

## Welcome!

In this newsletter we report on our **Branch Activities**, starting with our September Open Meeting when we found out all about voice banking and other communications projects. We are now looking forward to the next Open Meeting, our seasonal party. Although it will be held remotely, we are promised lots of fun as Jeremy Vine will be hosting one of his great online quizzes.



**Jeremy's first remote quiz was a great success**

In our **Fundraising** section (Page 3), we learn about Tribute Funds to remember those we have lost, with an excellent example from Steve White.

In our **Care and Support** section (Page 4), our Area Support Coordinator, Lisa Burnard, shares her thoughts on support groups and other forms of remote communication and support.

While our local **Campaigning** is still quiet, National Office continues its campaigns. The most recent is Act to Adapt and your input is invited. Read more on page 6.

This year marks the 25<sup>th</sup> Anniversary of the setting up of our branch. In a special supplement to this Newsletter we look back on those early days and some of the highlights. This includes a very warm message from Association CEO, Sally Light.

## Branch Contact

Don't forget we now have a Branch Contact – Jenny Gadsby. She is ready and waiting to hear from you! As Branch Contact, Jenny responds to enquiries from people living with MND, their family and friends. She can explain how the Association supports people affected by MND, direct you to appropriate sources of information, and tell you about our branch activities. You can contact Jenny on email ([gadsbyj@hotmail.com](mailto:gadsbyj@hotmail.com)) or through the dedicated Branch Contact number: 07879068870.



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 2020, Issue 112

# Branch Activities

## Our Open Meeting

Our Open Meeting went ahead on 20 September. Although held remotely by Zoom, it offered a great chance for people to chat and 'see' each other.

Kapish welcomed everyone and said how important it was to connect in these difficult times. He invited people to say how they were communicating with each other. We learned that both National Office and the AVs have put in a huge effort to stay in touch remotely with people living with MND. While not the same as direct contact, it is working. It was felt that there are some benefits in remote communications. In future, a mix of face-to-face and remote communications might be the way forward, especially for those who find it hard to travel.

Improving communications was the subject of our talk by Richard Cave, the Association's Project Manager of Speech and Language Therapy. Richard updated us on two current projects:

### Voice Banking

With voice banking a person records a set number of words and phrases. Then, they can type what they want to say into their communications aid; the words are retrieved from the voice bank and spoken out loud. While delivery is not always 100% natural, it is very close to the person speaking in their own voice.

As 8 out of 10 people living with MND can encounter speech difficulties, this is a real benefit. The Association can help set this up, will provide the recording equipment, and help with funding.

The process involves recording just 350 words and phrases. It used to be very time-consuming but can now be done in less than two hours. As Richard says, 'Do it and forget about it.'

### Project Euphonia



Speech recognition systems like Google Assistant are increasingly popular. In response to spoken commands they can control the TV, turn lights on and off, answer the door, seek directions, play music, and carry out thousands of other tasks.

However, people with speech difficulties (also known as dysarthria) often find that speech recognition systems don't reliably understand them. If Google Assistant can be trained to understand dysarthric speech, its functionality will be available to more people. It could also help transcribe dysarthric speech on a screen in real time. Both uses could really help people living with MND.

Euphonia, a Google Research project, aims to improve how such systems recognise impaired speech. To do this, the research team needs to record many examples of dysarthric speech. If you have a voice that is difficult to understand, and would like to help, please contact Richard:

[richard.cave@mndassociation.org](mailto:richard.cave@mndassociation.org)

Find out more here:

<https://sites.google.com/view/project-euphonia/>.

## Diary Dates 2020

Seasonal Party:  
Sunday 6 December

Open Meetings 2021:  
Dates to be confirmed

West London & Middlesex  
Branch Support Group:  
Tuesday 24<sup>th</sup> November  
Tuesday 15<sup>th</sup> December  
Tuesday 19<sup>th</sup> January 2021  
Tuesday 16<sup>th</sup> February 2021  
Tuesday 16<sup>th</sup> March 2021  
Meetings to be held by Zoom,  
starting at 11am.

Monthly Pan London Carers  
Group:  
1<sup>st</sup> December  
5<sup>th</sup> January 2021  
2<sup>nd</sup> February/2021  
2<sup>nd</sup> March 2021  
Meetings to be held by Zoom,  
starting at 11am.



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# Our Seasonal Party

## Save the date: Sunday 6 December

Due to Covid, we are holding our seasonal party remotely, by Zoom. It would have been wonderful to meet up in person, but we hope you will all join us for this remote get together to exchange seasonal greetings.

We are delighted that our branch Patron, Jeremy Vine, will be conducting one of his excellent quizzes online, helped by his daughter Anna.

The two of them held a remote quiz earlier in the year and it was a huge success. As it's online, the quiz is non-competitive – there is no 'winner' so it's all quite relaxed. Everyone is invited to submit answers in the 'Chat' function and share any other thoughts, or you can just watch. Whatever you choose to do, it's bound to be great fun.

We plan to start at 3pm. We will send out final details, with instructions on how to connect nearer the time. ***We do hope you'll join us!***

## Contact Us

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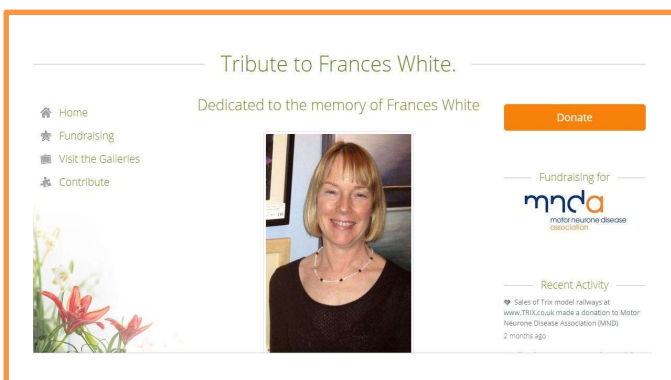
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## Fundraising

### Tribute Funds

Have you thought of setting up an online Tribute Fund? These are memorial pages where family and friends can remember someone special and raise money in their memory. Tribute Fund pages are easy to personalise with stories and photos of your loved one, helping you celebrate their life. You can also leave messages of support and invite others to dedicate donations in their memory. A well-known bereavement website is MuchLoved.com. It houses the MND Tribute Garden which you can see here: <https://mnd.muchloved.org/Tributes/>



You can also use Tribute Fund pages to sell items. Steve White set up the Frances White tribute fund in memory of his wife, Frances who died in 2018. <https://frances-white1.muchloved.com/>



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## Tribute Funds

As we have reported in previous issues, Steve has generously donated the proceeds from the sale of Frances's poetry book, 'Dandelion Child', to the Association. His model railway hobby has enabled him to donate a further £2000, from sales of vintage Trix model trains via his website [www.TRIX.co.uk](http://www.TRIX.co.uk). Steve has been collecting Trix for about 40 years and is an expert at repairing and valuing them. Locos, carriages, wagons and accessories are listed on the website's 'for sale' page. The page displays the MNDA logo and explains that profits are for the charity.

Steve says, 'During the Coronavirus crisis, Trix enthusiasts have had more time to pursue their hobby, and I've been able to buy and sell more. Very soon, I'll have another £1000 to donate to the MNDA. If you have any old Trix model railways, please get in touch.'

Steve posts updates on sales of the poetry book and Trix items on Frances' Tribute Fund page to encourage further donations. If you'd like to set up a tribute fund in memory of a loved one, and would like to support the Association, it's very easy. The MNDA website provides a step by step guide here: [www.mndassociation.org/tribute](http://www.mndassociation.org/tribute)

Would you like to share an opinion, letter, story, or idea with our readers?  
[allisonhmnd@gmail.com](mailto:allisonhmnd@gmail.com)

## Paddington Collection Cancelled

We had hoped to hold our Paddington Station Collection on 16 December. Unfortunately, because of Covid, we have decided to cancel. As Kapish explains, 'The Collection is a great fund raiser for us, but we are putting safety first. Social distancing at this time is a must, so we feel we can't run an effective collection. We hope to be back next year and, as usual, we'll be looking for volunteers.'

## Care and Support

### Grants Still Available

Grants are still available to support people living with MND who are struggling with additional everyday living costs as a result of Covid-19. Previously known as Emergency Grants, Covid Grants can be used to help with grocery shopping or other bills. Use this [Application Form](#) and National Office will arrange payment via BACS transfer, rather than sending cheques. The process is simple, and these grants are not means-tested. To find out more contact National Office Support Services via [email](#) or call 0808 802 6262.

The original cut-off date for these grants was October 31. This has been extended and will be further reviewed at the end of January.

Quality of Life Grants, Carers' and Young Persons' Grants remain available too. For more information and application forms, follow this [link](#).

### 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](http://www.mndassociation.org/benefitsadvice) to

send an e-mail or start a web chat



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### Virtual Communication is Catching On

In our last newsletter we reported that Lisa Burnard, our Area Support Coordinator (ASC), has been busy working on virtual support groups and other ways of staying in touch. We asked Lisa how things are going.

#### Support Groups

With Ahmed Abdeldayen, Lisa runs the pan London Carers' Support Group. With Sophie Stribling, she helps with our own West London Support Group for people living with MND. Both groups now hold their meetings remotely by Zoom. Lisa is very enthusiastic about the job these groups can do. They enable attendees to share thoughts, ideas – and emotions – with their peers. They cover a wide range of issues, from perhaps some advice on peg feeding, suggestions on equipment selection, or information about available grants. Any questions are welcome.

Sharing thoughts on different topics can benefit everyone, and sometimes a WhatsApp group is formed to explore a subject in more detail. A buddying system offers a further level of support. Those who have attended these remote meetings speak highly of them. Lisa invites all carers and people living with MND to give them a try.

The West London Support Group meetings are usually held on the third Tuesday of the month, at 11am. Future dates for these, and the Pan London meetings, will appear in this newsletter, on our website and via social media. Zoom joining instructions will be sent separately by email. If you want to know more, please contact Lisa Burnard at: [Lisa.Burnard@mndassociation.com](mailto:Lisa.Burnard@mndassociation.com)

#### Regional MND Association Contacts

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Lisa Burnard  
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01604 800658



#### 1-2-1 Contact Welcome Too

Lisa appreciates that some people prefer to handle certain matters, especially sensitive issues, privately. She emphasises that this can be, and is, done too.

The Chat function on Zoom, or a private phone call are always an option outside the group meetings. She adds that people need not worry about whether they should be contacting her or Jenny Gadsby, our Branch Contact.



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## Virtual Communication is Catching On

The two work closely together and either are happy to be contacted. As Lisa says, 'We cannot solve all problems, but we can certainly help with problem solving.' Although many prefer face to face contact, there are advantages in using these remote communications, especially for those who find it hard to travel, or have time limitations. Lisa believes remote communications are becoming the norm and will play some part in our life after Covid. As always, it will be about getting the balance right.

## 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](mailto:mndconnect@mndassociation.org)

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 No 294354.  
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 Disease Association,  
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## Campaigns

### Act to Adapt Campaign Launched

National Office has launched a new campaign: Act to Adapt. It is pushing for fairer and faster home adaptations and making moving to an accessible home easier for people with MND. National Office invites people living with MND, who have experienced difficulties getting such adaptations done, to share your story on the website or write to your local councillor. Find out more [here](#)



You can check out progress with other campaigns on the Association website too.

Branch is on Instagram

Want to see the branch in action? Follow us  
[@mndwlandmiddx](https://www.instagram.com/mndwlandmiddx)



## 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](mailto:communications@wlmnda.co.uk) with your request and giving your full name.



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