

West London & Middlesex Branch
August 2020, Issue 111

Welcome!

Welcome to this newsletter. Although the format of our events is very different due to Covid 19, we are determined to continue our fundraising and care and support initiatives.

Our AGM went ahead on 21 June remotely – by Zoom. John Gillies-Wilkes was our guest speaker and gave an update on Association activities and introduced our new ASC, Lisa Burnard (see pages 2–3).

A key event was the wonderful quiz – also held remotely – hosted by Jeremy Vine and his daughter Anna. This is covered on page 4.

Our annual ‘walk’ went ahead on 19 July but, rather than us all meeting up in Bushy Park, we were all encouraged to hold our own walk or other fundraising event. This led to some inspired activities as you can see on pages 6–7.

We hope that you will join us in our future activities. Although it isn’t the same as meeting in person, these remote events really are a good way for us all to stay in touch.

Of course, you are also welcome to Contact Us at any time to share thoughts, ask questions or request support. On that point, we are delighted to announce that we now have a new Branch Contact, Jenny Gadsby. Learn more about Jenny on page 9.

Branch Contact

As Branch Contact, Jenny Gadsby responds to enquiries from people living with MND, their family and friends. She can explain how the Association supports people affected by MND, direct you to appropriate sources of information and tell you about our branch activities. You can contact Jenny on email (gadsbyj@hotmail.com) or through the dedicated Branch Contact number: 07879068870.



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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Branch Events and Activities

AGM, 21 June

This year our AGM was held remotely - for the first time ever - by Zoom. While using Zoom means we miss out on seeing people in person, it does give an opportunity for those from far away to join us. So, we were delighted to welcome Emma Wilson, now living in the USA.

Branch Chair, Kapish also welcomed Jenny Gadsby our new Branch Contact, Sophie Stribling our new AV and Lisa Burnard from National Office, our new Area Support Co-Ordinator. Kapish expressed heartfelt thanks to all the volunteers who support the branch in so many different ways.

He then gave a quick overview of Association activities including its 22 care centres, the benefits and advice service and MND Connect, plus its ongoing initiatives in awareness raising and campaigning and the vital research programme.

At branch level, Kapish outlined the monies raised and different types of local support given last year and set out our future plans. These are covered in more detail in this newsletter.

Financial Report

Our Branch Treasurer, Naomi Neville, presented her fundraising report, thanking everyone for their generous efforts and financial contributions.

Our fundraising

2019 Income - £34,061

- Bushy Park Walk - £5,500
- Paddington collection - £1,285
- The Reid family - £800
- In memory of Frances White £1162
- In memory of Janis Parks £20,600 – for a special project
- and other individuals and companies gave generous donations

We have given financial support in the form of 14 grants totalling £5,300. Naomi emphasised that further grants are available if people want to apply (see also p. 9).

Kapish also thanked everyone for their generosity, including the vital support from Branch Patron Jeremy Vine who makes such a difference in raising awareness and vital funds through great events such as the recent live Facebook Quiz.

National Office Update

Our guest speaker was John Gillies-Wilkes, Regional Delivery Manager, based at National Office.

Diary Dates 2020

Open Meetings:
 Sunday 20 September
 Sunday 6 December

Support Group Meetings:
 'For the time being these meetings will be held by Zoom. Dates of future meetings to be confirmed.

Fund-raising:
 Paddington Collection:
 Wednesday 16 December

Branch is on Instagram

Want to see the branch in action? Follow us
@mndwlandmiddx



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AGM, 21 June

John spoke of the challenges presented by Covid 19 and the efforts being made to support people living with MND and their carers, and to work within the changing health and social care landscape. As visiting people living with MND became impossible, National Office embarked on a new approach: contacting everyone by telephone. Aided by volunteers, 4,000 people have been contacted nationally to offer advice and support. Virtual support groups for carers are also being set up; these remote ways of communicating are likely to continue as an effective supplement to in-person meetings.

Other challenges have been an inevitable reduction in fundraising and the need to furlough a proportion of staff. Despite these difficulties, everyone has been pulling together to maintain the best service and support possible. These new systems are likely to be in place long term as the Association plans to err on the side of caution given the vulnerability of those living with MND.

John also explained the recent changes in roles at National office.

The Regional Care Development Adviser (RCDA) and Volunteer Development Co-ordinator (VDC) roles have been converted into 2 new roles.

The Area Support Coordinator (ASC) provides 'hands on' support for those living with MND, working to meet their needs; this includes liaising closely with AVs, branches and others. From the Branch's perspective, the ASC provides a 'one-stop-shop' support point for members and volunteers alike.

The Service Development Manager works with local service providers and deals with particularly complex issues for people affected by MND.

We then met Lisa Burnard, our new ASC. Lisa also emphasised the importance of the online virtual groups for carers. A monthly pan London group is being trialled and Lisa hopes they will be well attended. Following these highly informative presentations, Kapish then brought proceedings to an end by asking everyone what they were looking forward to, post Lockdown. 'Haircuts' and 'Being with people' featured strongly!

Contact Us

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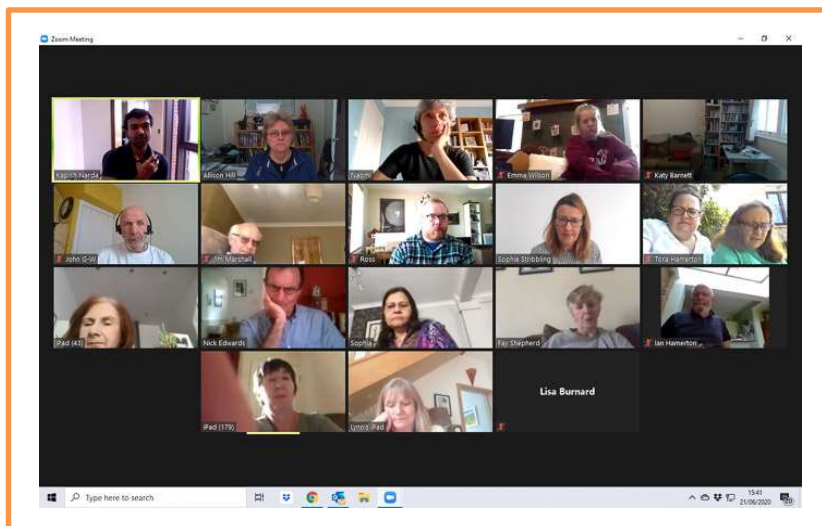
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Save the Date: Sunday 20 September

Our Next Open Meeting

Do join us for our next Open Meeting. As we did for the AGM, we are holding this by Zoom. Although we will not be able to meet in person, the Zoom format does give us a chance to see each other, ask questions, exchange views and get updates on what the Branch and Association are doing. We also hope to have a guest speaker and this will be announced soon. We do hope you will join us.

We will send out instructions for joining on Zoom nearer the time. Should you prefer to listen to the meeting by phone we'll provide a number for that too. If you haven't used Zoom before don't be put off. As well as the instruction we'll send, our Carer's Champion Ilse Hoberman is happy to talk anyone though the process of setting up Zoom and joining meetings. Just email Ilse to fix a time to talk.

ilse.hoberman@gmail.com.

Fundraising

A Fun-filled Quiz

Those of us who have had the pleasure of attending Branch Patron Jeremy Vine's quizzes at our Christmas parties will know what great events these are.

We wanted to mark this year being the 25th Anniversary of the setting up of the branch. Jeremy was keen to help, but the Lockdown was an obvious challenge. Then the idea of a remote quiz game was suggested. Perfect.

Russel Spivey and Richard White from National Office did a great job behind the scenes pulling it all together and on 15 May Jeremy and his daughter Anna held the quiz on Jeremy's Facebook page.

This great double act ran the quiz live on camera from 7-8pm. Jeremy began by introducing the Association and inviting participants to make donations to the MNDA. Then the quiz began.

 motor neurone disease association

 **LIVE QUIZ NIGHT**

HOSTED BY JEREMY VINE

7PM - 8PM
FRIDAY 15 MAY

JOIN IN LIVE
[FACEBOOK.COM/THEJEREMYVINE](https://www.facebook.com/thejeremyvine)

Raising money for the MND Association and
the Association's West London & Middlesex Branch.



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 to
send an e-mail or
start a web chat



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Huge Support

The quiz was 6 rounds with 5 questions per round. The first 4 rounds were multiple choice on Islands, Tech, People, and Fun and Games. Things then got harder with questions ranging from General Hannibal to Herman's Hermits. The final round was on flags – a favourite topic for Jeremy.

The quiz was fun rather than a competition, so participants kept track of their own scores as Jeremy and Anna took it in turns to pose the questions and provide the answers. There were lots of fun interactions as people used the Comments function to report their scores, remember loved ones, and ask for shout outs. This created a lovely atmosphere, helped by the banter between Jeremy and Anna.

The quiz attracted a total of 1400 comments and 27,000 views which shows how well it went.

You can relive the event on Jeremy's Facebook page:

<https://www.facebook.com/thejeremyvine/videos/281945373200836>]

Participants' contributions were split between the Association and our branch. We are delighted to report that this amounted to nearly £2000 coming to the branch. Huge thanks to Jeremy and Anna for your wonderful support. We are delighted to confirm that both Jeremy and Anna will be hosting the Eggheads Quiz for our Branch Christmas Party – truly something to look forward to!

A Close Shave

Another inspired fundraising effort was by Mohit Jain who raised £500 through the Great British Shaveoff on 28 June. Mohit decided to do this to mark the easing of lockdown and raise money to be split between the Motor Neurone Disease Association and Bowel Cancer UK. As Mohit put it at the time, 'To add some jeopardy my beard will go first, if I raise more than £500 I will shave my head and if I can raise more than £750 the eyebrows will get it....' When Mohit found himself £75 short of his target, his brother Romit donated the difference. Mohit's daughters then did their bit by helping to shave off his eyebrows. Well done Mohit – and family!



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Our Annual 'Walk'

On Sunday 19 July our annual Bushy Park Walk went ahead, but not as usual. As we weren't able to meet due to Covid 19, walkers were encouraged to cover the 5-mile distance nearer to home or engage in a fundraising activity of their choice. As ever, you rose to the challenge.

The Jain family have been supporters of the branch since 2003, after Savita's husband Omprakash was diagnosed with MND. (Sadly, he passed away in March 2013). Savita joins our Walk every year and this time invited her daughter-in-law Lisa, and Lisa's daughters, Sophia and Maya, to go with her. They walked through Elthorne Park and along the River Brent and Brentford Canal. With stops along the way, for the girls to see ponies and Maya to climb trees, they covered 9.8 kilometres in 2 hours.

Sticking with tradition, Savita ensured everyone had refreshing watermelons along the way and a buffet lunch on their return. As Savita says, 'We really enjoyed the day, but we did miss the whole atmosphere of our annual walk, with everyone there together.'



Savita, Lisa and Maya enjoying the walk

Others selected an alternative form of exercise. Never one to miss a challenge, Jim Marshall replaced the walk with a virtual cycle ride using an indoor cycling app called Zwift. As Jim describes, 'On the day of the walk, without leaving my kitchen I undertook a virtual stage of the Tour de France. Along with 2,619 of my closest friends from all around the world, we cycled up Mont Ventoux. The ride was 19km long and I climbed 1,476m at an average gradient of nearly 8%. It took me 1 hour 52 minutes. Walking round Bushy Park is much easier!'

Another keen cyclist, our long-standing committee member, Nick Edwards cycled 100 miles in a day and generously matched the first £200 raised with an equal amount.

Others did the walk around their gardens or locally, and many showed their support with generous contributions to the Just Giving page set up for the walk. If you'd still like to contribute here's the link: www.justgiving.com/fundraising/westlondonmndwalk2020



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Our Annual 'Walk'

The Hamerton Marathon Pentathlon

Anne Hamerton describes her family's Walk Day.

July and no MND sponsored walk!! For only the second time in over 20 years. What could we do instead? How about 5 different events to test each of the 4 of us? If we could take part for 12 hours it would be a marathon! And so, the "Hamerton Marathon Pentathlon" came into being.

At 7am, in the rain, the four of us, Victoria (Branch tea lady), Beth (assistant tea lady), Ian (my husband) and I, set up to walk, read, knit, cycle and hula-hoop until 7pm. Fortunately we have a large front garden where people walk past regularly, which we decorated with posters and balloons to attract attention, and advertised on social media.

Ian, the most active in the family, found the knitting the most difficult but managed several rows of stocking stitch. His son-in-law thought it was worth paying, just to see that! We borrowed a cycle trainer to cycle on the spot. Only the walking involved leaving the garden, which we did two at a time. We walked around the locality, wearing blue and orange wigs to attract more attention. Beth was champion hula-hooper - the rest of us improved as the day went on, but nobody else quite got the hang of it.

The weather was kind to us, not too hot and no more rain. Friends and neighbours came by to chat, share the home-made biscuits provided by my sister – and put money in the buckets.

The time seemed to go quite quickly. At 7pm we stopped and counted up. Along with the Just Giving donations, we raised nearly £1000 – a super sum and a good time was certainly had by all!



Whether you walked, ran, cycled, knitted, or contributed in any other way, very many thanks. Let's hope we can all meet again for our annual walk next year, in Bushy Park!



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Paddington Collection

Save the Date: 16 December

Our collection at Paddington Station, originally scheduled in June is now going ahead on 16 December – at least we hope so! This is a great time to attract the attention of Christmas shoppers and others in a festive spirit of generosity.

As well as collecting money, we will be displaying leaflets and banners at a table to help inform people about MND and the support available. This is an excellent opportunity for us, both to raise awareness and funds. If you can spare a two-hour slot to help out, between 07.00 and 19.00, please let Naomi know - WLMNDA@njneville.plus.com.

We will of course keep an eye on the Covid 19 situation and will only go ahead with the collection if we are advised that it safe to do so.

Thanking Naomi!

Central to our fundraising activities is our Branch Treasurer, Naomi Neville. National Office has recently recognised Naomi's 5 years of service. As our Chair Kapish says, 'We are incredibly lucky to have a Treasurer like Naomi. We are all very grateful to her for her huge efforts over the last five years.'

Care and Support

As mentioned in the report on the AGM, staying in touch with people living with MND and their carers has been a priority for the Association. Many initiatives are underway to deal with the current challenges, both at national and local level.

Our new Area Support Co-ordinator, Lisa Burnard, came on board in March and has been busy making contact with people to find out what support they need. She has been keen to set up virtual support groups, including trialling a monthly pan London Carers' Support Group. This offers time for carers of people living with MND to have a virtual cup of tea and friendly chat.

At a local level, the branch organises monthly support meetings too, led by our new AV Sophie Stribbling. For now, these will also be held remotely, by Zoom. To find out more about these groups, and how to join in, do contact Lisa (lisa.burnard@mndassociation.org) or Sophie (slstribbling@outlook.com).

Would you like to share an opinion, letter, story, or idea with our readers?
allisonhmd@gmail.com



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Grants Still Available

Emergency grants are still 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. Grants can be applied for until 31 October 2020. Use this [Application Form](#) and National Office will arrange payment via BACS transfer, rather than sending cheques. The process is simple, and these grants are not means-tested. To find out more contact National Office Support Services via [email](#) or call 0808 802 6262.

Quality of Life Grants, Carers' and Young Persons' Grants remain available too. As an example, the money could be used to fund a laptop, counselling sessions or a short break. You can apply direct to the Branch. A Health and Social Care professional can apply to National Office for an MND Support (Care) Grant which could fund the full cost of a piece of equipment or service. For more information and application forms go to: <https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/>

Find Out More

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/>

There is also a new webpage on [Bereavement support](#)

Regional MND Association Contacts

**Regional Fundraiser -
London and Thames Valley**
Russell Spivey
russell.spivey@mndassociation.org
07872 161672

Regional Delivery Manager
John Gillies-Wilkes,
john.gillies@mndassociation.org

Lisa Burnard
**Area Support Coordinator,
West London & Surrey**
Lisa.burnard@mndassociation.org
01604 800658

Our New Branch Contact

We are delighted to report that our new Branch Contact is Jenny Gadsby. Here are some words from Jenny by way of introduction.

I came to the MND West London Branch very shortly after it was set up. I met Janis at a drinks party, and she told me about it. I was happy to get involved in giving benefits advice and filling in forms. I also came to meetings and Janis and I became good friends.

I was a qualified social worker and, during a long career, I worked in a psychiatric hospital, then a general hospital, then in a school for children with physical disabilities and serious medical conditions. For a few years I worked in the field of adoption and long-term fostering.

I loved my work and found similarities between muscular dystrophy, which a number of the children I knew lived with, and motor neurone disease.

I'm now looking forward to carrying on this connection as Branch Contact.



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Campaigns

Due to Covid 19 our local campaigning activity has been limited. When circumstances allow, we aim to work further with Ealing Council on the implementation of the MND Association Charter and to persuade Hillingdon council to adopt the Charter.

Meanwhile, the Association remains active. A key current campaign is 'Support MND Carers'. This aims to ensure that both national government and local authorities address the needs of unpaid carers: via financial support, ensuring ease of access to food supplies and PPE, plus other needs arising due to Covid 19.

The 'Scrap 6 Months' campaign continues and is now in its second year. It aims to ensure that people living with a terminal illness, such as MND, can claim benefits without the current time constraints.

See the latest news on these and other campaigns here:

<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 with your request and giving your full name.

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

Registered Charity

No 294354.

Registered address:

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



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