

**West London & Middlesex Branch**  
May 2020, Issue 110

## A message from Kapish Narda, our Branch Chair



As I write this, I am sincerely hoping that all the Branch members are staying safe and well. We at the Branch of course know that those affected with MND may be finding the uncertainty around coronavirus, and the resulting lockdown, particularly difficult. Please know that the West London & Middlesex Branch is very much here to help, should anyone affected need it. To that end, feel free to get in touch with any one of our committee members, or myself on [knarda.mnda@gmail.com](mailto:knarda.mnda@gmail.com).

Whilst we have not been able to have our usual Open Meetings (we saw our members last in December, at the Holiday Party), we are very much trying to keep things 'business as usual'. To that end, we have decided to hold our next Open Meeting (which will be the AGM) in June via Zoom, the easy-to-use video conferencing app. I would very much encourage you all to attend – especially as it is particularly comforting to see the usual faces, even if on a screen! (We'll tell you how to connect with Zoom nearer the time.)

Separately, we are also going to go ahead with our annual Bushy Park Walk in July – either in person like always, or a "Virtual Walk" where we all commit to do separate walks at a time or place of our own choosing and post a lot of photos in solidarity with the Branch! As the lockdown eases, we will confirm exact details.

Given the impact of the lockdown, we as a Branch are particularly focused on fundraising as the usual channels of raising money become less accessible. Indeed, as this is the Branch's 25<sup>th</sup> anniversary, we are aiming to add more events to the calendar, so do watch this space.

### **In this Newsletter:**

Find out more about our AGM on page 2 and our Walk on p3.

We are delighted to welcome Ross Marshall and Ilse Hoberman to our Committee. Meet them on p4

Our fund-raising activities are a little limited at the moment, but we report on some excellent recent efforts on p5 and p6.

We are planning more Carers' Group Meetings - find out more about these on p7.

The Association continues its vital campaigning activities to ensure people living with MND receive appropriate support. To learn more, see p8.



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)



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

**West London & Middlesex Branch**  
**May 2020, Issue 110**

## Branch Events and Activities

**Save the Date:**  
**Our AGM will be held on 21 June at 3pm**

Our AGM, postponed from March, is going ahead on 21 June – but with a slight difference. We are going to hold it by video conference, so everyone can join in from home. Even if the ‘lockdown’ is over by then we want to do our best to reduce risks, especially to those who may be vulnerable.

Proceedings will begin at 3pm and close at around 5pm.

As usual at the AGM, our Chair, Kapish will give his reflections on the past year and outline future plans. Then, our Treasurer, Naomi will present her financial report.

We are delighted to tell you that we will also be ‘joined’ by John Gilles-Wilkes and Lisa Burnard, from National Office. John is our Regional Delivery Manager and he will give a brief update on how the Association is responding to the many challenges presented by Covid 19.

John will also talk about the recent changes at National Office including the newly created roles.

One of those roles is the Area Support Coordinator (ASC), and Lisa Burnard, our new ASC will tell us more about her role too.

If you would like to ask any question about any of these items, they will be very welcome. You can email Kapish in advance, or you can send them on the day through the Zoom Chat function.



Zoom is quite easy to use, as many of us have been finding in recent weeks! You simply follow the link we send you, then you will be able to see all the presentations on your PC screen, phone or other device. But don’t worry if you aren’t familiar with it. We will be sending some guidelines nearer the time and will have someone available to answer any questions.

We do hope you will join us at the AGM, from the comfort of your home, perhaps while enjoying some tea and cake!

### Diary dates 2020

Open Meetings:  
 Sunday 21 June – by video link  
 Sunday 20 September  
 Sunday 6 December

Bushey Park Walk:  
 Sunday 19 July

Carers’ Group Meetings:  
 Tuesday:  
 16 June  
 21 July  
 18 August  
 15 September  
 20 October  
 17 November  
 22 December  
 7.15-8.45pm  
 Nb: Venue/Video link to be confirmed

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



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

## West London & Middlesex Branch May 2020, Issue 110

# Save the Date: Bushy Park Walk, Sunday 19 July

We don't know yet if the walk will go ahead in Bushy Park, so, we are planning two options: the walk as usual and, if that can't happen, a virtual walk.

### Our Usual Walk

We all meet at the National Physical Laboratory Sports Club in Teddington and the walk starts at 10:30. It follows a 4–5 mile circuit through the lovely Bushy Park. As well as chatting to fellow walkers, it's a great opportunity so spot the local wildlife.

After the walk, all enjoy a lovely buffet lunch. A raffle and words of thanks follow before all depart home. It is a truly great day – both socially and as a fundraiser – so let's hope it happens. If the Walk does go ahead, we will email you with all the usual extra details such as where to park, help needed etc.

### A Virtual Walk

The other option is to walk an equivalent distance in your garden, neighbouring streets or local park (if allowed). We are not expecting you to raise £millions like Cpt Tom Moore, but his fantastic achievement does show how generous people can be if you get them on board.

We hope you will be inspired to plan a virtual walk, taking care to avoid accident, injury or over-stretching yourselves. And of course, please follow social distancing and other guidelines.

If you do a virtual walk, we'd love to hear about it – and see any photos. Please contact our newsletter editor Allison Hill with your stories. [allisonhmnd@gmail.com](mailto:allisonhmnd@gmail.com)

### Seeking Sponsors

The walk – in whatever form it takes – is a great opportunity to raise vital funds for the Branch. A special JustGiving website has been set up for this year's Walk. Here's the link: [www.justgiving.com/fundraising/westlondonmndwalk2020](http://www.justgiving.com/fundraising/westlondonmndwalk2020) This as an easy way to get people to sponsor you. It also means we can collect an extra 25% in Gift Aid (where applicable). If you set up your own JustGiving site, do follow our Guidelines for Online Fundraising on page 6.

We'll let you know by mid-June if the walk will take place in Bushy Park. Meanwhile, think about a virtual walk and start getting those sponsors on board.



### Contact us

Kapish Narda  
Branch Chair  
Campaigns  
[knarda.mnda@gmail.com](mailto:knarda.mnda@gmail.com)

Ross Marshall  
Branch Secretary  
[communications@wlmnda.co.uk](mailto:communications@wlmnda.co.uk)

Naomi Neville  
Treasurer  
[WLMNDA@njneville.plus.com](mailto:WLMNDA@njneville.plus.com)

Emma Wilson  
Twitter  
[emmawilson.mnd@outlook.com](mailto:emmawilson.mnd@outlook.com)

Linda Tilley  
Carer Support Group  
[linda.tilley@outlook.com](mailto:linda.tilley@outlook.com)

Alexandra Harris  
Web pages  
[Alexandra.mnda@outlook.com](mailto:Alexandra.mnda@outlook.com)

Allison Hill  
Newsletter Editor  
[allisonhmnd@gmail.com](mailto:allisonhmnd@gmail.com)

James Haslam  
Newsletter Design & Layout  
[james.a.haslam@gmail.com](mailto:james.a.haslam@gmail.com)



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease



## West London & Middlesex Branch May 2020, Issue 110

### Introducing Ross and Ilse

We are delighted to welcome two new members of our Branch Committee. Here are some words from them both by way of introduction.

#### Ross Marshall



I started volunteering with the Motor Neurone Disease Association not long after I first moved to London in 2012. Before joining the Branch, I didn't have much of an awareness of Motor Neurone Disease. I knew of Stephen Hawking, and I had heard of Lou Gehrig's Disease (one of the American names for MND), but I have no personal connection to the disease.

It was my friend, and our much-missed former chair, Janis Parks who introduced me to both the Association and MND. She needed an extra person to help out at a bucket collection. outside a Tesco and I was happy to pitch in.

Since then, I've done plenty more bucket collections, marshalled walks, produced online resources for the Branch (and arranged more than a few chairs at meetings), all of which led me to joining the Branch Committee last year, and shortly thereafter becoming Branch Secretary. It's my job to write the minutes at our meetings, send out our communications, and to look after the Branch's personal data (and I'm still arranging chairs!).

Outside of the MND, I work for *Magic Bus UK*, an education and mentoring charity that works to help lift children and young people in India out of poverty.

#### Ilse Hoberman



I lost my father to Motor Neurone Disease last year, just 11 months after he was diagnosed. This made me very aware of the little freedoms we all take for granted, and I really wanted to put some of my experience to good use and pay it forward. Living in South Africa, my dad got support from the local MND Association in Cape Town, but as I have now lived in London for 20 years, I decided to volunteer with the West London Branch.

I am a member of the Branch Committee, and recently took on the new role of Carers' Champion. I will be finding and sharing local services and resources for carers of people living with MND.

I work as a manager in a large software company, and in my spare time I like to read, cook and make jewellery from semi-precious beads. I keep fit with Pilates and walking in the many wonderful parks we have in West London!

#### 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



We never lose hope. We strive to find a cure for MND  
and to support everyone affected by this devastating disease

## West London & Middlesex Branch May 2020, Issue 110

# Fundraising

## Far More Than a Token Gesture!

Janet Cole is one of our supporters and has a great record of raising money through the John Lewis and Waitrose Community Matters schemes. She recently raised an impressive £1000. Here's how.

Janet's sister was diagnosed with MND in 2012 and lived with it until April 2015. Janet spent a great deal of time with her sister during that period. She discovered our Carers' Group meetings which she found a major source of help and support. This prompted Janet to raise some funds and she came across the Community Matters Scheme.

Each local branch of John Lewis's or Waitrose selects three charities to receive support. A collection box for each charity is put in store – in the café or other collection point. When customers make a purchase, they can collect a green token and put it in the box of their chosen charity. Those charities then receive a donation in proportion to the tokens received. In Waitrose, three charities per month share £1000 and in John Lewis, three charities share £3000 over a three-month period.

### A Great Effort

Janet worked hard to get MNDa as one of the selected charities in her local branches of Waitrose. Twice, around £400 was raised at Waitrose in West Ealing. Then another £400 at the Chiswick store. But she didn't stop there.

Janet works at John Lewis, White City. Last year she proposed MNDa to be included in the scheme. As the final selection is made by the staff, Janet actively canvassed her fellow workers.

As she says, 'Lots of them had never heard of MND. When I explained what it was their faces dropped and they really wanted to help.' It worked. MNDa was selected and £1000 was raised for our branch.



Janet still hasn't stopped. Her next goal is to have MNDa selected by yet another Waitrose branch. Next on her list is either Putney or Richmond.

### How You Can Help

Any Waitrose customer can propose a charity. Simply visit the Customer Services counter at your local branch and fill in the Community Matters form nominating MNDa as your charity of choice. You can also write a letter, email

[Community.Matters@Waitrose.Co.UK](mailto:Community.Matters@Waitrose.Co.UK) or apply on-line. When John Lewis stores re-open, you can likewise apply through their Customer Services Department.

Janet adds that, if your nomination succeeds, do encourage all your friends to visit that Waitrose branch, in the month allocated, so they can put those tokens in the MND box. Let us know so we can promote it too.

**Thank you, John Lewis and Waitrose for your contributions, and Janet for your hard work!**



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

## West London & Middlesex Branch May 2020, Issue 110

### Further Thanks to Steve White

Steve White has recently donated £1,000 from the Frances White Online Tribute Fund.

This is in addition to all the monies raised from the sales of Frances's poetry book that we reported in the last newsletter. Thank you, again, Steve.

### Paddington Collection

Our collection date, scheduled for Thursday 25 June, has been cancelled. We hope to get a further slot later in the year or early next year.

## Guidelines for Online Fundraising

We are very grateful to everyone who raises money for the Branch. Many of you choose to do this via your own Just Giving or other online sites. To ensure the money comes through to the Branch, please follow these guidelines:

When setting up a fundraising page, identify the MND Association as your chosen charity. We have to inform the Association, so they transfer monies received from the site to the Branch. Please email Branch Treasurer, Naomi Neville ([WLMNDA@njneville.plus.com](mailto:WLMNDA@njneville.plus.com)) making it clear that you want the Branch to receive the money, and she will pass this on to the Association.

Don't forget to make it clear on your fundraising page that you are fundraising for the Branch. This is required by law. If you have any questions do call or email Naomi.

Funds raised are primarily used to provide practical help and support to people living with MND in our area and may also go towards research and other services. The Branch does not receive any funds from the MND Association or the State. The help we provide depends on the donations we receive.

## Care and Support

### 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)



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

**West London & Middlesex Branch**  
**May 2020, Issue 110**

## Carers' Group Meetings

We are keeping the dates of our Carers' Group Meetings in the diary and will hope to resume them person to person at our St Barnabas Church venue, once we know it is safe to do so.

This new venue was found for us by our long-standing supporter and committee member, Anne Hamerton. Anne has seen many times how beneficial these meetings can be. As she says, 'The meetings are a great opportunity for carers to share practical tips in a confidential environment where they can share their frustrations, fears and other feelings with people who are in a similar position.'

Until the meetings resume after lockdown, we are looking at alternative options, such as holding them by Zoom video conferencing. Depending on demand, connecting with Zoom is a possibility, at least for the next one or two meetings. Of course, video conferencing is not the same as meeting in person, but it can give people a chance to ask questions, share thoughts and generally stay in touch.

If you'd be interested in connecting by Zoom, can you let Kapish know: [knarda.mnda@gmail.com](mailto:knarda.mnda@gmail.com). If we do go ahead, we'll get back in touch to explain how it works.

## A Useful Resource

Don't forget, if you want to find out more about Coronavirus and MND, there's lots of information and advice on the Association's website at:

<https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/>

### Coronavirus Emergency Grant

In response to the coronavirus pandemic, we are currently offering a one-off emergency grant up to the value of £250. This is to help people living with MND who may be struggling with additional living costs as a result of coronavirus (COVID-19), such as food shopping or bills. We do not normally accept claims for equipment or goods before they are purchased, but we will consider these in the current crisis. This will be reviewed at the end of June 2020.

If you would like to apply, a simple form asks you to outline how COVID-19 has affected your income or finances. You can download the form here <https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/>

Would you like to share an opinion, letter, story or idea with our readers?

[allisonhmnd@gmail.com](mailto:allisonhmnd@gmail.com)



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease



## West London & Middlesex Branch May 2020, Issue 110

# Campaigns

The MND Association is working hard to get the Government to recognise the particular needs of people living with MND as it develops its response to Covid-19. As we mentioned in our recent email, the Association is advising everyone with MND living in England to [register as a vulnerable patient](#). The Government has said that people with MND can qualify under the 'severe respiratory conditions' sub-group on the self-registration list.

Check out the Association's website for latest news on this and other campaigns

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

## 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.

## Regional MND Association Contacts

**Regional Fundraiser - London and Thames Valley**

**Russell Spivey**

[russell.spivey@mndassociation.org](mailto:russell.spivey@mndassociation.org)

07872 161672

**Regional Delivery Manager**

**John Gillies-Wilkes,**

[john.gillies@mndassociation.org](mailto:john.gillies@mndassociation.org)

**Lisa Burnard**

**Area Support Coordinator, West London & Surrey**

[Lisa.burnard@mndassociation.org](mailto:Lisa.burnard@mndassociation.org)

01604 800658

Registered Charity  
No 294354.

Registered address:  
Motor Neurone  
Disease Association,  
PO Box 246,  
Northampton, NN1  
2PR



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease