

Hertfordshire Branch Newsletter

November 2023



Wishing you all a very Happy Christmas and a Healthy New Year

A Message from the Chair

Hi everyone,

From all of us, thanks for the unwavering support you've bestowed upon the MND National Association and our Hertfordshire Branch throughout this challenging year. Your kindness has been a beacon of light, and for that, we extend our heartfelt thanks.

This Christmas, let us come together as a community, united in the spirit of compassion and joy. While we recognize the range of difficulties we all are facing, we aim to sprinkle a bit of festive cheer into your lives.

Picture this at Christmas: a virtual winter wonderland where smiles are the currency and laughter echoes in abundance. In the midst of our challenges, let the twinkling lights, the warmth of shared stories and the odd tipple boost our spirits! We invite you to join us in celebrating the resilience that binds us together.

Amidst the hustle and bustle of the season, let's take a moment to cherish some simple joys – a shared virtual cup of cocoa, a heartfelt message exchanged, or a merry carol sung in unity. This holiday, let's seek out moments of joy, spreading kindness and understanding like a blanket of snow.

As we reflect on the year gone by, we want you to know that your support has been the cornerstone of our efforts. Each act of kindness, big or small, has contributed to the strength of our community.

So, from the bottom of our hearts to yours, thank you. Thank you for being the shining stars that light up our cause. As we venture into 2024, let's continue to stand together, supporting and uplifting one another.

Wishing each of you and your family a heart-warming and joyous Christmas filled with love, laughter, and the warmth of shared community spirit.

Kent

Finance Report - September and October 2023

September and October have continued the trend for bumper months of fundraising. Paul Gilbert's Golf Day has raised a further £12K making a total in the region of £25K and rising whilst Mark O'Brien's open water swim has already raised over £3k with more to come. We have also received donations from Buntingford Community Choir, Welwyn Garden City Golf Course and a generous Silver Wedding Anniversary Collection. We were also thrilled to receive over £7K from Variety Express Theatre Group as their nominated charity for their recent successful Pirates production.

This has all meant that we have continued to be able to fund a variety of requests including -Holidays and Spa days, Physio, Massages, Pilates and Chiropody, Taxi's to Meetings, Hospice visits and Hospital Appointments, Stairlift rental, Riser Recliner Chairs, lightweight Wheelchairs, an ironing service and a Young Person's Grant for driving lessons. As always please do not hesitate to ask if there is anything you need to make life more comfortable.

Heather

Fundraising

Guiness World Record

Huge congratulations to Mark O'Brien who on Sunday the 24th September broke a Guiness World Record for the longest unaided open water swim by a person living with MND. Mark swam 11km non-stop and was in the water for 5 hours and 23 minutes. He was joined by his 3 children Lauren, David and Georgia for the final stages of this amazing accomplishment.

Mark took on this incredible challenge at Denham Water ski club supported by friends and family and in doing so raised money for the MNDA and both our Hertfordshire branch and the Bedfordshire branch.

Well done Mark and thank you.



I was asked to go along to Watford Football Club on Saturday 21st October. At half time during Watford's match against Sheffield Wednesday, Paul Gilbert, Mark O'Brien and I were invited onto the pitch. Paul & Mark are long standing members of the club and are both living with MND.



The club wanted to acknowledge the fantastic fundraising these two had done over the last few months. Paul had completed a 72 hole golf challenge last month with his two sons and a close friend, raising over £25,000 for the Hertfordshire Branch. Mark undertook an open water swim at Denham Lakes last month where his family joined him in the water for the last part of his swim, raising over £22,000 which is being split between the Hertfordshire Branch, Bedfordshire Branch (where he lives) and National Office for Research. Mark was interviewed about his and Paul's achievement and I was asked about the impact this would have for the branch – I was thrilled to be able to thank these two amazing men publicly for what they have done and how it has helped raise awareness and also allows the branch to continue to fund the many requests we have for equipment, respite care etc. It was a great day in the company of these two wonderful people and their families.

Hetty

Variety Express

Founded in 1980 Variety Express is a North Hertfordshire based community theatre group with a currant cast of around 40 members, which has raised over £123,000 for local and national causes. They produce a positive and entertaining show for all. The MNDA Hertfordshire Branch were very lucky to have been chosen as their charity for 2023. The Pirate's show was very entertaining, two rival captains and their crews race against time and the elements to find the fabled treasure of Captain

Lorrray. Along the way, they must deal with rogue ships, prophets, magicians, and an eye watering lack of personal hygiene.

Many thanks to them all for all their hard work and raising an amazing amount of £7,000.00.

Grant receiving the cheque.



Run 25 miles in December

This December, we are challenging you to run 25 miles in the fight against MND. The money you raise will provide care and support for families affected by MND and fund vital research to bring us closer to finding a cure.

One of our committee members, Grant, who is 60 and rubbish at running! thought this challenge might help in keeping him moving in December and raising money for a fabulous cause. To support Grant as he takes on this fantastic challenge, please visit his gofundmepage:- https://gofund.me/7ffbf0e7

You can visit our Hertfordshire MNDA website at https://www.mndassociation.org/support-and-information/local-support/branches/hertfordshire-branch for more information, support and details of how you can help us. Grant would welcome anyone who would like to join him. Well done Grant good luck.

MND Association Grants

Did you know there are number of grant schemes available through the MND Association, none of which are means tested?

The grants are here to help you, and your loved ones, with everything from items to improve wellbeing and quality of life, to aids and adaptations not available through statutory means.

Grants are not just for the person living with MND but can also be for their carers and loved ones, including children.

The **Cost of Living** Support Fund is a one-off payment of up to £350 to help with household bills and food shopping costs and is available to people living with MND once in a 12-month rolling period.



Quality of life grant: up to £500 and can be used for items and services to help with wellbeing and quality of life. For example, some people use it to get complimentary therapies and massage, help with accessible taxi fares, or go on holiday.

Carer's grant: up to £500 and can be used similar to the quality of life grant to fund items and services which help carers' wellbeing. That can also be anything from a weekend away, pamper days to costs of hobbies and activities.





Children and young person's grant: up to £250 per child under 18. This can also be for hobbies, activities, or even a new Nintendo!

Care grant: This is up to £1500 for assessed needs which cannot be met by statutory services. This can be rental of a stair lift for example, help with ramping or towards a wet room. It's the only grant which needs a healthcare professional to submit, usually the OT.



The application process is very simple, and all the forms could be found on the MND Association's website. If you're not sure what you can apply for, or need help with the application forms, contact justine.cox@mndassociation.org or your Association Visitor

For more information on the grants, including full T&Cs and application limits, please visit www.mndassociation.org.

FUTURE MEETINGS FOR YOUR DIARY

Hertfordshire Branch Meetings - November no meeting.

Christmas Lunch - Friday 8th December 12.15am - The Three Horseshoes Hooks Cross, Watton at Stone, Herts SG14 3RY - 01920 830391

The Three Horseshoes is closed for refurbishment during January and February.

Monday January 29th - ZOOM MEETING ID - 841 789 6055 - PASSWORD 515616

February no meeting.

Monday March 4th - A G M -VENUE AND TIME TO BE ARRANGED. TANYA CURRY, THE NEW CHIEF EXECUTIVE WILL BE JOINING US.

Get Togethers - Box Moor Trust Centre, London Road, Hemel Hempstead HP1 2RE For those living with MND their family and carers - First Wednesday of each month - **2pm** - 6th December - 3rd January - 7th February - 6th March - 3rd April

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

Daytime Group - Zoom - 3rd Tuesday of every month - **11am to 12.30pm -** 21st November - 19th December - 16th January - 20th February - 19th March - 16th April

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

South East Carers Coffee & Chat - Zoom - Carers only - First Tuesday of each month - **11am** - 5th December - 2nd January - 6th February - 5th March - 2nd April

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

Evening Carers Group - Zoom - Carers only - Last Wednesday of each month-**6.30pm** - 29th November - 20th December - 31st January - 28th February - 27th March - 24th April

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

BRANCH MANAGEMENT COMMITTEE

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Herts

REGIONAL FUNDRAISER

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AREA SUPPORT COORDINATOR (ASC)

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MNDA HERTFORDSHIRE BRANCH WEBSITE

www.mnd.n-herts.freeuk.com

OUR EMAILS

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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.

Mon - Fri 9.00am - 5.00pm and 7.00pm - 10.30pm.