

West London & Middlesex Branch

Annual Roundup

February 2025



Welcome

Welcome to our first Annual Roundup. We have decided to have one publication each year that highlights our past and planned activities and provides the background information, key dates and contact details that you might want to keep for reference. This replaces our newsletters. We will still send out regular email Roundups as reminders when key events approach and when we have news to share.

Here's what's in this Annual Roundup:

- Looking Forwards a message from Kapish on Page 2
- Recent Highlights including our Seasonal Party and other fundraisers and our Impact Report.
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- Fundraising in 2025 another fun WLQP Walk, Introducing Alisha and how we can help you fundraise. Pages 6–8
- Care and Support details on all the forthcoming Support Group Meetings and other support available. Pages 9–11
- Can You Help? could you be an AV or help with campaigning? Page 12
- Find Out More further sources of info, Contacts etc. Pages 13–15.



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



Looking Forwards - by Kapish Narda our Branch Chair

Hello Everyone,

Thanks for reading our Annual Roundup – we hope you'll find it informative and inspiring. Moving from periodic newsletters to Roundups reflects the changes we have made to our branch activities. As you know, we've moved away from 4 Open Meetings a year to having one or two main events. For plwMND and carers, the regular Support Group online meetings will, of course, continue and we will keep you informed about them in our regular email Roundups.

Focus on Fundraising

Another key activity is fundraising and this is the future focus for our branch. Fundraising is a great way to bring together members and supporters from across the West London and Middlesex area to get involved in a range of different activities. I'm delighted to welcome Alisha Pathania on board to help with these initiatives. Alisha is an experienced fundraiser and will, I'm sure, be a great help to us all. You can find out more about fundraising and read our interview with Alisha in this Roundup.

Our branch remains an important local hub for plwMND, their carers, families, friends and all our other members and volunteers. I'd like to thank you all for your support and hope we can continue working together in aid of this essential cause.

Wishing you all the best for 2025,

Kapish

Recent highlights

Our Seasonal Party





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More festive fun was had this year thanks to our great hosts Anne and Ian Hamerton. On Sunday 15 December, a friendly group of old and new faces spent the afternoon enjoying delicious food and each other's company. Anne and Ian's home is in Ealing and is the perfect venue for us all to meet. We thank them for their generosity and hard work – and all others who helped out too.

Walking with Pride



For the second year running the West London Queer Project used their Pride Month Celebration Walk to raise funds in aid of MND. The event took place on 8 June 2024 with everyone meeting at the picturesque Furnival Gardens in Hammersmith. Proceedings began just after 10 o'clock with welcome words from the highly entertaining drag queen Beary Poppins, event organiser Aubrey Crawley from WLQP, and local dignitaries including Councillor Patricia Quigley, the Mayor of Hammersmith & Fulham.

The gentle 10K walk then began, crossing Hammersmith Bridge and following the Thames Path along the south side of the river and ending at the Black Lion Pub in Hammersmith where all enjoyed drinks and burgers, and more great entertainment by Beary Poppins and the other fab drag queens.

Jim Marshall, Trustee of the MND Association, thanked WLQP for organising such a great event and paid tribute to Zoe Nixon who is living with MND and is the inspiration for WLQP's support.

As well as raising lots of awareness, the walk raised over £1,300, including Gift Aid.





Duchess Theatre

Ambi Devetta lost her dad to MND in 2019. As well as raising lots on the WLQP Walk, Ambi use her contacts to arrange a bucket collection at the Duchess Theatre in London. During the week of June 25, cast members from The Play That Goes Wrong held a collection that raised just over £2,000. So, huge thanks to Ambi and everyone at the theatre for another excellent outcome.

West London Strings



The MND Association was chosen as the charity of choice for the West London Strings concert held on December 8th. The concert took place at St Mary's Church, West Kensington at 4 pm. The concert had a maritime theme and included Elgar's Where corals lie', Boccheri's theme from the film 'Master and Commander' and 'My Heart will go on' by James Horner.

Our branch supporters Anne and Ian Hamerton and Alisha Pathania attended to help raise awareness and coordinate the collection. During the interval Ian said a few words about MND and the work of the Association and our local branch.

The concert was well attended with everyone enjoying a great atmosphere and some excellent music. The event raised over £750, split between WLS and the MND Association. Many thanks to all involved.





Further Thanks

We also say many thanks to our other generous supporters who have held dinners, coffee mornings and found other ways to support us throughout the last year.

Impact Report

Here's our impact report for 2024. It shows the importance of our fundraising activities and how these essential funds are allocated.

WLMNDA IMPACT REPORT 2024



Our 2024 Income - £ 9,479 (£2,0572 in 2023) Some highlights of our Branch fundraising and those who generously raised money for us; thank you all!

- Our London Walk and after party jointly with the West London Queer project
- · The Play That Goes Wrong Collection at the Duchess Theatre
- The Frances White Tribute Fund
- The Jain family fundraising events
- West London Strings Christmas concert

Our 2024 grant spend - £8,500 (2023 - £6,000) on full or part funding of support grants for plwMND and carers, young persons and Cost of Living grants. (National Office budgets are used to fund any Grant request which can't be met from Branch funds)

30 grants altogether (2023 - 12)

The exceptional demand for support has meant that we have used our income entirely for the benefit of people in our area in 2024.







Fundraising in 2025

Another Walk with Pride



We are delighted that WLQP is once again using their Pride Walk in June to raise funds to support The MND Association and our branch. The walk will take place on 7 June, meeting at 1000 at Lyric Square, Hammersmith. As usual, it will be around 10k long and be fairly gentle. Walkers will then gather at the Black Lion Pub in Hammersmith for food and drink and entertainment by a wonderful selection of gay pride performers.

It would be great if some of you can join us on the walk. As well as being an excellent fundraising opportunity it's a fun event and a chance for us to meet up in person. Do come along!

We'll be sending out further details in our email Roundups.





Introducing Alisha



We are delighted to introduce our new fundraising volunteer Alisha Pathania. We asked Alisha to tell us about herself and this is what she said:

'I lost my dad to MND in November 2023 at 52 years old. This was 2 ½ years after his diagnosis. I lived in Kent during my dad's illness, and the North West Kent branch were incredibly helpful throughout this time. I realised things may have stopped for us but there were still people going through the same things as we did, so I decided to sign up to become a volunteer to help fundraise for my local branch.

I joined the West London branch as a volunteer in September 2024. Since then, I have helped with the Royal Parks Half Marathon and the West London Strings Concert. I'm looking forward to helping with other fundraisers in the future as it's a great way to make a difference.'

Outside of volunteering, Alisha works as a Senior Research Executive at a healthcare market research agency. We are delighted to welcome her on board.





We Can Help

There are lots of different ways to raise funds, from intense physical challenges to holding a quiet coffee morning at home. Whatever you decide to do, there's plenty of advice online: https://fundraising.mndassociation.org/fundraise-your-way

As a branch we can help too. We can provide branded t-shirts, banners, collection buckets and leaflets to raise awareness. We can also help promote your event on social media and through our other communications. If available, one of our members might be able to attend your event and say a few words about MND and why fundraising is so important.

If you'd like to discuss an idea, ask questions or seek support do get in touch with Alisha.

Guidelines for Online Fundraising

If you are raising money for the branch through Just Giving or another online site, there are a few simple rules to follow, such as making it clear that it is our branch that you are raising money for. Do check them out here:

https://www.mndassociation.org/support-and-information/local-support/west-london-and-middlesex-branch/guidelines-for-fundraising

Or you can contact Naomi who will answer your questions: naomi.neville@mndassociation.org

Easy Fundraising

You can also raise money for the branch without holding a fundraiser or giving a personal donation. This clever concept is called Easy Fundraising. It's an online platform that enables you to raise money for the branch when shopping online. It doesn't cost you anything – the money is given as commission by the participating brands when you make a purchase. Find out more here:

https://www.easyfundraising.org.uk/causes/mnda-west-london/?utm_campaign=raise-more&utm_medium=clipboard&utm_content=rm





Care and Support

Support Group Meetings 2025

There is a range of support groups meeting on-line to provide information, help and support. Here are the groups available in this area and when they meet. The Contact person is happy to answer any questions so do get in touch.

What: South London Meet Ups – Led by Sally Roberts (Volunteer)

When: Sundays, every 2 months, from 2-4 pm.

Dates: 9 Feb, 8 June, 19 Oct. Royal Trinity Hospice, Clapham, SW4 ORN

13 April, 10 Aug, 14 Dec. St. Christopher's Hospice, Sydenham, SE26 6DZ

Description: A friendly laid-back space to meet others living with and affected by MND. This group meets in

person as well as on zoom.

Contact: sally.roberts@mndassociations.org

What: South London Carers Support Group - Led by Evelyn and Patrick (Volunteer)

When: Will be alternating months in 2025 - WeekdayDates: Contact Abigail or Evelyn for more informationDescription: Offering support for carers in South London

Contact: Evelyn.hayward@mndassociation.org **or** Abigail.igbokwe@mndassociation.org

What: Carers' Support Group (am) led by Lisa Burnard (ASC)

When: First Tuesday of the month, 11.00-12:00

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

Description: A virtual cuppa and friendly chat with other carers of people with MND in the Southeast

Contact: <u>lisa.burnard@mndassociation.org</u>

What: Carers' Support Group (pm) led by Charlotte Standford-Gibbs and Abigail Igbokwe (ASC)

When: Last Wednesday of each month, 6.30-7.30pm

Dates: 26 Feb, 26 March, 30 April, 28 May, 25 June, 30 July, 27 Aug, 24 Sept, 29 Oct, 26 Nov.

Description: Looking after you – an evening virtual support group

Contact: Charlotte.standford-gibbs@mndassociaton.org





Support Group Meetings 2025

What: Southeast region Peer to Peer Support Group
When: Third Tuesday of each month, 11:00-12:30

Dates: 21 Jan, 18 Feb, 18 Mar, 15 Apr, 20 May, 17 Jun, 15 Jul, 19 Aug, 16 Sep, 21 Oct, 18, Nov, 16 De **Description:** Tea, coffee and a catch up on-line. An opportunity to meet others living with and affected by

MND across the region.

Contact: liz.cooper@mndassociation.org

What: London Support Group led by Abigail Igbokwe (ASC)

When: First Wednesday of each month, 11am

Dates: 5 Feb, 5 March, 2 April, 7 May, 4 June, 2 July, 6 Aug, 3 Sept, 1 Oct, 5 Nov, 3 Dec. **Description:** A friendly and supportive chat with others living with MND and their carers.

Contact: Abigail.igbokwe@mndassociation.org or Charlotte.standford-gibbs@mndassociaton.org

What: Recently Diagnosed Support Group led by Lisa Burnard, (ASC)

When: Third Friday of each month, 2pm.

Dates: 21 Feb, 21 March, 16 May, 20 June, 18 July, 15 Aug, 19 Sept, 17 Oct, 21 Nov, 19 Dec. **Description:** Meet others in the same position, ask questions and find out about available support

Contact: lisa.burnard@mndassociation.org

What: MND Veterans Group

When: Fourth Wednesday of each month, 2:30-3:30 pm

Dates: TBC

Description: Not just about MND but about you, your background, and common interests

Contact: grace.kay@mndassociation.org

What: PMA-PLS Support Group

When: Second Monday of each month, 5-6 pm

Dates: TBC

Description: Meet up with other people living with or affected by Primary Lateral Sclerosis (PLS) or

Progressive Muscular Atrophy (PMA).

Contact: mndconnect@mndassociation.org

What: CHC Peer Support Group led by Anne Anderson, CHC Peer Support volunteer

When: Every 6 weeks, starting at 11am

Dates: 3 March, 14 April, further dates tbc.

Description: Understand more about the process of obtaining Continuing Health Care (CHC) funding"

Contact: chc@mndassociation.org



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Further Support Available

Here are some of the other support services available

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 call 0770425800.

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

Financial Support from the Branch - Our fundraising efforts mean we can offer grants to those who qualify. The support we offer can include funding equipment or services, cost of living support, and improving quality of life. We can also award grants to carers of plwMND and young people living with someone with MND. What we can fund, and how much we can give, is subject to MND Association guidelines. You can see those here:

<u>www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd</u>

MND Association Benefits Advice Service – can also help you find out what benefits you are entitled to and how to claim them. Call 0808 801 0620 or visit www.mndassociation.org/benefitsadvice

INS: Integrated Neurological Services supports adults with neurological conditions and their carers. Run by Sarah Vines, INS provides therapy, emotional and social support by providing one-to-one therapies and counselling, plus a range of exercise, therapy and creative groups. INS covers Richmond, Hounslow and the surrounding boroughs. If you'd like to learn more check out the website here: www.ins.org.uk email admin@ins.org.uk, or telephone 0208 755 4000.





Can You Help?

Besides fundraising there are many other ways you can lend your support to the branch and the MND Association. Here are two areas where we could use your help:

Become an AV

Do you have good listening skills? Are you a good communicator? Would you like to offer direct support to people affected by Motor Neurone Disease? Then you could become an Association Visitor (AV).

AVs play a vital role in the support we give to people living with MND and those close to them. They offer emotional support and provide information about the Association and other services to help people access what's right for them.

If you'd like to know more, contact abigail.igbokwe@mndassociation.org

Campaign

The MND Association continues to be extremely active campaigning on many issues. But help at a local level is vital too: whether it's signing a petition, sending an email or letter to your MP, or speaking to your local politicians. We'd very much welcome volunteers to help with campaigning for our Branch.

Find out more about what's involved here:

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

If you'd like to get involved, do contact Kapish.

https://www.mndassociation.org/get-involved/campaigning





Find out More

Lots to Read

There's a huge amount of information about the MND Association and its activities available online. Research updates, advice on fundraising, and lots more can be found here: https://www.mndassociation.org

A section of the site is dedicated to our branch. As well as receiving email Roundups of our news and future events, you can stay informed and involved by checking online here: https://www.mndassociation.org/support-and-information/local-support/branches/west-london-and-middlesex-branch

The Association's quarterly members' magazine Thumb Print is another great source of information. It covers the latest MND care, research and campaigning news, plus inspirational stories, interesting articles, fundraising ideas and more. Members of the Association receive printed copies, and it is also available online here: https://www.mndassociation.org/media/thumb-print

Getting in Touch

It's great to get information online but sometimes you simply can't beat 1-2-1 connections. Please do reach out if there's anything you want to ask or share.





Local Branch Contacts

Branch Chair: Kapish Narda – knarda.mnda@gmail.com

Branch Contact: Jenny Gadsby – gadsbyj@hotmail.com or 0770425800

Branch Secretary: Ross Marshall – communications@wlmnda.co.uk

Treasurer: Naomi Neville – naomi.neville@mndassociation.org WLMNDA@njneville.plus.com

Fundraising: Alisha Pathania – alisha.pathania@mndassociation.org

Communications: Allison Hill - allisonhmnd@gmail.com

Social Media: Emma Wilson – emma.wilson.wlmnda@outlook.com

Web Pages: Alexandra Harris - Alexandra.harris@mndassociation.org

Committee Member: Anne Hamerton – annehamert@aol.com

Local Association Contacts

Community Support Coordinator

Abigail Igbokwe

Email: abigail.igbokwe@mndassociation.org

Phone: 01604 816573

Regional Fundraiser - London and Thames Valley

Deborah Armantrading

Email: deborah.armantrading@mndassociation.org

Phone: 07872 161672

Head of Regional Care Partnerships

Claire Bickley

Email: claire.bickley@mndassociation.org

Phone: 01604 800654





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

Follow us on X @WL_MND

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



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- Receive a printed copy of this Roundup by post (if you can't access it on a device)
- Unsubscribe from these communications

Please email Ross: communications@wlmnda.co.uk with your request and giving your full name.

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