Newsletter

West London & Middlesex Branch
August 2022, Issue 119

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motor neurone disease association

Welcome!

Welcome to our summer newsletter. We hope you are coping with the heat and finding some time to relax. As always we look back at key events and forward to what we have planned. We do hope you enjoy reading and will be persuaded to come and join us.

On Page 3 we set out our plans for the next Open Meeting on 4 September with guest speaker Nick Goldup from National Office, talking about Care.

On Pages 4 and 5 we report on our last Open Meeting and the excellent talk from Chris Wade on how we can work better together in our volunteering.

Our annual Bushy Park Walk was blessed with perfect weather. Check it out on Pages 6 and 7.

Jim Marshall reflects on his first year as Honorary Treasure to the Association and talks about the importance of legacies. See Pages 7–9.

The Care and Support Groups continue to work well. Further information, including meeting dates, is on Page 10.

Walkers on the annual Bushy Park Walk

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

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

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Feedback Invited

We are aware that many things have changed in the last few years. As well as Covid, how people meet and communicate has evolved, people are under time and financial pressures and even our meeting venues have changed. Given all this, we'd like to get a feel for how this affects what we do as a branch and, in particular, how we can best organise our meetings.

We'd welcome answers to the following questions:

1. Branch Annual Bushy Park Walk: What would you like to see done differently? What should we continue to do?

2. Open Meetings / Christmas Party: Is the frequency / format of Open Meetings what you are looking for from the Branch? What should we do to enhance the experience more?

3. Branch Emails, Newsletter and Social Media: How do you usually get news about the Branch? How would you like us to change our communications to you as members? What should we continue to do?

A message from Kapish:

Your direct replies to me (even very short) would be very, very, much appreciated. The feedback on the above points is vital for us to continue supporting our members effectively and in the most impactful manner. So, your answers - even one-word ones - are incredibly important for us.

Do let Kapish have your thoughts: knarda.mnda@gmail.com

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!

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

Regional MND Association Contacts

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Branch Activities

Our Next Meeting

The next Branch Open Meeting will be held on 4 September. We do hope you will come along so we can all get together, have a chat and enjoy some tea and cakes.

We will also be able to hear an interesting talk from our speaker Nick Goldup, who is Director of Care Improvement at National Office. He will update us on the Association's future plans in this area including the delivery of multi-disciplinary care, and specific projects such as voice banking.

These meetings are a good opportunity to share experiences with other plwMND, their carers and our volunteers. We are always keen to hear how the branch can help, so do come along and share your thoughts. We know that attending a meeting for the first time can be a bit daunting so, if that's you, please be assured you will be very welcome. It's a friendly and informal atmosphere.

Time and Place

We will meet at 3pm at our new venue:
St Faith's Church Hall,
122 Windmill Road,
Brentford
TW8 9NA

St Faith's is just North of the A4. The E2 bus stops right outside. The Church Hall and its parking area are behind the church. Access from immediately beside the church. Don't continue into the residential road as it's quite a long detour to get back! For wheelchair users, we can confirm St Faith's has step-free access. It also has a disabled toilet.

Do Let Us Know

It would be really helpful if you let us know if you're coming to the meeting. This helps with planning and catering. If you are coming, please email Communications@WLMNDA.CO.UK to tell us how many of you there will be. If you don't decide that you're coming until the day itself, it's fine just to turn up.

Also, do let us know if you have any questions about our meetings, the venue, or if you need help with transport.

Events Diary Dates

Branch Open Meeting:
Sunday 4 September

Seasonal Party:
Sunday 4 December

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A Warm Welcome

Our recent Open Meeting took place on 12 June at St Faith's Church Hall in Brentford. Once everyone had had a chance to meet and chat, our Branch Chair Kapish warmly welcomed everyone and introduced Chris Wade. After Chris's talk there was more chatting and snacking before people set off home.

Chris Wade gave a great talk

Effective Participation

At the meeting we heard a fascinating talk by Chris Wade, Director of Engagement at National Office. In his talk 'A Participative Approach' Chris shared his thoughts on how we can work better together to beat MND.

He identified the following ways to get involved:

Tell Stories: Sharing personal experiences is an effective way to build awareness of MND and all our activities. It can be done in many ways, for example via social media or even joining a speakers' network. As always, lots of help and guidance is available.

Gather Data: Getting people to help gather information, especially about what is happening locally, is key to campaigning, seeking change and making sure the right support is available. Answering a few questions takes little time but can make a big difference.

Share Connections: Bring people together by building on the common connections we all have. This can be via branches and groups within the Association,

Contact Us

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A Warm Welcome

as well as external networks of common interests, such as sports and other activities.

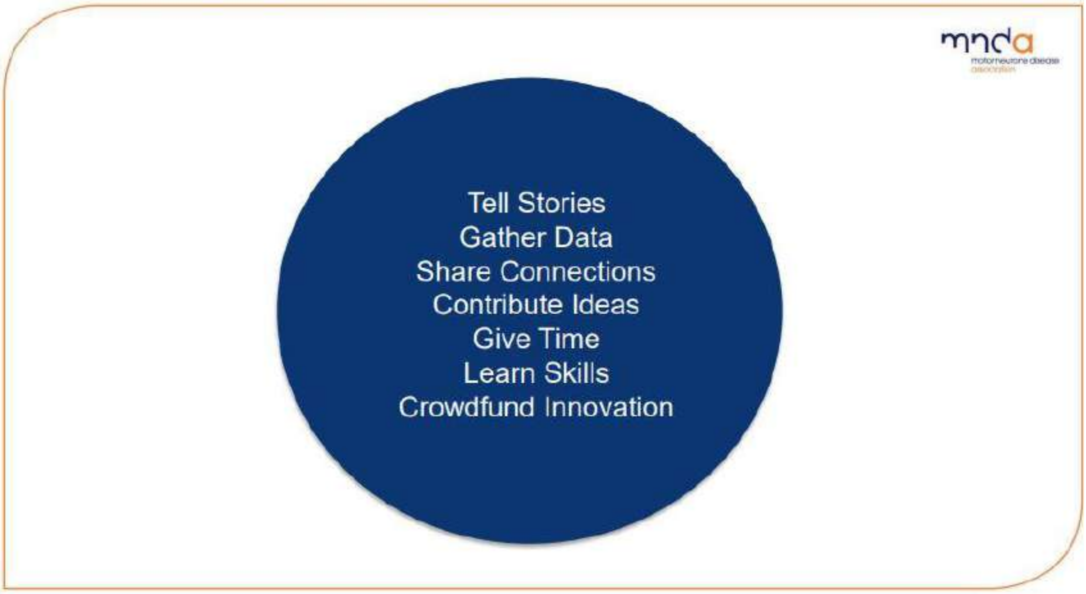
Contribute Ideas: Share ideas and experiences of what’s working, so we provide services we know people want. National Office is looking at different platforms to encourage collaboration and participation.

Give Time: All activities require giving time; this can be as much or as little as people feel comfortable with. Offer people the opportunity to get involved in tasks they feel are meaningful and that fit their skill set and experience.

Learn Skills: Help people increase their skills through buddying, mentoring and the many learning platforms available, including National Office webinars.

Crowdfund Innovation: Another approach is getting people to crowdfund new products and services to extend the range available and reward innovation.

During the lively discussion that followed the talk, Chris emphasised that the face of volunteering has changed over the years and now is a good time to reflect on what’s needed. Beating MND isn’t just about seeking donations, as important as those are. We should also recognise the specific knowledge and experience that individual volunteers can offer and find ways of effectively reaching out to them.



Tell Stories
Gather Data
Share Connections
Contribute Ideas
Give Time
Learn Skills
Crowdfund Innovation

Our Wonderful Walk

Our annual Bushy Park Walk took place as planned on Sunday, 3 July. About 40 people attended, including our friends from the South London Branch. Some dogs happily joined us too.

We met at a new venue, the Teddington Town Cricket Club. It proved to be an ideal meeting place and we were made very welcome by Ralph Meyer and the team. Unfortunately, our Branch Chair Kapish Narda had Covid and couldn't be there, so Nick Edwards welcomed everyone and gave the safety briefing.

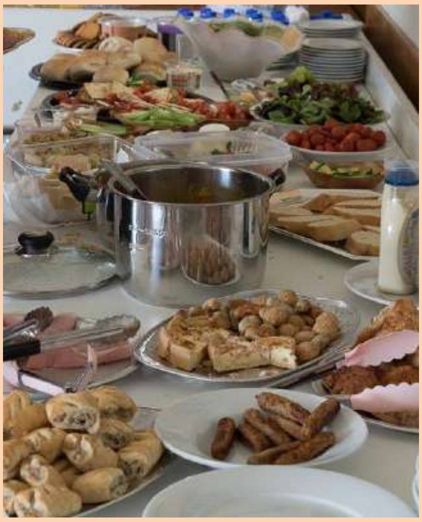
The walkers set off at around 10.30 and took the familiar 5 mile route through the park. The park was looking wonderful, and the weather was perfect. Everyone enjoyed seeing the beautiful surroundings, including the resident deer. As always, walkers were guided by our ever-helpful marshals, with Tora Hamerton on standby as first aider.

Back at the clubhouse, all then settled down to lunch. Anne and Ian Hamerton, who usually provide an excellent spread, were away in Australia so Anne organised things remotely. Savita Jain provided a delicious vegetable curry with rice and samosas, and a great selection of cold buffet items was provided by committee members and others. Lisa Burnard and Deborah Armantrading (our new regional Fundraiser for London) added invaluable support in the kitchen.

After we'd eaten, Nick thanked everyone for their efforts and organised the raffle draw. The fantastic selection of raffle prizes once again was provided by Nikki Wadge.

Thanks to everyone else who helped make the day possible including, of course, the walkers and all who donated. Naomi Neville, who handled all the financial aspects of the event, reports that the amount collected was £1880.

Our Wonderful Walk

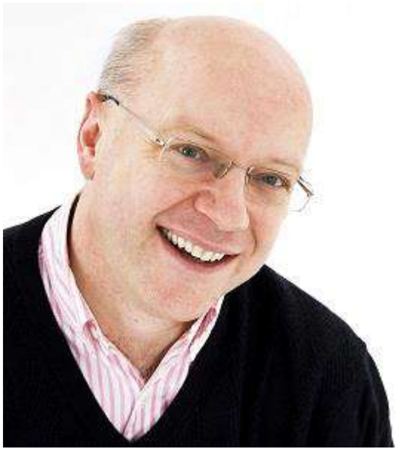


Fundraising

Jim Marshall Reflects

Last year Jim Marshall became a Trustee and Honorary Treasurer of the Association. We checked in with him to see how things are going.

How has your first year as Honorary Treasurer been?



It has not turned out quite as I expected! I thought the challenges of fundraising during the pandemic would dominate my time. Perhaps having to make some tough decisions around which projects we continue and which we stop or defer.

But instead, due to the remarkable support of the MND community, people living with MND, members, supporters and staff, the year has been totally different.

Jim Marshall Reflects

In 2021 the Association generated almost £29m in income, a record year for fundraising. And that was on the back of a very strong year in 2020. This year has started well, and if we meet our forecasts, it will be the third best ever year for fundraising (second best if you exclude the Ice Bucket Challenge year). Although given the current economic climate and war in Ukraine, we remain a little cautious on how 2022 will turn out.

This means we are now investing record amounts into research, care and work on the Association's promises. We currently plan to spend £28m in these three areas. So, this year has been very much thinking about what we can expand and build on, rather than what we need to cut back.

As well as chairing the Association's Finance & Audit Committee, I also sit on the Governance, Remuneration and Engagement committees. At the last meeting of Engagement, we looked at work that was done by WL & M branch some years ago on what support people living with MND can get from their local councils. That work was done by Ross. We are now thinking if that work can be rolled out nationally.

I've also been asked to be one of the trustees that appoints a new CEO in succession to Sally Light, who has recently announced her retirement.

So, a very busy year, but not the one I expected. And I've still not actually met some of my fellow trustees face to face!

We've heard about the wonderful fundraising by Rob Burrow and others, but we hear little about money left as legacies. To what extent are these gifts important to the Association?

Legacies are an important part of the Association's income and one that has been growing recently with over £8m received in 2021, which was about 30% of total income. The Association has been putting additional resources into helping people consider what they might include in their wills and what they may consider leaving to the Association.

Individuals can specify how any legacy has to be spent, eg on care or research and the Association is obliged to follow these wishes.

Jim Marshall Reflects

Having no such restrictions means the trustees have more flexibility on how the money is spent and can direct the funds to the areas of most need.
Assets can also be left to the Association, but it’s generally easier if legacies are just a specified amount or a percentage of the estate. That means the Association gets cash and does not have to worry about selling assets.

Of course, ongoing donations are vital too. Jim, can you tell us more about your latest bike ride?

This is the 5th year I have cycled Ride London raising funds for the Branch. Ride London is a 100 mile cycle ride on closed roads. In previous years it has started at the Olympic Stadium, gone through West London, down into the Surrey hills and finished on The Mall.

This year’s ride started on The Embankment, went out through East London, into Essex and finished at Tower Bridge (The Mall was closed for the Jubilee celebrations).

Although Essex is a lot flatter than Surrey, we had the same amount of climbing; lots of long gentle climbs rather than the short, very steep climbs in Surrey.

It is great fun cycling on closed roads without having cars and lorries to worry about. But I found this year quite tough, simply because I didn't train enough! So, my own fault. But a nice amount raised for the branch of about £1,800 plus gift aid.

Finally, a shout out to Duncan Haynes, Branch and Association supporter for giving me a complimentary bike service before I set off.

Leaving a Legacy

You can find out lots more about leaving a legacy to the Association on the website:

https://www.mndassociation.org/get-involved/fundraising/leave-a-gift-in-your-will/

You can download the ‘Gifts in Wills Guide’, seek help from the Legacies Team (Call: 01604 611 799 or email: legacies@mndassociation.org) or sign up for the Association’s Free Will Service.

You can also join a Legacies Event to learn more. The next event is online at 11am on 6 September and will cover lots of information about writing your will.

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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Care and Support

Support Groups

Our support groups continue to go really well with attendees saying how helpful they find them. In addition to the groups mentioned in previous newsletters, here are two more to tell you about:

- **The Under 50s Group** which aims to exchange information and share knowledge in a friendly space for those in that age group and their loved one. It meets on the 4th Tuesday of each month at 6.30 pm

- **PMA-PLS Support Group**: Progressive muscular atrophy (PMA) and primary lateral sclerosis (PLS) are specific forms of MND and this group focuses on the particular needs of those living with or affected by the condition. It is an international group.

As a reminder, the four groups we have mentioned before are:

- **The Northwest & West London Support Group** for local people living with MND and their carers. It takes place from 11am to 12 noon.
- **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. It provides useful guidance for those navigating the health and social care system for the first time.
- **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.
- **The Evening Online Carers Group** meets on the last Wednesday of the month at 6.30pm. It's proving very popular with carers who find it hard to meet up during the day.

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)

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.

Group Diary Dates

London Carers Group: 6 Sept, 4 Oct, 1 Nov, 6 Dec, at 11am.

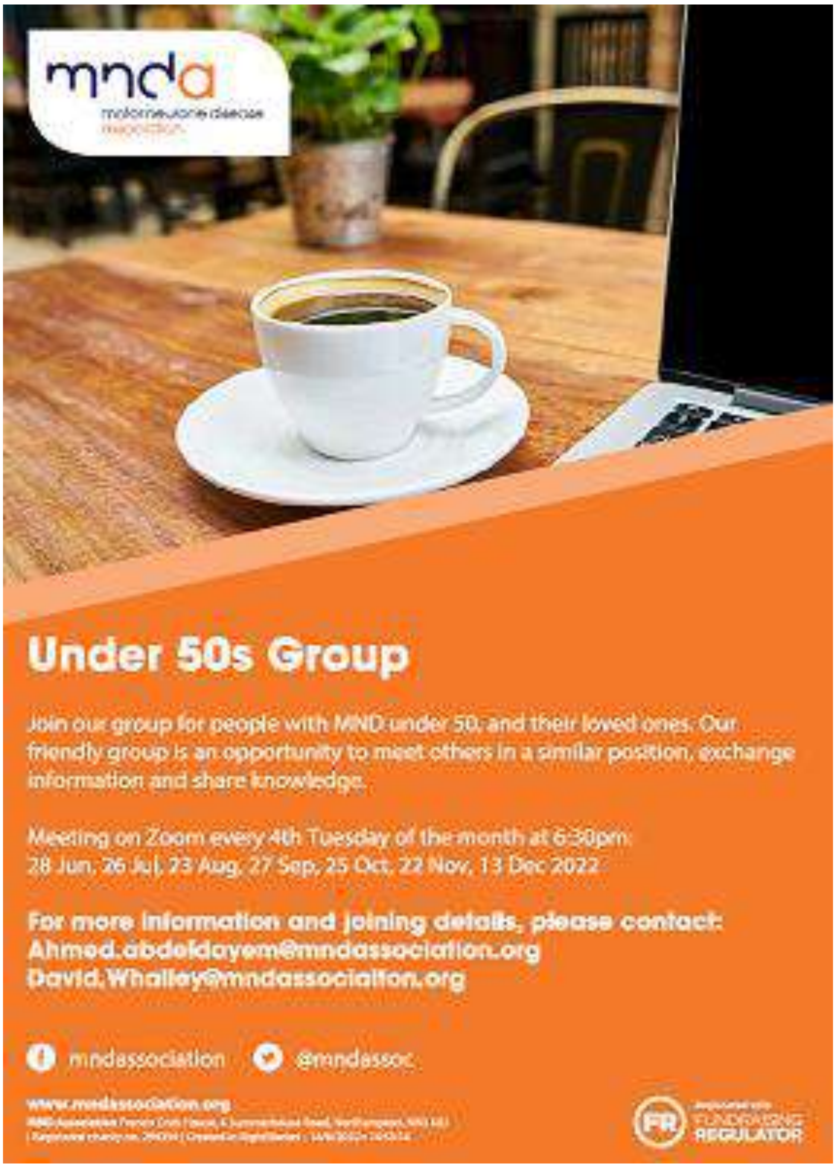
Evening Online Carers Group: 31 Aug, 28 Sept, 26 Oct, 30 Nov at 6.30pm.

NW & West London Support Group: 17 Aug, 21 Sept, 19 Oct, 16 Nov, 19 Dec at 11am.

Recently Diagnosed Group: 19 Aug, 16 Sept, 21 Oct, 18 Nov, 16 Dec at 2pm.

Under 50s Group: 23 Aug, 27 Sept, 25 Oct, 22 Nov, 13 Dec at 6.30pm.

PMA-PLS Support Group: to be confirmed



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Under 50s Group

Join our group for people with MND under 50, and their loved ones. Our friendly group is an opportunity to meet others in a similar position, exchange information and share knowledge.

Meeting on Zoom every 4th Tuesday of the month at 6:30pm:
28 Jun, 26 Jul, 23 Aug, 27 Sep, 25 Oct, 22 Nov, 13 Dec 2022

For more information and joining details, please contact:
Ahmed.abdeldayem@mndassociation.org
David.Whalley@mndassociation.org

mndassociation @mndassoc

www.mndassociation.org

Campaigns

The MND Association continues to campaign on many fronts to build awareness of MND and achieve important changes. Find out more here: https://www.mndassociation.org/get-involved/campaigning

Activity at a local level is an important part of this, including contacting MPs, local councillors and others. To do this effectively, we need help. If you'd like to volunteer some time, do contact Kapish – even if it's just for a chat to see what's needed.

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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

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.

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.

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

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