

West London & Middlesex Branch
May 2022, Issue 118

Welcome!

In this issue we look back at our Spring Party – our first in-person meeting for some time. What a special day it was (P1 & 2).

We also look forward to our next Open Meeting on 12 (P3) June and our annual highlight, the Bushy Park Walk on 3 July (see P4 & 5).

Our Fundraising section reflects what we achieved last year (P6), and our recent fabulous first: holding a collection at Brentford Football Club (P7).

Our Care and Support activities continue with our set of Support Groups which are proving very effective. Check out the forthcoming dates and more on P9.

Although Campaigning activities have been a little diminished in Covid times, we are keen to continue. We share some useful advice given by volunteers from other branches on how they campaign locally (see P10).

Branch Activities

Spring Party



After such a long time apart, it was just great to see everyone again at our Spring Party. It took place on Sunday 13 March at our new venue, St Faith's Church Hall, Brentford.



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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Spring Party

It was a good turnout, and everyone quickly relaxed into chatting and catching up while enjoying the lovely food provided, as ever, by the Hamerton family. Other treats were donated by Kapish, and Savita's samosas were delicious too.

Kapish warmly welcomed us all, especially new members, and introduced us to our new meeting venue. He thanked the branch members for their continued support and involvement during the prior 24 months whilst we had to go 'online' for all our events owing to the pandemic. Kapish also thanked the committee, who have been tireless in their efforts to keep the branch going.

Kapish then handed over to our Treasurer, Naomi, who took us through the Branch Impact Report (see P6). This was followed by a great talk from our guest speaker, Sarah Vines.

For the rest of the afternoon, we were treated to music from our friends from The Old Standards, now renamed 'Younger than Springtime' with a slightly altered line up. They played some wonderful pieces to build our happy atmosphere, made even happier when Keith Lawrence returned to the drums for a brief session. It was just like old times.

Diary Dates

Walk: Saturday 3 July

Open Meetings:
12 June, 4 September, 4
December

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Introducing Sarah Vines and INS

A highlight of our Spring Party was the fascinating talk from Sarah Vines, Chief Executive of Integrated Neurological Services.

Sarah explained that Integrated Neurological Services has been operating in West London for over 25 years with the aim to support adults with neurological conditions and their carers, in Richmond, Hounslow and the surrounding boroughs. The organisation provides therapy, emotional and social support by providing one-to-one therapies and counselling, plus a range of exercise, therapy and creative groups.

Since COVID, INS has developed a blended model of face to face and online/telephone services. It provides face-to-face services from the main base in Hampton Road, Twickenham, and has satellite groups in Barnes and Feltham.



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



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Introducing Sarah Vines and INS

As Sarah explained, 'We work in partnership with charities and other statutory providers throughout the area. We are there to complement the other services you may be already using.'

Some recent activities have covered speech therapy, mindfulness classes, creative writing, work outs at different levels (included while seated), fatigue management, yoga, music therapy, crafts, and carers coffee mornings.

If you'd like to learn more about this excellent service, check out the website here: www.ins.org.uk email admin@ins.org.uk, or telephone 0208 755 4000.

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Our Next Open Meeting

Save the Date: 12 June

Do join us for our next Open Meeting on 12 June. As ever this will be a chance to meet old friends, share insights and advice, and give your thoughts and feedback on how you'd like to see the Branch move forwards.

Guest Speaker

We are delighted to report that our speaker is Chris Wade from National Office. Chris is Director of Engagement and is responsible for volunteering, HR and learning. He will be talking about the role of volunteers and other Association activities. Chris is keen to hear about our experience as volunteers and share ideas and future plans.

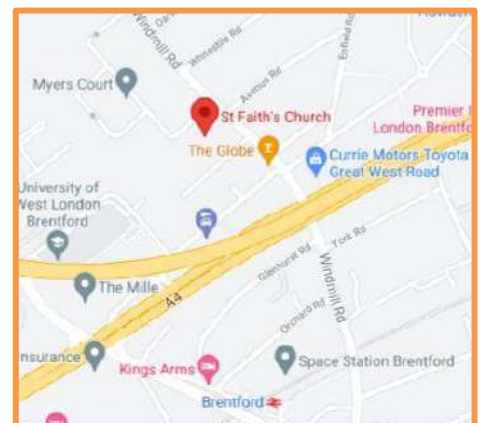
Time and Place

We will meet at 3pm in St Faith's Church Hall, Brentford, where we held our Spring Party.

St Faith's Church Hall,
122 Windmill Road,
Brentford
TW8 9NA

Note: It is 122 Windmill Road not 22 Windmill Road as stated in the last newsletter. Our mistake!

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



St Faith's 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.



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Bushy Park Walk

Save the Date: 3 July



Our wonderful Walk in Bushy Park is taking place on Sunday 3 July. Getting everyone back together for last year's walk was very special, and we hope even more of you will join us this year. As well as being our major fund raiser, the Walk is a wonderful social occasion. We are delighted that our friends from the South London branch are joining us again this year to add further to the fun and funds.

A New Meeting Place

We used to meet at the Bushy Park Sports Club in Teddington. This year we have a change of plan. We will be meeting at Teddington Town Cricket Club which is not far from our previous meeting point. (NB: Be careful not to confuse Teddington Town Cricket Club with Teddington Cricket Club as they are near each other!)

Getting There

Approach from Queen's Road, Teddington and take the turning opposite Park Lane. You'll see signs to NPL & Bushy Park Sports Club as well as Clapperstile Car Park. In a few yards, at the roundabout take 2nd exit following signs to 'Rugby & Cricket Clubs'. In a few more yards, at T junction, turn right and in a short distance, Clapperstile Car Park will be on your right. If you are driving, park here.

If you are using sat nav have Clapperstile Car Park as your destination. Post code is: TW11 0LY

Look out for the Clapperstile Gate, opposite the Clapperstile Car Park. Enter here. Immediately turn right and walk for about 200 yards until you get to a single storey, brown wooden building on your right. That's the Teddington Town Cricket Club/ Teddington Rugby Club Sports Centre – our venue.

Marshals will be there to guide you and direct you to the registration desk. Registrations starts at 0945. Please allow plenty of time for this as we need to set off no later than 1030.



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Bushy Park Walk

Beautiful surroundings

We will follow our usual route – a circuit of about 5 miles, that's flat and wheelchair accessible. Bushy Park is home to many deer, waterbirds and other wildlife. So don't forget your cameras.

You're welcome to bring your dogs too.

Marshals Needed

We need more volunteers to act as marshals, helping walkers follow the correct route. If you'd like to assist, please contact Nick Edwards:

needwards@hotmail.com

Lunch Time

The walk takes about 2 hours and is followed by lunch. Our lovely lunches are usually organised by Anne Hamerton and her team. This year Anne and Ian will be in Australia and will miss the walk, so we need some extra help. Anne is doing the pre-planning for a finger buffet, so please let her know if you can provide some finger food, and/or lend a hand with serving food and drink on the day. If you can help, please email Anne: Annehamert@aol.com.

NB: Contactless machines will be available for contributions towards paying for the food or donations to the Branch.

Raising Funds

A special JustGiving website has been set up for this year's Walk:

<https://www.justgiving.com/fundraising/westlondonmndwalk2022>

JustGiving makes it really easy for your friends, family, colleagues and neighbours to sponsor you. It also means we can collect all the Gift Aid (where applicable), adding 25% to the money we raise. If you decide to set up your own JustGiving site, please be sure to follow our Guidelines for Online Fundraising (see P8).

The walk is our major fundraiser and we really do hope you can join in.

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.

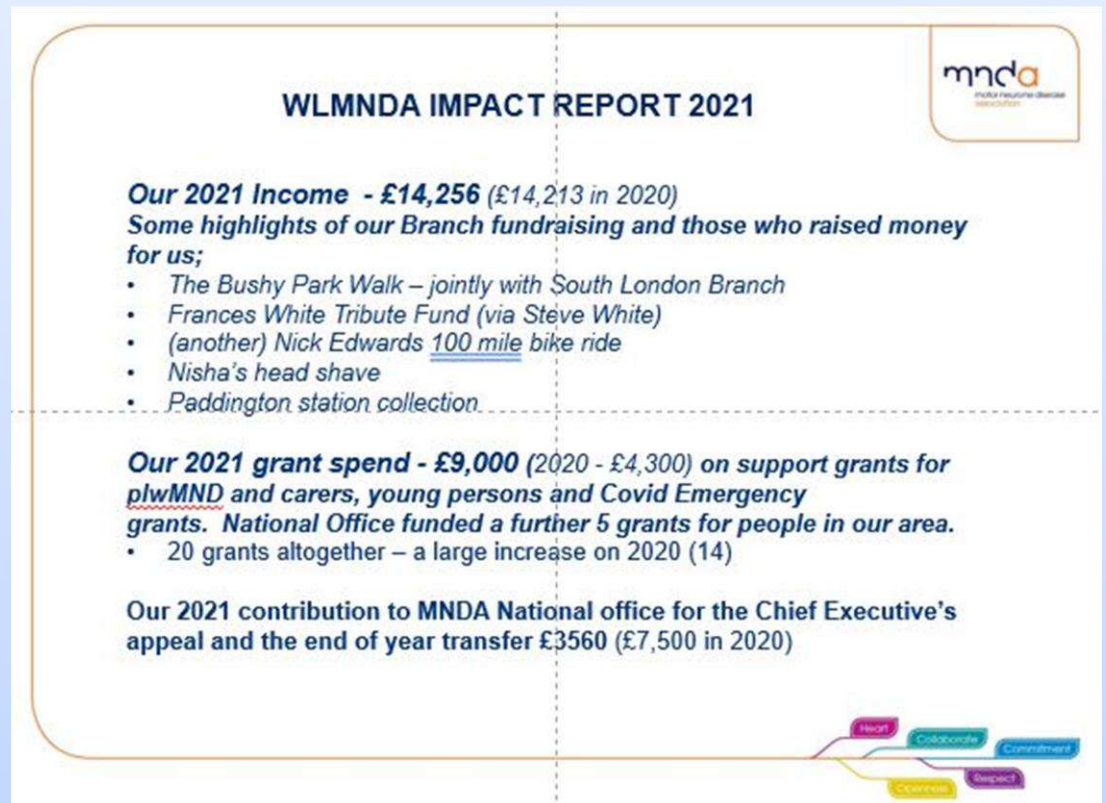


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Fundraising

Impact Report



WLMNDA IMPACT REPORT 2021

Our 2021 Income - £14,256 (£14,213 in 2020)
Some highlights of our Branch fundraising and those who raised money for us;

- The Bushy Park Walk – jointly with South London Branch
- Frances White Tribute Fund (via Steve White)
- (another) Nick Edwards 100 mile bike ride
- Nisha's head shave
- Paddington station collection

Our 2021 grant spend - £9,000 (2020 - £4,300) on support grants for plwMND and carers, young persons and Covid Emergency grants. National Office funded a further 5 grants for people in our area.

- 20 grants altogether – a large increase on 2020 (14)

Our 2021 contribution to MNDA National office for the Chief Executive's appeal and the end of year transfer £3560 (£7,500 in 2020)

Heart, Courage, Commitment, Respect

This year, in lieu of holding an AGM, we produced a WLMNDA 2021 Impact Report. It provides a summary of the Branch's finances and fundraising events from 2021.

Over the course of 2021, the Branch raised over £14,250, which was a tremendous achievement in the face of the restrictions and limitations presented by the COVID-19 Pandemic. The Branch provided £9,000 in Support Grants to individuals and families across West London, an increase from £4,300 in 2020, ensuring more people received much needed support. Our heartfelt thanks go out to everyone who fundraised and donated.

Our fundraising efforts continue. As well as our Bushy Park Walk, and individual initiatives from our wonderful supporters, we always welcome new fundraising opportunities. Below we report on a recent fabulous fundraising first.



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A Fantastic Bucket Collection at Brentford FC



We were given a wonderful opportunity by Brentford Football Club to raise funds, with a bucket collection at their match on Saturday 7 May.

Brentford FC were promoted last year to the Premiership, so they have been playing the top sides in the country in their spacious new stadium. Their match against Southampton promised a very large crowd.

The club's generous offer included 12 tickets for collectors to watch the match. Plus, extra tickets for people living with MND and their carers, with easy access to parking nearby.

The collectors were active both before and after the game at different locations around the ground. The collection, and some background on MND, was publicised by the Club. A Just Giving page for this event was set up too, with QR codes displayed on the collection buckets to make it easy for those without cash to donate.

A Great Success

Thanks to all these efforts over £1650 has been raised so far. A truly fantastic sum! Among our collectors were Emma Wilson and her mum Lynn. Both are very active on our Branch social media pages (Emma on Twitter and Lynn on Instagram) and kindly took the photos. Emma says of the event:

“The collection at Brentford Community Stadium was a roaring success! We had so much fun shaking our buckets and chatting with the Brentford and Southampton fans, who were, by the way, incredibly generous. In fact, many of those we spoke to had been affected by MND in some way and some had done fundraising for MNDA themselves. To top it all off, we got to watch a great game and Brentford came away with a 3-0 win!

Thanks to all our other collectors too, many of whom travelled quite a distance to be there. We also want to thank everyone who contributed and, of course, Brentford FC. We'd love to do this all again one day.



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Thanks to our great team of collectors:

Beth Hamerton, Ian Hamerton, Tora Hamerton , Ross Marshall, Pete Morris, Steve Morton, Kieran Richards, Jill Thompson, JoJo Thompson, Jackie Watts, Emma Wilson, Lynn Wilson

Guidelines for Online Fundraising

If you raise money for the Branch through your own Just Giving or other online sites, please follow these guidelines:

When setting up the fundraising page, identify the MND Association as your chosen charity and be clear that you are fundraising for the Branch. This is required by law.

Email our Branch Treasurer, Naomi Neville (WLMNDA@njneville.plus.com) to confirm that you want the Branch to receive the money. Naomi will pass this instruction to the Association who will then transfer monies received from the site to the Branch.

Any questions: do get in touch with Naomi.

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.



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Care and Support

Support Groups

The four support groups continue to go really well with attendees saying how helpful they find them. The four groups 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. 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.



Diary Dates 2022

London Carers Group

7 June, 5 July, 2 Aug, 6 Sept, 4 Oct, 1 Nov, 6 Dec

Evening Online

Carers Group: 29

June, 27 July, 31 Aug, 28 Sept, 26 Oct, 30 Nov

NW & West London Support Group: 22

June, 20 July, 16 August

Recently Diagnosed Group:

17 June, 15 July, 19 August

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

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.



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Campaigns

Spotlight on Campaigning

As part of its provision of information and training for volunteers, National Office held a Spotlight on Campaigning event on 23 March. The online evening session was organised and hosted by Amy Ramsay, Senior Campaigns Advisor.

It began with an update from Niall Murphy, also a Senior Campaigns Advisor, on the Association's current campaigns. Niall explained that, thanks to campaigning efforts, real progress was being made with United to End MND, Scrap 6 Months and Act to Adapt. (See the latest news here:

<https://www.mndassociation.org/category/campaigns-news/>)

Amy then hosted a Q and A session where a panel of three volunteers (Ian Lev - who is living with MND, Sue Heal and Mark Gately) talked about their experience of campaigning for the Association.

Why Campaign?

The panel saw the purpose of campaigning as raising awareness about MND, and the changes that need to be made, with local councillors, MPs, GPs and other decision makers. It's a step-by-step approach and can take time. But all agreed that when change does occur, it's extremely satisfying.

Passion, Patience and Persistence

The characteristics needed are being able to listen to others' points of view, understanding the purpose of the campaigns, and feeling comfortable talking and networking. Ian mentioned the need to be willing to approach people who you've not met, plus the benefit of having a good sense of humour! Mark summed it up as having passion, patience and persistence.

Although this might seem daunting at first, all three volunteers emphasised that there's lots of support available from the Association. It's a role people grow into at their own pace. Sue said she really felt part of a team and had learned lots.

Next Steps

Our Branch would like to campaign more, but we need another volunteer – or even two – to help. If you think this is something that might suit you, do contact Kapish - even if it's just for a preliminary chat.

To learn more about the current campaigns and the many tools and resources available, check out the website: <https://www.mndassociation.org/get-involved/campaigning/>

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



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