

Welcome!

Welcome to our first half-yearly newsletter of 2024. Here are some highlights:

We look back at our [Festive Fun](#) party when it was lovely for a group of us to gather in person and enjoy excellent seasonal cheer.

Another great way to meet up is to join in a walk. This year we look forward to another [West London Queer Project Walk](#) which is raising funds for our Branch. [Fundraising](#) comes in many shapes and sizes, from climbing mountains to entertaining people at home. Check out some key events and our [2023 Impact Report](#).

Care and Support is core to our activities. We look at the role of [Association visitors](#) and set out descriptions and dates for the many excellent [Support Groups](#) now available on zoom.

Interested in [Campaigning](#)? See how you can help.

Branch Activities

Festive Fun

Thanks to the generous hospitality of Anne and Ian Hamerton we shared some festive good cheer at their Ealing home. We spent the afternoon on Sunday 3 December enjoying food, drinks and each other's company.

Anne put on a great spread of food, aided by contributions from our committee members, and as always Anne's husband Ian and daughter Tora provided lots of help. Lisa Jain was also there with her excellent supply of Association Christmas cards.

During the party we played - and later shared with you all - the song 'I'm by Your Side'. It was written by Ross Lorraine and sung with Teresa Jennings; they both performed it in person at our 2022 seasonal party. It's a song that resonates very strongly with people living with MND, their supportive families, friends and carers.

It was a lovely afternoon and great to catch up in person with our fellow members.

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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Festive Fun



Tora Organising Food



Fav and Ross



Nick Speaking



The Branch is
on Instagram
Want to see
the branch in
action?
Follow us
[@mndwlandm
idx](https://www.instagram.com/mndwlandmidx)



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Monthly Get-togethers Are Paused

We have decided to pause our monthly Get-togethers as attendance has been low. We would love to find a format where our local branch members and supporters can meet up, exchange information and ideas and enjoy each other's company. Equally we recognise that times have changed and how people 'meet' is now very different. So, over the next few weeks we are going to review different ways to carry out our branch activities and attract more support. As always, we will invite and welcome your input. We'll get back to you on this soon.

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Our Next Walk



Getting Ready for the 2023 Walk

We are delighted that this year the West London Queer Project is once again holding a walk in support of our branch.

Date: Saturday 8 June

Start Time: 1000



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West London & Middlesex Branch Issue 122



Our Next Walk

It's a gentle 10K walk, starting in Hammersmith. It will follow a route along the Thames Path, through Barnes and Mortlake, ending in Chiswick at the Black Lion pub. The walk will be followed by food, drinks and fun entertainment in celebration of Pride Month

We hope lots of you will come along and join in. It's a great opportunity to get together with fellow branch members, meet new people, enjoy a great scenic walk and help raise money too. The perfect combination!

We'll send out further details in our monthly emails, and you can find out more on the WLQP website: <https://www.wlqp.org/event-details/10k-walk-celebration>

Last year's walk was great fun and this year's is bound to be even better. Do put the date in your diary.

Fundraising

There are many different ways to fundraise as we have seen in previous newsletters. Here we report on three more events held last year, ranging from fun with friends at home, a major challenge climbing Kilimanjaro and supporting a famous fundraiser.

Savita Serves Up Super Support

Savita Jain has once more done some great fundraising. It is 10 years since her husband Omprakash was lost to MND and Savita marked the occasion with fundraisers for the Branch.

On two separate evenings last summer she invited groups of 10-12 people to her house in Hayes. These were a mix of friends and ex work colleagues, some of whom have been supporting her cause for many years.

As well as savouring Savita's excellent home-made vegetarian snacks, everyone enjoyed the social side with lots of chatting and good laughs. Guests were given MND Association T-shirts which prompted some great photos.

Savita's target was £1000 and all donations were entirely voluntary. Friends who couldn't attend donated online. It all went very well, as Savita reports: 'I was very pleased with the outcome. My target was met thanks to the generosity of dear and near ones.'

Savita would be happy to host more gatherings of up to 10-12 people. If you are a local branch member who would like to plan something with Savita, let us know and we'll put you in touch with her.

Many thanks Savita for the fantastic support you continue to give to our Branch.

Regional MND Association Contacts

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Savita Serves Up Super Support



Savita and friends

Generations of Generosity

Many of our members and supporters have close ties with someone who is living with, or has been lost to, MND. This commitment to raising funds and awareness can run through entire families and continue for many years.

Committee member Anne Hamerton has been one of the core members of our branch since it began. Her inspiration was the loss of her uncle, Jim Knapton. As Ann explains, "Jim, was a Doctor working at The Royal Marsden. I used to see a lot of them when I came to London as a student. I first got involved with the MND Association when he was diagnosed over 40 years ago. I went to some of the early meetings with him, in Westminster, when it was a very small charity run from someone's front room in Northampton!"

As we know, Anne has worked tirelessly for the Branch ever since. Last June, Jim's son Antony decided to raise awareness of MND and funds for the Association by climbing Mount Kilimanjaro with his wife Caroline. Jim was lost to MND, aged just 49, when Antony was only 16 years.

As Anne says, "This was a spectacular effort by Antony and Caroline. I know Jim would be so proud of them."

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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Generations of Generosity

We invited Antony and Caroline to tell us about their great adventure. Here's Caroline's fascinating account:

Team Knapton's Kilimanjaro Climb

By Caroline Knapton

There are different routes up Kilimanjaro. We chose the 8-day Lemosho route; it's very scenic and offers more time to acclimatise. We set off from the small town of Moshi, in NE Tanzania, with our 6 guides, and fellow hikers. There were 15 of us from all over the world. We spent Day 1 eagerly getting to know each other as we climbed steadily through spectacular rainforest to our first camp.

A Great Team

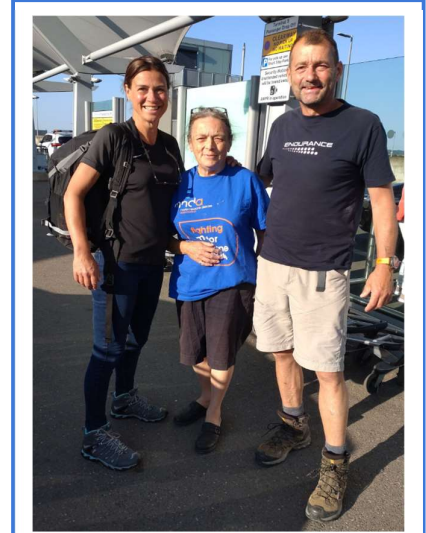
Here, we met the rest of our amazing local team – 8 kitchen crew and 33 porters. Our success was down to them. We had three hot nutritious meals every day, freshly prepared with local ingredients. Our water was collected from mountain streams and purified. Our tents were waiting each night and our bags carried from camp to camp. We even had two toilets! Our health was monitored twice daily and we could only carry on if our oxygen levels were up to 80% (normal levels are at 96-99%).

We spent 5 days climbing steadily from 7,742ft to 15,331ft. We passed stunning savannahs, moorland meadows, rolling hills, an alpine desert and volcanic rock formations. After climbing the 900-ft cliff Barranco Wall, we reached base camp at the foot of Uhuru Peak.

Reaching the Top

At this height it was harder both to walk and breathe and we were tired from days of tough trekking. Now we were going to attempt the final 4000ft. We nervously ate our evening meal and had a short rest. At midnight we began our final ascent, wearing 5 layers of our warmest clothing and head torches. It was -17 degrees and pitch black as we trudged slowly and silently upwards, snaking in single file, conserving every breath. Our bottles of drinking water soon froze.

At 5.20am we reached Stella Point, at 18,885ft. But Antony was had altitude sickness; his oxygen levels were at a dangerously low 60%. He had to stop. I carried on and reached the summit 1 hour and 17 minutes later. As I watched the sun rise over Africa, I felt elated, exhausted, and absolutely gutted not to have Antony with me.



**Anne with Antony and Caroline
 at the airport**



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Generations of Generosity

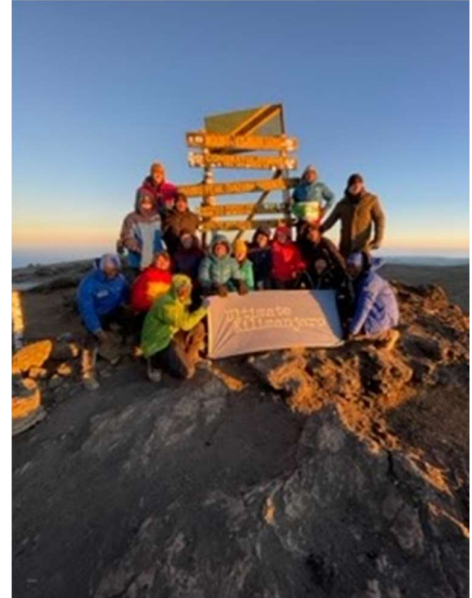
Wonderful Memories

Back at base camp, Antony was waiting, fully recovered. After a short rest we set off on the 2-day return trek. On arrival we showered and toasted our success, each other and our amazing team. It was the most difficult thing we have ever done, but unbelievably rewarding. Above all, we are so proud to have done it for Jim.

Antony and Caroline have raised £4,439 for the Association. If you'd like to add to that, go to:

<https://www.justgiving.com/team/theknaptons>

#doingitforjim!



At the summit

Impact Report

Here's our impact report for 2023.

WLMNDA IMPACT REPORT 2023



Our 2023 Income - £20,572 (£13,997 in 2022)

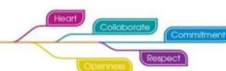
Some highlights of our Branch fundraising and those who generously raised money for us; thank you all!

- Our London Walk and barbecue jointly with the West London Queer project
- Zoe Dixon and family Skydives
- Ron and Wendy's 80th birthday fundraiser
- Geetha Menon's dance and dine celebration
- Ruislip Methodist Church Wednesday ladies Group

Our 2023 grant spend - £6,000 (2022 - £9,000) on support grants for plwMND and carers, young persons and Cost of Living grants. National Office funded a further 8 grants for people in our area.

- 12 grants altogether (2022 - 17)

Our 2023 contribution to MNDa National office for the Chief Executive's appeal and the end of year transfer £12,195 (£5000 in 2022)



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Kevin Sinfield's Ultra Marathons

Association Patron and rugby legend Kevin Sinfield made the headlines again in December with another fantastic fundraising achievement: his ultra marathon of 7 marathons in 7 days in 7 cities.

Starting on 1 December, he ran in Leeds, Cardiff, Birmingham, Edinburgh, Dublin and Brighton, finishing in London on 7 December. In each event he set an extra mile aside to run and walk with MND Association members and supporters. As the London extra mile was in Richmond Park, this was the perfect opportunity to go and support Kevin. Many of us did just that.



We met up in the park at the Extra Mile starting point on Queens Road. Kevin, who began his marathon at Twickenham Stadium, reached us at 12.20. He stopped to say hello and thank everyone for their support. After lots of selfies, everyone then set off for the mile run/walk with Kevin. It was a very heart-warming occasion – despite the cold weather.

At the end of the mile, Kevin carried on to finish his marathon in The Mall. There he talked to the waiting crowd about the experience and just how exhausting it was. His phenomenal achievement has raised well over £1million for different charities, with just over 40% going to our Association. What a wonderful effort!

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. 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



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Easy Fundraising

Don't forget to join easyfundraising an online platform that enables us 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. It's a great way of raising money and if you make 5 purchases in a month you can enter a prize draw that could win £3000 for our branch.

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

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)

Could You Be 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.

Association Visitors (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.

Being an AV

Kevin, one of our local AV's, describes what being an AV means to him:

“There is nothing more valuable than the company of someone who cares and listens with an open heart. An AV learns the skills to listen and support without judgement and to allow our clients to feel safe and understood. We learn so much about our clients and their needs and we learn a lot about ourselves.



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Could You Be an AV?

Coming away from visiting a client, or at the end of a phone call with them, there is a sense that whatever little contribution you have made can mean a lot.

The opportunity to be an AV is enriching. It diminishes our ego-centred self and opens up our true potential and respect for our fellow human. It develops our sense of compassion.”

We would very much welcome more AVs to fill this vital role.

If you become an AV you'll get full training and support. The role is very flexible and is carried out through phone or email contact, or home visits.

If you'd like to know more, contact Kathryn.Parkin@mndassociation.org

You can also find out about the AV role here:

<https://www.mndassociation.org/get-involved/volunteering/become-a-volunteer/ways-to-volunteer/support-volunteering/association-visitors>

Online Support Groups



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Online Support Groups

These online group meetings continue to provide useful help and support and a great opportunity to exchange ideas and experiences. The days/dates for 2024 are below. If you'd like to know more, or want a zoom link, please email the relevant contact for that group.

The Daytime Carers Group is for those who care for people living with MND in London and the South East. Meets on the first Tuesday of every month at 11am.

Dates for 2024: 7 May, 4 June, 2 July, 6 Aug, 3 Sept, 1 Oct, 5 Nov, 3 Dec.

Contact Lisa.Burnard@mndassociation.org

The Evening Online Carers Group is very popular with carers who find it hard to meet up during the day. Meets at 6.30pm on the last Wednesday of the month.

Dates for 2024: 24 April, 29 May, 26 June, 31 July, 28 Aug, 25 Sept, 30 Oct, 27 Nov.

Contact Justine.Cox@mndassociation.org

The North, NW & West London Support Group - Join us for a friendly and supportive chat with others living with MND and their carers. We meet on the first Wednesday of the month at 11 am.

Dates for 2024: 1 May.

Contact Kathryn.Parkin@mndassociation.org

The Recently Diagnosed Group - If you or a loved one has recently been diagnosed with MND you are welcome to join this friendly group. Meet others in the same position, ask questions and find out about the support available. It meets on the third Friday of the month at 2pm.

Dates for 2024: 19 April, 17 May, 21 June, 19 July, 16 Aug, 20 Sept, 18 Oct, 15 Nov, 20 Dec.

Contact Lisa.Burnard@mndassociation.org

Peer Support CHC Group – To better understand how to obtain Continuing Health Care (CHC) funding or to resolve problems with an existing package. Meets every 6 weeks at 11am. Next Date: 8 April.

Contact Anne.Anderson@mndassociation.org

South East Region Peer to Peer Support Group – Offers the opportunity to meet others with MND across the region. On the third Tuesday of the month from 1100 -1230.

Dates for 2024: 16 Apr, 21 May, 18 Jun, 16 Jul, 20 Aug, 17 Sep, 15 Oct, 19 Nov, 10 Dec.

Contact Dawn.Pond@mndassociation.org

PMA-PLS Support Group - For those living with or affected by Progressive Muscular Atrophy (PMA) or Primary Lateral Sclerosis (PLS). This group helps you link up with other people living with or affected by PLS or PMA. It meets on the second Monday of each month from 5- 6 pm.

Dates for 2024: 8 Apr, 13 May, 10 Jun, 8 Jul, 12 Aug, 9 Sep, 14 Oct, 11 Nov, 9 Dec.

Contact mndconnect@mndassociation.org

The Veterans Support Group - Enables MND veterans to support each other, sharing their experiences and common interests. Meets on the fourth Wednesday of the month from 2.30- 3.30pm.

Dates for 2024: 24 Apr, 22 May, 26 Jun, 24 Jul, 28 Aug, 25 Sep, 23 Oct, 27 Nov

Contact Dawn.Pond@mndassociation.org



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Campaigns

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.

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

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.

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

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



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