd July 7th August 4th September 2nd October
- 6th November

For more information contact - Lesley Ralston - <u>leshenhouse@gmail.com</u>
\*\* ZOOM's \*\*



- 21st May 18th June 16th July 20th August 17th September
- 15th October 19th November

For more information contact - <u>Dawn.Pond@mndassociation.org</u>



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

## On First Tuesday of each month at 11am

- 7th May 4th June 2nd July 6th August 3rd September -1st October
- 5th November

For more information contact - <u>lisa.burnard@mndassociation.org</u>

**Evening Carers Group - Zoom - Carers only -**

On Last Wednesday of each month at 6.30pm.

- 29th May - 26th June - 31st July - 28th August - 25th September - 30th October - 27th November



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







## **Contact Details**





### ~ BRANCH MANAGEMENT COMMITTEE ~ 2024 OFFICERS

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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.com/MndaHerts

Twitter X

#### **OUR EMAILS**

mndaneherts@gmail.com

mndassoc.southherts@gmail.com

THE MND HELPLINE - Tel 0808 8026262 mndconnect 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** 

