

# Oxfordshire Branch Newsletter



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# Oxfordshire Branch

## “Walk to D’Feet MND” 2024



On Saturday 5th October in the glorious Blenheim Palace setting and on a sunny, blustery day, it was time, once again, for the annual MND Association Oxfordshire Walk to D’Feet 2024 event. What an amazing, uplifting day it was too! The sun shone down on an unprecedented 187 walkers taking part this year. Participants chose between the 2 mile and 5 mile wheelchair-accessible routes and raised a staggering **£6,068!**

None of this would be possible without the wonderful Jill Garner, who masterminds this annual event. Jill said “It’s over a year ago now, that my father sadly passed away from MND. It was his strength and support that drove me to want to help, in any way I could, with raising funds and awareness for the MND Association. It was wonderful to see everyone again this year and what a turnout! A huge thank you to everyone involved and their generous donations”

**Here’s to next year!**



# Witney ParkRun

The Oxfordshire Branch of the MND Association 'took over' the Witney parkrun on Saturday 21st September. A parkrun 'take over' means that in return for providing at least ten volunteers, a charity can give a shout out to the charity and its work. Through the Facebook page the week before, all parkrunners were encouraged to dress in the MND Association colours of orange and blue.



Jill Garner gave a wonderful shout out on our behalf to the throngs of runners. She eloquently explained that support for the MND Association leads to awareness, which leads to fundraising, which will one day hopefully lead to a cure for this horrendous disease. Jill also publicised the upcoming Branch Walk on 5th October at Blenheim Palace.

In total, there were 235 parkrunners, including visitors from Edinburgh, London, Leamington, Poole, Derbyshire, Chipping Sodbury and Chippenham, and a Hen Party from Warwick!

The MND Association volunteers who made the 'takeover' possible included the whole Ferry family – Ian, Helen, George and Jessica; John Connaughton, Dave Little, Luke Robson, Jill Garner and her partner Doug Millar, and Cathy Burch (see picture). Very many thanks to you all!

We are deeply indebted to Tamsyn Wymer (Co-event Director and parkrun organiser extraordinaire) and her husband Dan Wymer (Race Director) for allowing us to share awareness of MND, the work of the Association and the annual Branch Walk to so many people. It was a hugely positive and supportive event!

## New branch volunteers: Emily & Charlie

Hello! We're Emily and Charlie and we are the new volunteers helping out as social media officers for the MNDA Oxfordshire branch. This charity means so much to us as our dad had ALS, so we decided we wanted to do something to help and do our part. As we grew up around social media, we thought this would be the perfect opportunity. As part of our volunteering, we've established the Instagram for the Oxfordshire branch, please follow and tag us at ***mnda\_oxfordshire***.'

We really want more people to know about the new Instagram, so if you have any other ideas to incorporate this more in the newsletter, we would love that.



Thank you so much,  
Emily and Charlie

### Fundraising & Awareness

Let us know what's happening.....We'd love to hear about your fundraising or awareness activities and include your stories in the next newsletter. Please email details and attach photographs, if you have them, to:

Keith Bird - Newsletter Editor - [keith.bird@mndassociation.org](mailto:keith.bird@mndassociation.org)

# A Celebration for Lesley



In August, we gathered to celebrate Lesley Ogden's 80th birthday and mark her steps towards officially retiring. Lesley has been an exceptional and highly-valued volunteer within our clinic here at the John Radcliffe Hospital in Oxford. It has been an absolute pleasure working alongside her in providing care for those living with MND.

The event brought together the MND clinic team, colleagues from the MNDA, and Lesley's family, including her daughter Kate, son Gareth, and husband John. The surprise element of the day was made possible by her family, who did a great job in getting her to the event without whispering a word about it! We held the event in one of our new seminar rooms and Hayley Pill decorated the venue beautifully.

We were also delighted to have a virtual guest appearance from Joyce Prince, who shared fond memories and reminisced with Lesley about MNDA's earlier days. The event was a beautiful celebration of Lesley's remarkable contributions and reminded us all of the invaluable role she has played in supporting the MNDA, especially within our clinic team here at Oxford. It was truly a day to remember.

## A huge thank you!

Your fundraising efforts and donations, large and small this year have enabled the branch to provide financial support to local people and their families affected by MND.

- Support grant contributions to respite care, wet room adaptations, stairlifts, a profiling bed
- Quality of Life grants for therapy sessions, ramps, contributions to a holiday, a manual wheel chair, short breaks
- Carers grants towards holidays, short breaks and a special treat
- Young persons grants towards a holiday

Also, funding for our support meetings and expenses for Association Visitors who provide individual support. The branch also contributes to research projects and services provided by the MND Association.

## Oxfordshire Branch Contact and Links:



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[www.mndassociation.org/support-and-information/  
local-support/branches/oxfordshire-branch](http://www.mndassociation.org/support-and-information/local-support/branches/oxfordshire-branch)





# An update from Rachel Woolrich

## – Clinical Psychologist

This is just a brief update on my role as clinical psychologist in the team. For more of a general overview do review my update in the Summer newsletter. I continue to contribute to the new patient clinic and feel that this is a useful point to frame the psychological landscape for families as they adjust to news. It has helped me follow up people who are more vulnerable and hopefully it has felt easier for people and families to reach out to me having met me already. I was privileged to take part in the 2nd UK PLS information day in Oxford. I gave a talk on the psychosocial impact of living with Primary Lateral Sclerosis. People joined from other countries and subsequently have messaged me to say how much they value our team's attention to the psychological impact. Colleagues and I have submitted our grant application to undertake a research project investigating this, so hopefully more news in the Spring.

Recently I've been asked to contribute to the expert core group of the MNDA alongside psychologist Emily Mayberry, so I look forward to broadening my contribution to the MND community. One of the biggest challenges for me is trying to be responsive and available as quickly as possible to patients/families in need. I think it's really important not to have a waiting list and so far I've just about managed this. It does however mean that there are periods when time between appointments is longer than is ideal and I continue to be mindful of this and whether I've struck the right balance. If any of you have had support from me, I always welcome feedback about what and how it was offered so I can keep improving things.

To finish, I'd like to recommend to people to watch the most recent MNDA Stephen Hawking Lecture given by Professor Rebecca , Consultant Clinical Psychologist from London, which provides an overview of her research into the efficacy of a type of psychological therapy for people living with MND (Acceptance and Commitment Therapy – ACT). This is the therapeutic model I use and it's wonderful to see it be proven effective in a trial. Hopefully this will add weight to the case for more investment in psychological support for people and families living with MND. Warm regards to you all.



## More Oxfordshire Fundraising - Sue Butler



On the 2nd November we were invited to the Upper Thames Caravan Club, by their Chair, Lisa Dymock Hemmings, to their AGM. We were presented with a cheque for an amazing £8,300. MNDA was their chosen charity for the last 3 years. Martin, myself and Linda Proto, who helps with fundraising, attended, which included a lovely lunch. We thank them very much for their amazing fundraising efforts.



On the 17th November we were invited to run a Tombola stall at Harwell Charity Fair. We had many wonderful donations and await a balance of funds raised for MND. We will receive full proceeds of the Tombola stall plus half of the proceeds from the coffee/tea stall and the raffle shared, with MS. We are expecting to have raised in excess of £1,000. Thank you, Kathryn Roberts Locke and Jeanette Roberts, for inviting us to run the stall which we will do next year too.

### Oxfordshire Branch Committee Contacts

Chair: Martin McLeman - [martin.mcleman@mndassociation.org](mailto:martin.mcleman@mndassociation.org)  
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# Oxford Clinic team

## - day retreat

The Oxford MND Clinic team had a day 'retreat' at Green Templeton College on September 12th to review all aspects of how the clinic operates and identify any areas for improvement. Part of this involved thinking about how to integrate all of the expanding research activity, which includes the vital contribution by people living with MND, in giving blood and other samples, but also taking part in trials, including the new EXPERTS-ALS ([www.experts-als.uk](http://www.experts-als.uk)) drug screening platform currently in development. All of this care and research activity now involves a much wider team from the John Radcliffe Hospital and Oxford University's Nuffield Department of Clinical Neurosciences.



from left to right: Sama Mugloo (EXPERTS-ALS laboratory scientist), Elizabeth Gray (MND research coordinator), Rachel Woolrich (MND clinic psychologist), Monica Passoni (EXPERTS-ALS laboratory project manager), Martin Turner (MND clinic neurologist and research lead), Jessica Newman (MND specialist nurse), Rachael Marsden (MND nurse consultant and clinic coordinator), Adrian Pacheco (Clinical research nurse), Alex Thompson (MND clinic neurologist & research co-lead), Sarsha Wilson (Clinical research coordinator), Hayley Pill (MND clinic secretary), David Lester (Clinical research neurologist-in-training), Nichola Simpson (MND clinic coordinator secretary), Phillippa Sharpe (MND clinic occupational therapist).

## WANTED

### Building a small equipment demonstration kit and loan library

We still need help.

Since my update in the autumn, we find ourselves still needing small items of equipment that you purchased that were useful, but are no longer used? We'd love to hear from anyone who would be willing to donate them to a small equipment demonstration/loan library? Phill Sharpe, Occupational Therapist at the MND Oxford Care Centre is keen to build up a small demonstration kit and if possible, a loan library for items such as button openers/cutlery or other small aids that might be helpful for people with MND.

Please do email Phill if you have anything you think might be of benefit to others that you are willing to donate. (NB – Small items only due to space and storage issues). [phillippa.sharpe@ouh.nhs.uk](mailto:phillippa.sharpe@ouh.nhs.uk)

**Please support your branch on  
our Just Giving page:**



[www.justgiving.com/fundraising/oxfordshirebranchmnda](http://www.justgiving.com/fundraising/oxfordshirebranchmnda)

**PLEASE NOTE THE  
CHANGE TO  
OPENING HOURS FOR  
MND CONNECT (BELOW)**

If you would like to talk to someone about MND, please contact our MND Connect team on:  
MND Connect is available 9am to 4pm Mondays to Fridays

**0808 802 6262**



# A warm welcome at the Family and Friends support groups

The first snow of winter fell on the day the Family and Friends group met in Abingdon in November, which was a bit different from the warm September one held there before. Those who braved the wintry weather were warmly welcomed and were treated to a visit by the lovely therapist, Amanda Munday, who came to offer relaxing hand and shoulder massages to those who wanted it. As a qualified nurse, she often has advice to give about painful legs and ankles as well. Newcomers to these meetings are made very welcome as we understand it can be a bit daunting coming for the first time. They often find it useful and supportive to share experiences and information with others who understand the difficulties that MND can bring, as well as hearing about each other's lives and interests, while enjoying a cuppa with tasty cakes made by our volunteers. The next Abingdon meeting will be in March.



Our Banbury support group met in October at the Cricket Club room. It is usually attended by Area Support Coordinator, Matthew Hollis who has a fund of information about MND and what the Association has to offer. This time it was hosted by regular volunteer, Ginny McCluskey. There were two newcomers - a person living with MND and a relative of someone with MND in a different county who wanted to find out more about it. They were joined by two other regular members. They are planning to meet again on December 17th and again in February.

On Saturday 25th January 2-4pm in Abingdon everyone will be welcome to the popular New Year Event talk about research by Dr Alexander Thompson from the Oxford MND Care and Research team (see details in this newsletter)

# **Oxfordshire Branch of the Motor Neurone Disease Association New Year Event**

Saturday 25th January 2025  
in the Christ Church Suite, Abingdon  
2pm -4pm

## **Working out why MND happens**

A talk on research by **Dr Alexander Thompson**



Dr Thompson is Associate Professor & Consultant Neurologist at the Oxford MND Care and Research Centre and is involved in developing neuro chemical markers for MND.

Our new year event is open to all our members, fundraisers and supporters, with time to socialise and ask questions about current research.

Cathy will be sending invitations but if you do not receive yours, please contact:  
[cathy.burch@mndassociation.org](mailto:cathy.burch@mndassociation.org)

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