

# NW London Branch Newsletter - Spring 2023

## Message from Co-Chairs

Dear Readers

Welcome to our first newsletter in 2023. Did you see the recent BBC documentary on the fundraising challenges of MND patron Kevin Sinfield OBE? If you haven't had the chance to watch *Kevin Sinfield: Going The Extra Mile* yet, it is available on BBC iPlayer. What a hero!

### SAVE THE DATE- ANNUAL CONFERENCE

This year the MND Association will return to an in-person Annual Conference at the Leicester Marriott Hotel on **Saturday 1 July 2023**. This will be our first Conference since the start of the Covid-19 pandemic, and further details on the conference programme and how to register will be available soon. Please note this date in your diaries and we hope that you will be able to join us.

### SUPPORT MND CARERS

After the successful launch of our new priority campaign Support MND Carers, we are now entering the next phase. We are asking MPs to write to the Secretary of State for Health and Social Care to join our call for the Government to launch a review into the adequacy of, and access to, carer's assessments. To bring about significant change as soon as possible, please urge your MP to support our campaign. Contact us to find out how.

### COST OF LIVING SUPPORT GRANT

The MND Association has recently launched a new Cost of Living Support Fund to offer financial support to people with MND who are struggling financially during the current crisis. This is a one-off payment of up to £350 to help with household bills, which is available in addition to the £3,000 grant limit in each 12 month rolling period. For more information, please contact: [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

### NECK COLLARS

We have been approached by a PHD student who is researching bespoke neck collars for people living with MND using 3D technology. He is looking for volunteers to discuss their experiences with neck collars and to take part in a feasibility trial. Please contact Sarah if you are interested.

### VOLUNTEERING OPPORTUNITIES

The NW London branch is run entirely by volunteers and we are always looking for committed volunteers to join us. There are various roles available subject to your time and skills. Going ahead, will be shaking buckets at Tesco Extra in Willesden on 25 April. We also plan to book bucket collections at TFL stations. Please let Cheryl know if you'd like to join us or be added to our list of collectors or discuss volunteering opportunities.

We hope to see you at one of our summer events.  
With best wishes

*Cheryl & Sarah*

March 2023

## BRANCH CONTACTS

|                           |               |  |              |
|---------------------------|---------------|--|--------------|
| NW London Co-Chair        | Sarah Ezekiel | <a href="mailto:ezekiel.sarah@googlemail.com">ezekiel.sarah@googlemail.com</a>       |              |
| NW London Co-Chair        | Cheryl Stroud | <a href="mailto:cherylstroud@hotmail.com">cherylstroud@hotmail.com</a>               | 07855 750812 |
| Area Support Co-ordinator | Alli Anthony  | <a href="mailto:alli.anthony@mndassociation.org">alli.anthony@mndassociation.org</a> | 01604 800612 |

## Online Support Meetings



### NEW! Support Group - Lets Talk CHC

**Next online meeting: Wednesday, 8 March at 5pm**

**Future dates:** sessions take place on 2nd Wednesday of the month at 11am: 12 April, 10 May

Join our peer support group for people with MND wanting to understand more about the process of obtaining NHS Continuing Healthcare (CHC), or are facing problems with an existing care package. The group is facilitated by our CHC Peer Support volunteers, and is open to people with MND and their family members across England. For more information and joining details, please contact [ahmed.abdeldayem@mndassociation.org](mailto:ahmed.abdeldayem@mndassociation.org)



### Recently Diagnosed Support Group

**Next session: Friday, 17 March at 2pm**

**Future dates:** 3rd Friday at 2pm: 21 April, 19 May, 16 June, 21 July, 18 August, 15 September, 20 October, 17 Nov, 15 Dec

**Online Group for newly diagnosed people living with MND.** If you or a loved one have recently been diagnosed with MND, you are invited to join this online support group. These small group meetings are facilitated by staff from the MND Care Centres and the MND Association. **Future dates:** 16 December at 2pm. Please contact [ahmed.abdeldayem@mndassociation.org](mailto:ahmed.abdeldayem@mndassociation.org) for further information.

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## Carers' Support Meeting

**Next am session - Tuesday, 7 March at 11am/ Next pm session - Wednesday, 29 March at 6.30pm**

### Future Dates:

**Am - 1st Tues at 11am:** 4 April, 2 May, 6 June, 4 July, 1 August, 5 September, 3 October, 7 November, 5 December

**Pm - last Weds at 6.30pm.** 26 April, 31 May, 28 June, 26 July, 30 August, 27 September, 25 October, 29 November, 20 December

**Online Group for carers of people living with MND.** Are you caring for someone living with MND? If so, you may wish to join this online meeting for a friendly supportive chat with other carers. For further info, please contact [alli.anthony@mndassociation.org](mailto:alli.anthony@mndassociation.org)



## NW London Support Meeting

**Next Session: Wednesday, 5 April at 11am**

**Future dates: 1st Wednesday at 11am:** 3 May, 7 June, 5 July, 2 August, 6 September, 4 October, 1 November, 6 December

**Online Group for people living with MND in NW London.** Our virtual meetings give you the opportunity to meet online other people living with MND in your area. These small group online meetings take place regularly and are run by our branch's Area Support Coordinators. For further information and zoom link, please contact [alli.anthony@mndassociation.org](mailto:alli.anthony@mndassociation.org)



## PMA-PLS Support Group

**Next session: Monday, 13 March at 5pm**

**Future dates:** April (tbc), 8 May, 12 June, 10 July, 14 August, 11 September, 9 October, 13 November, 11 December

Meet up online with other people living with or affected by PLS or PMA. For further information and zoom link, please contact [alli.anthony@mndassociation.org](mailto:alli.anthony@mndassociation.org)

## MND CONNECT HELPLINE

MND Connect helpline is available to anyone seeking information and support about motor neurone disease, linking you to a trained team within the MND. The hotline is live between 9am-5pm & 7pm-10.30pm and calls are free from landlines/mobile phones.

**Contact:** [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) | Tel: 0808 802 6262

## Summer Branch Events



## Summer Garden Party 2023

**Sunday 25 June, 2.30-5.30pm**

**Mo's Garden, 2 Prestwood Close, Kenton, Harrow, HA3 8JY**

We are delighted to invite you and your family to our annual garden party. This is an excellent opportunity to meet your branch members in the idyllic setting of Mo's garden.

There are no restrictions on numbers so do bring your family and friends. Children of all ages are welcome and there is plenty of space for them to play. The garden is fully accessible and will be weather-proofed with a marquee. As usual, we will provide home made refreshments and hot and cold drinks. There are no parking restrictions in the street, but please let us know in advance if you need priority parking or assistance with transport. There is no charge to attend but we do encourage donations to cover the catering costs. We will be fundraising by selling raffle tickets and cakes and there will be a tombola and raffle.

**RSVP:** phone or email Mo: mobile 07876 793012, email: [modunning@btinternet.com](mailto:modunning@btinternet.com)



## Wheels & Walkies / Walk 2 D'Feet MND

**Sunday, 3 September at 3pm**

**Hendon Park 17 Queens Rd, London NW4 2PN**

Last year we had a lovely walk through Hendon Park with our four legged friends and we raised over £500 on the day. We hope you will join us this year for a gentle stroll, followed by refreshments in the Park. Further details will follow. In the meantime, please save the date.



## Canalboat Trip

**October tbc**

We are currently finalising the date for the canal trip, which is a very popular fixture in our calendar. Further details will be in our next newsletter. Watch this space! **RSVP:** Mo Dunning: mobile 07876 793012, email: [modunning@btinternet.com](mailto:modunning@btinternet.com)