

## Welcome!



In this newsletter we report on our **Branch Activities**, which are hopefully returning to 'normal' after the COVID-19 lockdowns.

We look back on our Bushy Park Walk (pages 2–4) which was a very welcome reunion after such a long break. As ever, it was a fun day in lovely surroundings.

We are so looking forward to the next Open Meeting, our Seasonal Party, when Jeremy Vine will host one of his excellent Egghead quizzes. It will be great to be together again for what is always a very special event. **Please note the change of venue, and directions on page 5.**

In our **Fundraising** section (page 6), we summarise this year's fabulous fundraising efforts by our supporters and invite volunteers to help with the Paddington Collection.

In our **Care and Support** section (pages 7-8), we look at the different Support Groups and who they are for.

In **Campaigning** (page 9), we summarise National Office initiatives and seek your help for local action.



Find the Branch Facebook page by searching for West London and Middlesex MND or via  
<https://www.facebook.com/WestLondonandMiddlesexMND/>



Follow us on Twitter  
[@WL\\_MND](https://twitter.com/WL_MND)



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## West London & Middlesex Branch

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## Help Needed

The Branch is looking for volunteers in 2 specific areas:

**Fundraising** – to help us add another fund-raising event to our annual plan, and build support for our existing events.

**Campaigning** – to give local support to National Office activities and develop our own initiatives; by connecting with local MPs, Councillors, opinion leaders, influencers and others.

If you'd like to help, or if you'd like to know more, do get in touch with Kapish. We need you!

## Branch Activities

### Our Walk and Open Meeting

The Bushy Park Walk is a highlight of our year. This year's event was no exception. Held a bit later in the year than usual, it took place on Sunday 5 September. In our first get together since 2019, we were delighted to be joined by our friends and colleagues from the South London Branch who truly entered into the spirit of the day.

We all met at the Bushy Park Sports Club in Teddington where Nick Edwards greeted us and went through the various safety checks. We set off – on time – and made our way around the delightful Bushy Park. We were so lucky with the weather; it was sunny, but not too hot.

As well as our friends from the South London Branch, we were joined by Usman Khan, Chair-Elect of the MND Association and Ahmed Abdeldayem, one of our Area Support Coordinators. Ahmed entertained us all playing 78 rpm records on his gramophone, carried along on a 1950s pram. It was a great way to attract attention from passers-by.

#### A Lovely Lunch

Back at the Club House, we hugely enjoyed the COVID-safe lunch that Anne Hamerton and her team prepared for us, and which we were able to eat outside. Kapish organised the raffle draw and it was lovely to see many of the winners pass on their prizes to the younger attendees.

#### Diary Dates

**Open Meetings 2021**  
**Seasonal Party Sunday 5**  
**December**

**Provisional dates for 2022**  
**Open Meetings**  
**Sunday March 6th (AGM)**  
**Sunday June 5th**



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# Our Walk and Open Meeting

Kapish then gave updates on our Branch Activities and future plans to bring the formal proceedings of the Open Meeting to a close. Evelyn Hayward, Chair of the South London Branch, also said a few words, thanking people for their support and saying how much their branch had enjoyed taking part.

We then relaxed and enjoyed ourselves for a while longer before setting off home. All agreed that it had been wonderful to see each other in person after so long away.

The Walk is a truly fun event, but it has a serious side too: fundraising. We are delighted to report that between our Branch and South London, we raised more than £6,000.



### Contact Us

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## Our Walk and Open Meeting

### A Message from Kapish

'It really was wonderful to see everyone on the walk. I'd like to thank all those who helped organise it, especially Nick and Naomi – it's a huge job. A big shout out to Anne for organising the food and to Nikki Wadge who generously donated some super raffle prizes. Thanks also to the marshals and the many other helpers .

I do hope everyone will join us again next year for this very special event.

## Our Special Seasonal Party

### Save the Date: Sunday 5 December

We are looking forward to seeing you all at our Seasonal Party/ Open Meetings on 5 December. Join us for mince pies, cake, mulled wine, some tea or coffee, and that much missed catch up with old friends.

### MND Eggheads is Back

We are delighted to confirm that Branch Patron, Jeremy Vine, will once again host the fabulous MND Eggheads Quiz. Now that we are meeting in person, we will revert to the original competition format. We will invite you to form teams to display your knowledge of a variety of topics in the opening rounds. In the final round, the two leading teams select a representative for the thrilling head-to-head. Not to be missed!

### Time & Place: PLEASE NOTE NEW VENUE

The party takes place on Sunday 5 December at 3pm, but please note, we are no longer able to use St Paul's at Brentford as our meeting place. But we are pleased to say we have found another venue nearby for our Seasonal Party: St Faith's Church Hall, Brentford.

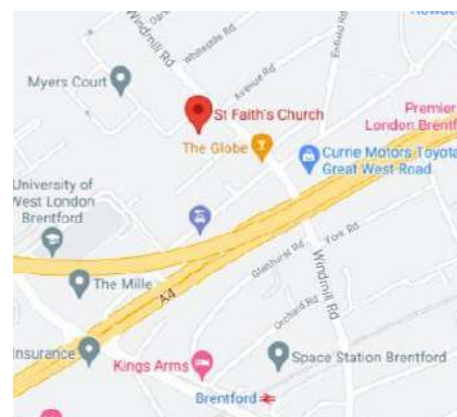
St Faith's offers equally hospitable facilities. There is plenty of space for us to enjoy our food and drink, chat, dance to live music and join in the quiz.

For wheelchair users, we can confirm St Faith's has step-free access. It also has a disabled toilet.

The address is:

St Faith's Church Hall,  
22 Windmill Road,  
Brentford  
TW8 9NA

It is just North of the A4. The E2 bus stops right outside. Car parking is available



### Regional MND Association Contacts

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## Our Special Seasonal Party

For further directions see <https://www.achurchnearyou.com/church/15510/find-us/>

COVID Safety: The venue is COVID safe and will be well-ventilated. Nearer the time we will also remind everyone of what measures we invite all those attending to take (eg mask wearing, handwashing etc).

### Fun for Everyone

Activities will be held throughout the afternoon for children of all ages, so do bring them along.

Thanks to Lisa Jain, Christmas cards will once more be on sale in aid of the Branch. There will also be a free raffle with prizes kindly donated by our helpers. Plus, we have heard that Santa might possibly put in an appearance, bearing yet more gifts. The fun will continue with dancing to live music performed by our friends, The Old Standards.

This really is a great event and everyone is welcome – carers, friends and family and, of course, people living with MND. If you are newly impacted by MND, or this is your first meeting, we understand you might feel hesitant about joining us. Please be assured, you will be very welcome. Our volunteers will be there to answer any questions, make introductions and help you feel at home.

To make it easier to organise refreshments (and gifts) could you let Anne know if you are coming and the age and gender of any children accompanying you. You can contact Anne at [annehamert@aol.com](mailto:annehamert@aol.com).

Of course, your safety remains paramount, and we will continue to closely monitor COVID-19. If we have to change these plans, we will let you know well in advance. Meanwhile, let's keep the date free and look forward to another special reunion. See you on 5 December!



### MND Association Benefits Advice Service

*Find out what benefits  
you are entitled to and  
how to claim them*

0808 801 0620

[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice) to

send an e-mail or start  
a web chat



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# Fundraising

Although our fundraising opportunities have been limited due to COVID-19 restrictions, our loyal supporters have stood up to the challenge. In total, we have raised a remarkable £7,600 this year. The Bushy Park Walk was a key event raising just under £3,300 and, as we reported in the last newsletter, Nisha Jain's head shave raised over £1,330.

Another fund-raising effort since the Walk has raised over £2000 for the branch. Nick Edwards, a co-founder of the Branch and an active committee member for over 27 years, recently did a 100-mile bike ride to celebrate a 'Big Birthday'. Instead of receiving presents, he asked family and friends to consider making donations to a JustGiving website (see below).

### An Excellent Effort

22 September looked as if it would be free from rain, so Nick headed south from Dorking. He met a friend at Cranleigh and the pair cycled southeast through Adversane and Steyning to the Sussex coast at Shoreham. After a stop for refreshments, they returned via Partridge Green and Rusper. At this point, Nick's companion made his way back to Guildford, while Nick carried on via Charlwood and Reigate to make up the remaining 35 miles. He made it back home after about 7 hours of cycling time.



Over the years Nick has run several marathons and half-marathons and completed other long distance cycling events. He says, "I've always felt lucky to still be able to do these events. It's a big psychological boost to know my efforts are raising money to help others who are less fortunate than me."

The Just Giving sites remain open for anyone who wants to donate. Do pass on these links to anyone you know who might feel like making a seasonal contribution – either to the Branch general site or to support the inspirational individual initiatives.

- Branch website: [www.justgiving.com/fundraising/westlondonmnda](http://www.justgiving.com/fundraising/westlondonmnda)
- Nisha's Headshave: <https://www.justgiving.com/fundraising/nishajain>
- Nick's Ride: <https://www.justgiving.com/fundraising/NickEdwards70th>
- Our Walk: [www.justgiving.com/fundraising/westlondonmndwalk2021](http://www.justgiving.com/fundraising/westlondonmndwalk2021)

Note: All amounts mentioned above include Gift Aid.



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## Paddington Collection

We are pleased to report that this important fundraising event is back on. The Branch will be collecting at Paddington Station on **Wednesday 8 December**, between **07.00 and 19.00**. We usually raise over £1000 on the day and this year we will have contactless terminals to capture donations from those who don't carry cash.

As well as collecting money, we will be displaying leaflets and banners at a table to help raise awareness about MND and the support available. This is a great opportunity for us and we really welcome your support. If you can spare a two-hour slot to help out, please let Naomi know - [WLMNDA@njneville.plus.com](mailto:WLMNDA@njneville.plus.com).

## Care and Support

The three Support Groups available to our Branch are going well with people very much welcoming the peer support on offer. Here's a reminder of what the different groups do:

**The London Carers Group** is dedicated to those who care for people living with MND. It is held on the first Tuesday of every month. Area Support Co-ordinator Lisa Burnard says, "This group continues to grow. It's well attended by 5-8 carers each month. Carers really value sharing ideas and information and we've had very positive feedback." This group is likely to continue to meet online (rather than in person) as this works well for carers who tend to be pushed for time. A WhatsApp group creates further connections between meetings.

**The North West & West London Support Group** is our local group for people living with MND and their carers. Between 4 and 8 people usually attend, with good representation from West London. Lisa says group members have very much welcomed the opportunity to share information and support among their peers in this way. Meeting online will continue over the winter.



### Diary Dates 2021

#### London Carers

**Group:** Tuesday 7  
 December at 11 am

#### NW & West London Support Group:

Monday 22  
 November at 11am;  
 Monday 20  
 December at 11am

#### Recently Diagnosed Group:

Dates to be  
 confirmed



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## Care and Support

**The Recently Diagnosed Group** covers London, Essex, Surrey and Kent. This too is very well attended and Lisa has had positive feedback from families who have been correctly sign-posted towards the help they need. As Lisa says, "Navigating the Health and Social Care system for the first time can be very daunting, so it's a real benefit to be able to offer this help." In the New Year, this group is going to be slightly re-vamped to focus on specific topics of particular interest to those recently diagnosed. Once they have received this initial support, members may then want to move on to their local group. Given the geographical area this group covers, it will continue to meet online rather than in person.

Contact Lisa for details on how to join these meetings by Zoom, or for further information. [Lisa.Burnard@mndassociation.com](mailto:Lisa.Burnard@mndassociation.com).

In addition to these group meetings, Lisa makes contact with branch members every few months to ensure they are OK, and remind them of the local support available. Our Branch Contact, Jenny Gadsby, is always on hand too.

## Emergency Grants Extended Again

Emergency grants are available to support people living with MND who are struggling with additional everyday living costs, such as grocery shopping or bills, as a result of COVID-19. The deadline to apply has been extended to 31 January, 2022.

The grant is up to £250. The simple application form asks the applicant to outline how COVID-19 has affected their income/finance. It can be completed on behalf of the person with MND. The process is simple, and grants are not means-tested. Use this [Application Form](#) and National Office will arrange payment via BACS transfer. To find out more about these grants, contact MND Connect.

**Branch is on Instagram**  
 Want to see the branch in action? Follow us  
 @mndwlandmiddx



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## Campaigning

The Association continues to campaign for people living with MND. You might have heard the news about **United to End MND** - calling for £50 million from the Government to fund a virtual institute for MND Research. It has been announced that this money has been secured. This is great news!

Work on two other key campaigns continues:

- **Act to Adapt** - pushing for more accessible homes and a fairer and faster system for delivering home adaptations for people with MND.
- [Champion the Charter](#) - calls on councils to adopt the MND Charter to help positively influence the lives of people living with MND and their carers in their community.

You can check out progress on all campaigns on the Association website:

<https://www.mndassociation.org/get-involved/campaigning/take-action/>

The Association very much depends on local branch members to help with contacting MPs, signing petitions, building awareness on social media, and more. You can help individually and please do so if you can. As we saw with **United to End MND**, such action really can make a difference.

We'd also like to do more in this area as a co-ordinated Branch activity. So, we'd love someone with a bit of time to spare to come forward and help us campaign as a Branch. If you'd be interested, please contact Kapish.

## Current campaigns

Find out more about our current campaigns for people with MND. You can also find out what we have been doing during the [COVID-19 pandemic](#).



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## Branch Contact

Jenny Gadsby, our Branch Contact, remains ready and waiting to hear from you. Jenny responds to enquiries from people living with MND, their family and friends. She can tell you all about our Branch activities and the local support available, as well as introduce you to the MND Association and the wide range of information and support it provides. You can contact Jenny by email ([gadsbyj@hotmail.com](mailto:gadsbyj@hotmail.com)) or on the dedicated Branch Contact number: 07879068870.

## MND Connect

MND Connect provides information and support for people living with MND, those affected by MND, carers and health and social care professionals. Whether you have a specific question, or just want someone to listen, the team is here to help.

MND Connect is available Monday to Friday between 9am to 5pm and 7pm to 10:30pm. Call **0808 802 6262** or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Receiving this Newsletter

If you would like to:

- Receive our newsletter and emails on a regular basis (and have not yet subscribed)
- Receive a printed copy of this newsletter by post (if you can't access it on a device)
- Unsubscribe from this newsletter and emails

Please email Ross: [communications@wlmnda.co.uk](mailto:communications@wlmnda.co.uk) with your request and giving your full name.

Would you like to share an opinion, letter, story, or idea with our readers?  
[allisonhmnd@gmail.com](mailto:allisonhmnd@gmail.com)

**Registered Charity No 294354. Registered address: Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR**



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