



Welcome!

Hello and welcome to our first newsletter of 2022. We very much hope this year will be a little different from the last 2 and that we can plan some enjoyable and rewarding events for the Branch.

We were very sorry to cancel the Seasonal Party in December but are pleased to say we are going ahead with our Spring Party on 13 March. We are so looking forward to being able to meet up in person again. Further details are on P.2, including directions on how to get to the new venue.

In **Fundraising** on P.3–4 we report on the Paddington Collection we held in December and look ahead to our wonderful annual walk.

Our Support Groups are proving popular, and another has started for carers who prefer to meet up in the evenings. Find out more about **Care and Support** on P.5–6.

Finally, on P.6. we give a quick update on **Campaigns** – and please note, we are still seeking a volunteer to help in this area.

Branch Activities

Our Spring Party

Some good news: our Spring Party is going ahead on Sunday 13 March. As we had to cancel our December Seasonal Party, we want to make this event a fun reunion. Our friends, The Old Standards, will be performing as we enjoy some food, drinks, and a chance to catch up.

We really hope you will join us. It will be a great opportunity for us a to get together in a safe space after so many months apart. As Branch Chair Kapish says, "We are keen to inject new energy into all our branch activities in the coming months. Our Spring Party is a wonderful way to get things started. I look forward to seeing you all on this special day."

(Continues on P.2.)

f Find us on Facebook

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



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Our Spring Party

Time & Place

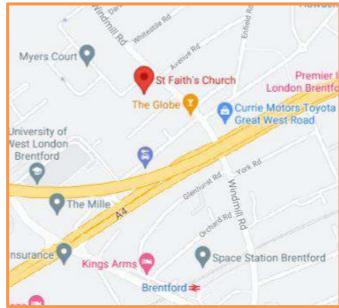
The party will start at 3pm

PLEASE NOTE THE NEW VENUE

As we have previously announced, we will now be holding our Open Meetings in a new venue: St Faith's Church Hall, 22 Windmill Road, Brentford TW8 9NA

St Faith's is just North of the A4. The E2 bus stops right outside. Car parking is available.

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



COVID Safety: The venue is COVID safe and will be well-ventilated. We will confirm the latest guidelines in our final reminder email.

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



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Regional MND Association Contacts

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Diary Dates

Open Meetings: 13 March, 12 June, 4 September and 4 December 2022



We Still Saw Santa



Santa's Message to West London MNDA

Despite our Seasonal Party being cancelled, we were able to pass on some Christmas cheer. Santa very kindly recorded a message especially for us which he put on You Tube. Our musical friends, The Old Standards, who have performed at many past parties, helped out too. They let us have a recording of 'Santa Claus is Coming to Town' which we emailed to everyone. Thanks to them all.

Fundraising

Paddington Collection

One of the few activities we were able to undertake last year was the Paddington Collection. On 8 December a group of loyal volunteers spent two-hour slots inviting donations from people passing through Paddington Station.

Due to COVID and the cold weather, it was much quieter than when we have held collections during the summer months. Wearing masks made it more difficult to make contact with potential donors too. But, despite these challenges, we raised £619.92.

(Continues on P.4.)



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Contact Us

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Paddington Collection

The day isn't only about receiving donations. We aim to raise awareness as well, with our table of leaflets and members on hand to answer any questions. Our wigs and tabards also helped us to be seen!

We might be at Paddington again this year, perhaps in warmer weather. If so, we'll be seeking volunteers.



Ross Marshall at the Paddington Collection.

Bushy Park Walk

Our walk remains one of our highlights and it was great to see it go ahead last year. As well as being a key fundraiser, the walk is a very special get together in lovely surroundings. We are currently busy making plans for this year's walk and we are hoping the South London branch will join us again to make it an even bigger and better event.

As always, we will let you know more details as soon as we have them.

Sad News

Last August we featured an article on David Peace and his fabulous efforts in raising awareness of MND and funding for research. David was diagnosed with MND in 2019 and sadly passed away in December. He will be very fondly remembered for his inspirational and tireless work.

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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!



Care and Support

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) or on the dedicated Branch Contact number: 07879068870.

Support Groups

These groups, for carers and people living with MND, continue to offer excellent support and are well attended. The groups we have previously reported on are:

• The Northwest & West London Support Group for local people living with MND and their carers.

• The Recently Diagnosed Group covers London, Essex, Surrey and Kent. It is for those who want to learn more about living with MND, and each meeting focuses on a separate topic.

• The London Carers Group is for those who care for people living with MND. It is held on the first Tuesday of every month and a WhatsApp group adds further opportunities to stay in touch.

For the time being, all meetings will continue to be held on Zoom. Contact Lisa for details on how to join the meetings, or for further information. (Lisa.Burnard@mndassociation.org)

As some carers have found it difficult to link up during the day, an Evening Online Carers Group has been set up; it meets on the last Wednesday of the month at 6.30pm on Zoom. To find out more about this group contact Alli Anthony (<u>Alli.Anthony@MNDassociation.org</u>)

Of course, support on a one-to-one basis is always available too. If you'd like to have a chat with someone, do get in touch with Lisa, or our Branch Contact: Jenny Gadsby.



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Diary Dates 2022

London Carers Group

1 March, 5 April, 3 May,7 June, 5 July, 2 Aug, 6 Sept, 4 Oct, 1 Nov, 6 Dec

Evening Online

Carers Group: 23 Feb, 30 March, 27 April, 25 May, 29 June, 27 July, 31 Aug, 28 Sept, 26 Oct, 30 Nov.

NW & West London Support Group: Dates TBC

Recently Diagnosed Group: Dates TBC

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



Financial Support

Don't forget that there are a number of ways you can seek financial 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 emergency grants of up to £250 to help people living with MND who may be struggling with additional living costs as a result of COVID-19 (for example, extra costs due to having home deliveries) are still available too, until 30 April.

We rarely fund items retrospectively, or which health and social services are required to supply, so, do contact us before incurring any costs. You'll also need a recommendation from a health or social services professional if you're looking for equipment or adaptations.

To find out more about the items and services we can fund, and how much we can give, see the MND Association guidelines here: https://www.mndassociation.org/support-and-information/our-services/financial-

https://www.mndassociation.org/support-and-information/our-services/finances/support-information-for-people-with-mnd

You are also welcome to get in touch with Naomi who coordinates all requests for funding from the Branch and is more than happy to help.

Campaigning

The Association continues to campaign for people living with MND. We had some excellent news in November when The United to End MND campaign finally secured a government investment of £50 million over five years for targeted MND research. This shows that campaigning really can make a difference.

Of course, other campaigns continue, including Act to Adapt which is pushing for more accessible homes and a fairer and faster system for delivering home adaptations for people with MND. You can check out progress with this and other campaigns on the Association website: <u>https://www.mndassociation.org/get-involved/campaigning/take-action/</u>

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 mentioned in our last newsletter, we'd really like to do more in this area as a co-ordinated Branch activity. If you could help us campaign as a Branch, please contact Kapish.

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

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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: <u>communications@wlmn</u> <u>da.co.uk</u> 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@mndassoci ation.org