

West London & Middlesex Branch
February 2020, Issue 109

Branch News and Events

In This Edition

Welcome to our first newsletter of 2020. In this issue we look back on recent branch activities and look forward to this year's key dates.

See the photos of our heart-warming seasonal party on pages 2 and 3.

We are looking forward to reviewing the past year at our next Open Meeting on Sunday 15 March. We will be joined by MND Association Regional Head, John Gillies-Wilkes, who will be updating us on recent events. For full details see page 4.

Our chair, Kapish Narda shares his perspective on branch plans and priorities on page 5. We are keen to get your feedback on our activities and we are still looking for volunteers!

Further dates, fundraising events and ideas, hints and tips on equipment, and lots of other useful information can also be found in this newsletter. This newsletter is your newsletter, so do tell us what you think of it and if we are missing things you'd like to hear more about.



Our Seasonal Party

 Find us on
Facebook

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



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Our Special Party!

Our Seasonal Party took place on Sunday 1 December and we were delighted to see such a good turnout. As usual the venue was St Paul's Church in Brentford; the room looked fantastic, all lit up to set the seasonal spirit.

Once everyone had arrived and settled in, Kapish welcomed us to this special annual event. He went on to extend warm thanks to all those who had helped with fundraising during the year, as well as the committee members, the wonderful AVs, the Association's Regional Contacts and many others.

With the formalities over, it was time to party. Once again, we were delighted to be entertained by Keith Lawrence and his excellent band of musicians and singers. They set a cheerful tone to the proceedings right from the start and throughout the afternoon. Their 'Have Yourself a Merry Christmas' had many humming and smiling broadly. It's become our favourite finale from this great group.

Our Quiz

Unfortunately, due to the general Election, Jeremy Vine was unable to make the party this year, so Nick and Naomi kindly stepped in to run the quiz. We are grateful to Simon Edmands, Chair of the East Surrey Branch who kindly supplied the questions.

The intriguing selection covered diverse topics including 'Name the Year' and 'TV Relatives' with a photo round on 'Dingbats, Famous People, Logos and Films'. Something for everyone!

Naomi took on the task of asking the questions and eight teams enthusiastically discussed their answers. These were then marked by Nick and Naomi – quite a job – and the winners announced. Well done to the winning team: 'Tinsel Town', otherwise known as the Jain family, and not to be confused with 'Tinsel Team' who thought they had won for a few brief moments! The 'Band' and 'The Hopefuls' tied for second place. It was a valiant effort by all. Nick and Naomi did a great job, and as Naomi said, 'It made us really appreciate how hard Jeremy and Anna worked last year!'

A Special Visit

As ever there was an excellent array of snacks donated by committee members and others and served by Tora and Beth. The adults received some delicious edible gifts and the children each had a present from Father Christmas who managed to find time to pay us a very welcome visit. Our 'Free Raffle' prizes were an added bonus for the lucky winners.

Lisa Jain supplied an excellent selection of Christmas Cards to be sold in aid of the Association.

Diary dates 2020

Open Meetings:

Sunday 15 March
 Sunday 21 June
 Sunday 20 September
 Sunday 6 December

Bushy Park Walk:

Sunday 19 July

Paddington Collection:

Thursday 25 June

Carer's Group Meetings:

Tuesday:

18 February
 17 March
 21 April
 19 May
 16 June

7.15pm – 8.45pm

Please note change of venue:

St Barnabas Church,
 Pitshanger Lane W5 1QG.
 Entry via the back door, in
 Denison Road The meeting
 room is up a short flight of
 stairs.



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Our Special Party!

Lisa sells the cards both at our Open Meetings and through a charity shop – this year that has amounted to a profit for the branch of just over £400. Steve White attended too and sold more copies of Frances White’s wonderful poetry collection ‘Dandelion Child’.

Kapish brought proceedings to a close with season’s greetings and best wishes for 2020. He also invited feedback from everyone on how we can further improve our communications and other services. For more on this ongoing review see Kapish’s article on page 5

Many thanks to both Lisa and Steve for your great efforts!

Contact us

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



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Save the Date

Our Branch AGM

Do come along to our AGM on Sunday 15 March. One of our quarterly Open Meetings, the AGM is the time when we reflect on our branch activities over the past year and plan for the next. Branch Chair, Kapish Narda, will be sharing his thoughts and plans then Treasurer, Naomi Neville will present the branch accounts for 2019. We would very much welcome your views and ideas as well.

After a short break, we will be joined by John Gillies-Wilkes who is head of the East Region at National Office. John will explain all the changes he has been closely involved with over the past year; these are aimed at extending and improving the services provided by the Association. He will take us through the new care and volunteering structure and introduce us to those new team members already in place. This is a great opportunity to ask questions and give feedback.

Of course, our Open Meetings are also a chance to relax, chat and enjoy some snacks. That will all be happening too.

We do hope to see you there.

Date & Timing

Sunday 15 March

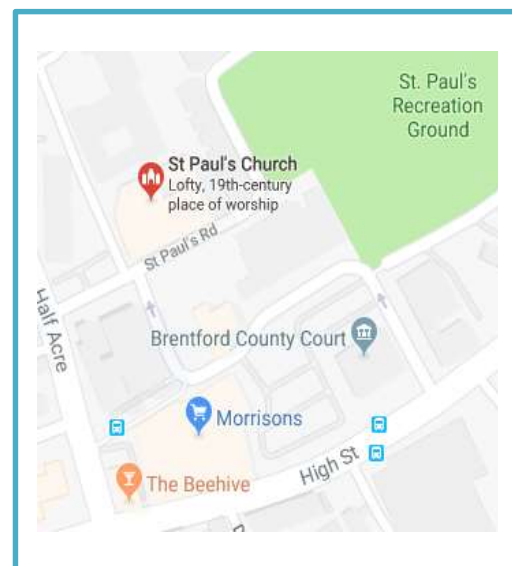
3pm: AGM starts

Not before 4pm: Our Guest Speaker

Followed by refreshments, support and catching up.

Venue

St Paul's Centre, St Paul's Church, St Paul's Road, Brentford TW8 0PN
 (parking in local roads).



All Are Very Welcome

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.

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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Looking Ahead



Our Chair, Kapish Narda sets out his thoughts:

This summer, the West London & Middlesex Branch will be celebrating its 25th anniversary. The branch was founded to provide support to individuals and families affected by motor neurone disease (MND). The branch – run entirely by volunteers – has been heavily involved in providing one-on-one assistance to people with MND, spreading awareness, raising funds for the Association, and campaigning with local and national bodies to shape policy and decision-making.

It's a team effort

I began volunteering with the branch about four years ago, when Janis Parks, our former Chair and one of the co-founders of the branch, brought me on as a volunteer. Janis' vision was an

inclusive one where new branch members were as welcome as long-standing ones – all motivated to come together to make a difference and provide a supportive environment for those living with MND.

As we take stock and look ahead to the coming years, our first priority is to continue the work done by the branch over the last two decades and a half. One of the ways to do that is to ensure that the branch reaches out to more people in West London. There are many who have been recently diagnosed, or have already been living with MND, but who don't know about the branch and the support it can offer. We would like to change that.

Communications

Over the last 12 months the committee has been discussing ways to make our communications more effective. Three areas of focus that have come up are:

- (i) better interaction with GPs, who in turn can ensure those with MND know about the local branch;
- (ii) seeking out regular feedback from our newsletter (so when you are done reading this article, please let us know what you think!); and
- (iii) coordinating our social media presence across Twitter, Facebook, and Instagram.

Luckily, National Office, as always, has been more than ready to provide us with relevant advice and technical help.



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Looking Ahead

Fundraising

Another priority for the branch would be to have in our calendar another smaller fundraising event apart from the Bushy Park Walk (which is the key fundraising event for us) and the Paddington Collection. Our fundraising efforts allow us not only to support the Association at national level, but also to help out local individuals and carers with support grants, thereby directly improving their quality of life.

We are thinking of perhaps an annual pub quiz, a charity talk, or raffle. Personally, I love even small initiatives, like Amazon Smile (see below on page 7).

We welcome ideas from our members on fundraising events: what would you like to do?

All of this, however, is only possible with the support of the branch committee members, who have been nothing short of fantastic in taking up all responsibilities seamlessly – This goes for those who co-founded the branch and those who came on board only last year! So, if you would like to help us with our mission, please do reach out to us (you can contact me directly!)

Regional MND Association Contacts

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Fundraising

Save the Dates

Here's an early reminder of our two important fund-raising dates planned for this year. We'll give more information nearer the time. We'd love you to join us, so do put the dates in your diary:



Paddington Collection, Thursday 25 June – We will be collecting at Paddington station again this year. As well as raising funds, this is a great opportunity to raise awareness of MND among the wider public. Could you be one of our collectors?

Bushy Park Walk, Sunday 19 July - The walk is around 5 miles long, is wheelchair accessible and will take its usual route around the lovely Bushy Park. It will be followed by an afternoon of fun events, including a well-deserved lunch, and a raffle. The walk is a hugely enjoyable day and an excellent opportunity for those who wish to raise some funds or support us in other ways. If you are interested in either event – or have any questions – do contact Naomi - WLMNDA@njneville.plus.com

Try Amazon Smile

Do you buy books on Amazon? If so, and if you sign up to 'Amazon Smile', Amazon will donate 0.5% of the net purchase price* to your chosen charity. You can now make the



MND Association your charity of choice to receive these donations when you buy on Amazon.

The process is simple. To set it up, go to smile.amazon.co.uk. Follow the prompts and fill in the box to say that the Motor Neurone Disease Association is your chosen charitable organisation. Or, if you go to this link, it should do that automatically: <https://smile.amazon.co.uk/ch/294354-0>.

Then carry on shopping as normal and the donations will be made whenever you shop on Amazon Smile.

These donations go to National Office rather than your local branch; it's a great way to add to those vital funds without it costing you anything. To find out more, see this page on the Association website: <https://www.mndassociation.org/get-involved/fundraising/amazonsmile/>

*The net purchase price excludes VAT, returns and shipping fees and applies to eligible purchases. Amazon does not charge any admin costs for this. For full details see their website: <https://smile.amazon.co.uk/about>



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A Unique NHS Service Available to MND Patients in London

Coordinate My Care (CMC). CMC is an urgent care planning service, and at the heart of it sits a digital care plan created by you together with your GP or hospital team.

This plan can be viewed by all the healthcare professionals involved in your care, but most importantly by all the urgent care services, NHS 111, London Ambulance Service and Out of Hours GPs.

The care plan is designed to be the important 'headline news' a clinician or paramedic would need to know about your condition especially in the out of hours periods like evenings, nights and weekends, where your regular team might not be available.

The plan *includes important information about your illness, how and where you'd like to be cared for and who to contact in an emergency and makes sure your wishes are considered by everyone who will be looking after you.* This means that everyone involved in your care will know what you need and what you want, which will give you the reassurance that everyone is on the same page.

As an organisation representing the needs of people living with MND, we feel this type of service could really benefit them on a day to day basis and in an emergency or urgent care situation.

There are two ways of creating a CMC care plan.

1. **ONLINE:** You can go to the CMC website www.coordinatemycare.co.uk and click on my CMC. You will be able to start your own plan; a short video will guide you through the process. Then your GP or hospital key worker can complete the plan with all your medical details. Once it has been completed and approved the plan is immediately accessible to all the urgent care services.
2. **WITH YOUR DOCTOR OR NURSE:** You may prefer to ask your doctor or nurse to create a CMC urgent care plan with you. If you wish to create a plan with your GP, please make an appointment and let the reception staff know that you are making the appointment to create a CMC urgent care plan. Similarly ask your hospital key worker for time to sit down, discuss and create a plan together.

Once your CMC care plan is finalised your clinician can activate the 'enrol' function so that you can view your CMC care plan, on your smart phone, computer or device of your choice. You can also make requests to edit details within the care plan, and give other people access to your plan.

To learn more about Coordinate My Care visit the website at www.coordinatemycare.co.uk.

If you have any further enquiries, please email www.coordinatemycare@nhs.net or

Tel: 020 7811 8513 Mon - Fri 9am - 5pm



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Hints & Tips

Those who eat slowly and find their food gets cold might be interested in one of these: the Soft Grip Keep Warm Thermo Plate, available from www.nrshealthcare.co.uk/



Thanks to Mandy Garnett for this tip!

Check Out the Forum

Another great place to find tips and share experiences is the MND Association Forum. It has a sub section dedicated to Equipment which is full of feedback on many different items used by people living with MND. If you have a recommendation to give, or a question to ask, do check it out. See: <http://forum.mndassociation.org/forumdisplay.php?19-Equipment>

Disclaimer: These are simply tips, to be used with common sense. Always seek appropriate professional advice before making any decisions that could affect you or others.

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

To Unsubscribe

No longer wish to receive this newsletter and our emails?

To unsubscribe, please contact Ross via email: communications@wlmnda.co.uk.

Please make sure you give your full name.

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



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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) 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.

Requesting Support from the Branch

The support we offer can include funding the full cost of a piece of equipment, service or quality of life item. We can also award grants to carers and young people directly affected by MND.

The range of items and services we can fund, and the amount awarded, is subject to MND Association guidelines. For more information go to www.mndassociation.org/getting-support/financial-support-information-for-people-with-mnd/.

Most items of equipment and adaptations require the recommendation of a health or social services professional. Please get this recommendation at the outset, not least to make sure it's right for you.

Other than in exceptional circumstances, we do not fund items retrospectively, or which health and social services are required to supply. So, do contact us before incurring any costs.

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



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