

West London & Middlesex Branch
November 2022, Issue 120

Welcome!

It will soon be our Seasonal Party and we so hope you can join us on Sunday 4 December. We are delighted that Branch Patron, Jeremy Vine will be attending and he will once again put on the wonderful MND Eggheads quiz for us. Find out more on P2&3.

We report on our last Open Meeting which took place in September when we had a fascinating talk by Nick Goldup from National Office on care delivery. See P4–7.

We've been fortunate to have another Fundraising opportunity at Brentford FC, this time at a London Irish rugby match. See P7–9.

The online Care and Support Groups remain popular. On P10-11 we run through the range of groups available and forthcoming dates, plus an interview with ASC Lisa Burnard.

Links to Campaigns updates and other contact details are on P12. We also set out how you could help us campaign locally.

Branch Activities

Our Seasonal Party

How wonderful that we will be getting together in person for our Seasonal Party. It's on Sunday 4 December and we are delighted to confirm that Branch Patron, Jeremy Vine will be there too.

Join us for mince pies, cake, mulled wine, some tea or coffee, and a catch up with old friends. Plus, we have some great prizes we are giving away in our 'free raffle'.

MND Eggheads

Jeremy will once again host the fabulous MND Eggheads Quiz. We'll invite you to form teams to display your knowledge of a variety of topics in the opening rounds. In the final round, the two leading teams select a representative for the thrilling head-to-head. Not to be missed.



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](https://twitter.com/WL_MND)



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West London & Middlesex Branch

November 2022, Issue 120

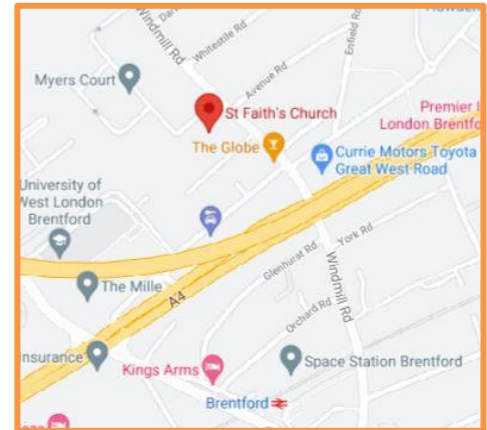
Our Seasonal Party

Music Too

This will all be accompanied by some great jazz numbers performed by Maureen's Riverside Trio. We look forward to hearing this inspiring combination of guitar, bass and sax.

Time and Place

We will meet at 3pm at:
 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 could let us know if you're coming to the meeting. This helps with planning and catering. If you are joining us, please email Communications@WLMNDA.CO.UK to tell us how many of you there will be – and if any children will be with you. If you don't decide that you're coming until the day itself, it's fine just to turn up. But let us know in advance if you can.

Also, do let us know if you have any questions or if you need help with transport.

Xmas Cards on Sale

A great selection of Christmas Cards will once more be on sale at the Seasonal Party. This has been organised by Lisa Jain for many years and she also arranges for card sales at the Ealing Christmas Card Charity Shop.

Like many other Jain family members, who dedicate much time and support to the Branch, Lisa does this in memory of her then father-in-law, Omprakash Jain.

Regional MND Association Contacts

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West London & Middlesex Branch
November 2022, Issue 120

Our Seasonal Party

Lisa emphasises that all the proceeds from her card sales go to the MNDa - even those sold in the Ealing shop, as it is run by volunteers. The proceeds are split between the Association (85%) and our Branch (15%). In the last 10 years Lisa's total card sales have raised more than £11,400. Thank you, Lisa! This year some cards are at a special discount, so do think of getting your cards from Lisa.



The Ealing Christmas Card Charity Shop is located at Christ the Saviour Church, New Broadway, Ealing W5 2XA. It will be open from 1 Nov to 19 Dec. If you live in the Ealing area and need help getting your cards, Lisa might be able to help. Email lisa.jain73@gmail.com

Planning Ahead

Our committee members are busy thinking about activities for next year. As Kapish mentioned in his previous requests for feedback, we are very aware that times have changed. Covid, the economy and other factors are altering how we do things. So, we want to be sure that next year's Branch activities are events that you want to join in with, at a time and in a place that suits you.

Events Diary Dates

Seasonal Party:
 Sunday 4 December

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



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West London & Middlesex Branch November 2022, Issue 120

Planning Ahead

One option is to have our Open Meetings in a pub (with wheelchair access of course); rather than inviting speakers, we could spend the time having a more informal get together. We are also looking at moving some or all of our meetings from a Sunday afternoon to a weekday; this could be lunchtime, afternoon or early evening. What do you think? Do email Kapish with any thoughts or, if you come to the Seasonal Party, that would be the perfect place to share your ideas.

The MND community is very special. While online resources and Zoom meetings have transformed the way we connect and stay informed, meeting in person remains important to us all. As a Branch we want to make the most of these opportunities for everyone. To do this, we need to know what you want – so, please do tell us!

Kapish would love to hear from you: knarda.mnda@gmail.com

Contact Us

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Our September Open Meeting

At our Open Meeting on 4 September we had a fascinating talk from Nick Goldup, Director of Care Improvement at National Office. Nick gave us an update on the Association's plans and current projects in care delivery.

Nick began by reflecting on the Association's recent articulation of its Promises which together set out a map for future ambitions and activities.

As Nick works in care delivery, he focused his talk on Promises 2 and 3.



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West London & Middlesex Branch
 November 2022, Issue 120

Our September Open Meeting

Promise 2 – Everyone gets the care they need when they need it

Key activities in this area, working with external entities, have been:

Accessing Multi-disciplinary Care – there are now 22 Care Centres in the country and Nick and his team have been working at creating networks of health professionals to share best practice and deliver the different types of care needed by plwMND at a local level. Specifically targeting 14 areas of the country, the team's aim is to fund community outreach posts.

Revising the NICE Guidelines – the National Institute for Care and Health Excellence sets out guidelines for H&SC professionals on how to treat different conditions. Their 2016 Guidelines addressed MND. The Association is collecting evidence to influence an update of the NICE Guidelines to reflect recent developments such as voice banking.

Supporting Research – this involves working with relevant professionals in the research space to ensure the health care needs of plwMND are fully understood and met. For example, ensuring that those with ventilation difficulties who might be considering a tracheostomy are able to make informed choices.

Promise 3 – Every day with MND counts

These activities focus on the quality of life in the home and other internal settings. Nick updated us on these projects and programmes:

My MND/My Care- ensuring that the support provided to people living with MND and their families fits their personal needs. This includes support for children and young people, equipment loans, dealing with bereavement, and much more.

Financial Support Grants – The Association is reviewing its grants system to be certain that financial support is reaching the right people. This is particularly relevant given the current economic climate and the rising cost of energy



Our Big Tech Partners



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West London & Middlesex Branch
November 2022, Issue 120

Our September Open Meeting

New Technologies – technology can improve the quality of life and increase the independence of plwMND. The Association is working with major big tech partners to come up with some great solutions. A key priority is addressing speech difficulties and Nick told us about two exciting solutions:

- I Will Always be Me - a major step forward in voice banking. (See more below.)
- Project Euphonia (recently rebranded 'Relate') – adapting Google Assistant so it will be better able to understand slurred speech. Find out more here: <https://sites.research.google/euphonia/about/>

Nick is pleased with the progress being made in all these areas as the Association aims to deliver on its promises. We thank him for taking the time to come and talk to us about these transformative initiatives.

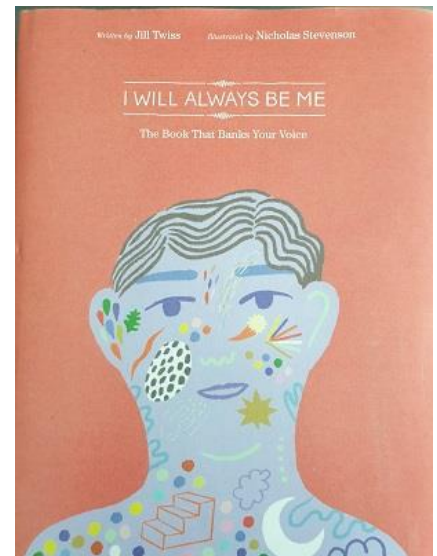
The Book the Banks Your Voice

'I Will Always Be Me' is a book designed to make voice banking easier. Written by American author Jill Twiss, it's written from the perspective of someone living with MND explaining to their loved ones what MND is and how it affects people. The core message is that whatever the physical changes MND brings about, the inner person remains the same loved and loving being.

The short story takes less than half an hour to read out loud. The reading is recorded and then uploaded and transformed into a digital voice to be used when needed.

When a plwMND can no longer speak clearly, they type what they want to say into their laptop, PC or mobile phone and the words are spoken out loud using their banked voice.

This is a huge step. Previously those wishing to bank their voices went through a recording process that could take many hours. Reading 'I Will Always Be Me' is much quicker and has the added benefit of helping families understand MND and the changes it brings.



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West London & Middlesex Branch
November 2022, Issue 120

Our September Open Meeting

The emotional story also results in a set of banked words that sound far more lifelike. Find out more here: www.iwillalwaysbeme.com

The MND Association will provide funding for people with MND living in England, Wales and Northern Ireland to take part in voice banking, thanks to donations from Dell Technologies and Intel who have been key partners in this project. If you'd like to know more, please contact Richard Cave at Richard.cave@mndassociation.org



Tora Hamerton has now been preparing and serving our food and drinks at Open Meetings for 25 years. Aply assisted by other members of the Hamerton family. A fantastic job, Tora – our meetings would not be the same without you!

Fundraising

Another Brentford Collection



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West London & Middlesex Branch
 November 2022, Issue 120

Another Brentford Collection

A Great Opportunity

As we reported in our May newsletter, we did a bucket collection at a Brentford FC's ground which raised approximately £1,700 for the branch. So, we were delighted to get the chance to make another collection. This time at a London Irish Rugby match, as they too are based at the GTech stadium.

Once more, the opportunity arose from people and their contacts: a combination of Jim Marshall (Branch member and Honorary Treasurer of the Association), and long-standing committee member Nick Edwards. Jim knows the people at Brentford FC, and Nick and Naomi Neville (our Branch Treasurer) used to work with a couple (Andy Roberts and his wife Viv) who are top fans of London Irish. Andy is Secretary of the LIRFC Supporters Club and was key to making everything happen, along with Viv and fellow supporter Keighley.

This helped us reach the right decision makers and it was soon agreed that we could do a collection for the London Irish match against Gloucester on the evening of Friday 21 October.

Although the crowds at rugby matches are smaller than at premier league football matches, we felt the history of MND cases among top-level rugby players might attract more donations. Not least as Jarrod Cunningham was a London Irish player who sadly died with MND in 2007, and Ed Slater of Gloucester announced his retirement from rugby in July after his MND diagnosis.

Behind the scenes

Jim and Nick worked hard in the run up to the match, sorting out all the finer details. Jim did a pre-match survey of the grounds to work out the best place for collectors to stand; he identified 6 ideal collection points. Nick organised groups of volunteers to be in place, properly equipped with collection buckets, contactless card machines and laminated cards showing our Just Giving page QR code.

They also made sure supporters were told about the collection well in advance. It was announced in the pre-match social media and the match programme. London Irish's support in these areas was crucial to the success of the evening.

On the night



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West London & Middlesex Branch
November 2022, Issue 120

Another Brentford Collection

As well as our own members volunteering, London Irish found fans to help collect. This meant we had 19 volunteers in total. Some started collecting 2 hours before kick-off. It poured with rain – at times very heavily – but that didn't stop them. Our branch volunteers collected right up to the start of the match at 7.45 when they were able to watch the match for free – a great bonus.

At half time, our MND logo was put up on the main screen with the QR code for our Just Giving page. The amount raised so far was announced and all were invited to carry on contributing.

As the match drew to an end – sadly London Irish lost by a single point – the volunteers regrouped at their collection points for another 20-30 minutes.

Being able to pay by card or phone really helped. As did letting people know they could pay this way. Branch volunteer David Young and Nick keenly called this out many times and it made a huge difference. Thanks to everyone's efforts, our collection raised a fabulous £3,295.

Thanks!

Sally Light sent a message of personal thanks to all involved in achieving so much on such a wet night. Our branch volunteers were Jackie Watts, Steve Morton, Alastair Cox, Mohit Jain, Anne, Tora and Ian Hamerton, Allison Hill, Nick Edwards, Jim and Ross Marshall, David Young and his friends Karsten and Adrian, and Deborah Armantrading (our regional Fundraising Adviser) and her friend Mark.

We would also like to pass on our thanks to our friends at London Irish: as well as Andy, Viv and Keighley mentioned earlier, Kelly Adey (Head of Operations) and Katy Murphy (Head of Marketing) provided invaluable help and support. Thanks to them and everyone else who helped.

Despite the weather, it was an inspiring and rewarding evening. We are certainly hoping to collect next season at both at a football and a rugby match. We'll let you know when in case you'd like to volunteer. It's well worth it.

And if, after reading this, you feel you'd like to contribute too, it's not too late. You can do so at the special JustGiving page created for the event:

<https://www.justgiving.com/page/london-irish-and-gloucester-rugby-for-mnd>

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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West London & Middlesex Branch

November 2022, Issue 120

Other Efforts

Big events such as those at Brentford are great fundraising opportunities. But individual efforts are vital too and these continue. For example, our great supporter Lynn McCarron, who lost her husband John to MND, organised a cream tea in August which raised £300 including Gift Aid for the Branch. Many thanks to Lynn and everyone else who contributed to this and any other funds.

These contributions are shown on our Just Giving page.

<https://www.justgiving.com/fundraising/westlondonmnda>

You are welcome to add your own contributions to these fund raisers, or perhaps organise your own.

Care and Support

Our Groups

A number of online Support Groups are now in place to meet different needs. They continue to be very popular.

- **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.
- **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.

If you have any questions at all about any of these groups, do contact our Area Support Coordinator Lisa Burnard. She'd be very happy to tell you more about the groups and welcome you along if you'd like to join in. (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

NW & West London Group
 Monday 19th December @
 11am

Carers Group
 Daytime - 6 December @ 11am.
 Evening - 30th November &
 28th December @ 6.30pm



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West London & Middlesex Branch

November 2022, Issue 120

Do Register

There could be a tough winter ahead for us all. For plwMND any disruption to energy supplies could be particularly challenging. Our ASC Lisa points out that it can be a huge help for a plwMND to register as a 'priority customer' with their water, gas and electricity network suppliers. If supplies fail, you will be given priority (eg for engineer home visits if needed) and other benefits (eg provision of hot meals). You might also be exempt from limitations such as hose pipe bans. It really is worth registering.

Lisa Looks Back



Our Area Support Coordinator Lisa Burnard will be moving to become ASC of Sussex. As we get ready to say farewell and many thanks for a fabulous job, we invited her to reflect on her time working with us.

Lisa's role is to provide support for plwMND by bringing together all the support they need – from health and social care professionals, and all our volunteers - including AVs (Association Visitors). The support can be anything from organising care visits, to advising on grant applications, or obtaining specialist care; plus, adjusting the level of support as circumstances change. Lisa is the go-to person who gets things done. It's a wide-ranging remit that requires specialist knowledge, a great deal of communication and lots of patience!

Lisa joined us in March 2020 at the start of lockdown. This was when National Office altered its approach and began to actively reach out to plwMND. Lisa quickly built many 1-2-1 contacts, and these relationships continue today. As she says, 'a quick phone call can make all the difference.'

Lisa adds that, 'Covid certainly changed the way we work, and this is likely to be here to stay. Lots of people, especially the vulnerable, often prefer remote communications to meeting up in person. While home visits can be key, we've seen that AVs can be really effective remotely too.'

The Care and Support Groups we now have also grew from the need for remote communications, and Lisa sees them as set to continue, at least for now. They are particularly popular with carers who are often time poor. The groups also enable an exchange of information, peer support and guidance across different areas.

But as Lisa concludes, 'It isn't one size fits all. A hybrid approach of in-person meetings and remote contact is probably the way forward. My job is to understand individual needs and find the best way of meeting them. That's what I really enjoy doing.'

Lisa is likely to move in the New Year. We wish her well and thank her for the huge help and support she has given, and also enabled in others.



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West London & Middlesex Branch
November 2022, Issue 120

Campaigns

Can YOU Help?

We are still looking for volunteers to help us with ongoing campaigns. These campaigns seek to positively influence the lives of people living with MND, and their carers. They are centrally organised by National Office, but their success depends on our local input. Each campaign is looking to MPs or local councillors to take action. And those MPs and councillors listen most to their local people, the people who vote for them. That's all of us – we have the power to bring about change. By helping with these campaigns.

It doesn't have to be daunting and it's not a full-time role. It could just be lots of people sending a tweet or letter, or someone meeting up with their local councillor to chat things through. Could that be you?

Current Campaigns

There are often two or three different campaigns active at any one time. You might want to get involved in all of them, or you might have a particular goal you want to promote. For example, you could focus on improving social care, or you might want your local council to speed up home adaptations. Bringing your own personal experience on board, and telling your story, can really make a difference. That's what inspires our decision makers.

Check out the current campaigns here and see what inspires you:

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

What Can You Do?

There are many ways to help: raising awareness on social media, connecting with councillors and MPs, collecting evidence and spreading the word.

When it comes to letters and social media, we'd welcome action from as many people as possible. If you could regularly retweet our campaign messages, or mail your MP when asked, that would be great. It all helps raise awareness and can be done remotely at a time to suit you. Perhaps you are a busy parent with little time on your hands? These quick bursts of activity, when you have a few minutes to spare, would be ideal.

If you are comfortable meeting people and building relationships, then you might be able to help by meeting with your MP and local councillors to keep them updated on current campaigns. You don't have to be an experienced campaigner as the Campaigns Team at National Office is always on hand. They send out regular updates, hold webinars and are available 1-2-1 to answer questions and offer advice. The MNDa website is a mine of information too.



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West London & Middlesex Branch
November 2022, Issue 120

What Can You Do?

It's likely you have previous experience that is transferable. Put those communication and people skills to good use. Volunteers in other branches include a retired teacher, a police officer, and a salesperson. What they all have in common is knowing someone with MND and understanding what's needed to help them.

It's totally flexible – you can increase or decrease your input to suit you. You can find out more – and sign up if you like – here: <https://t.co/pNRGqjKOnn>. Or give Kapish a call to chat anything through. Do think about it. We'd really welcome your input – whatever it is.

Support MND Carers

A campaign called Support MND Carers has recently started. It's a great way to get involved in campaigning.

The MND Association conducted a survey looking into the experiences of unpaid carers of people living with MND. The findings clearly demonstrated the need for additional support. Carers are entitled to Carer's Assessments to see what might help make their life easier. But the survey found that many MND carers aren't receiving assessments. Even when they are assessed, the recommendations for support aren't always carried out.

The Support MND Carers campaign is calling on the Government to launch a review into the adequacy of and access to Carer's Assessments. It's to be launched at the All-Party Parliamentary Group on MND meeting on 29 November. MPs will hear first-hand from carers of plwMND who will illustrate what life is like for them. The Association will be calling on MPs to ensure carers are better supported and encourage them to call for a review.

It's vital that we get as many MPs as possible to attend and show their support. We are all invited to take 'e-action' by writing to our local MP inviting them to the November launch. The link is here, it only takes a couple of clicks:

<https://ecampaigns.mndassociation.org/page/109974/action/1?ea.tracking.id=staffcomms>



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West London & Middlesex Branch
November 2022, Issue 120

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: **0787 906 8870**.

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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