

# Oxfordshire MNDA

Branch Newsletter

Spring 2023



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# Oxfordshire branch's New Year event



**The Oxfordshire branch's New Year event was held in the welcoming rooms at Christ Church in Abingdon. More than 40 people attended and listened with interest to our two speakers and were able to ask questions. Tea, cakes and socialising were enjoyed afterwards.**

Our first speaker was **Dr Rachel Woolrich the Clinical Psychologist at the Oxford MND Care and Research Centre**. Her post is relatively new and was funded by the Oxford Branch from a legacy. She works every Monday at the clinic, but unfortunately the funding for the post runs out in November 2023. She is preparing a business case for ongoing funding which will be submitted to the local NHS Trust for consideration. She gave a very clear explanation of what she has achieved in the last 18 months. She has had contact not only with the people with MND but also carers. Referrals are made to her from clinic staff but people can also email her with concerns. She received 61 referrals in one year, 80% were seen as video contacts. People are usually offered 2 to 6 sessions and contact is monthly. She bases her work on ACT (Acceptance and Commitment Therapy). This is a form of psychotherapy like cognitive-behavioural therapy that helps people develop resilience in the face of adversity, focusing on self-awareness and flexibility. For the rest of her post she is reviewing whether she can offer some group support alongside the team Occupational Therapist, and she will continue to contribute to the national MNDA developments in psychological provision. She can be contacted at [Rachel.Woolrich@ouh.nhs.uk](mailto:Rachel.Woolrich@ouh.nhs.uk)

Our second speaker was **Professor Martin Turner** one of the neurologists from the **Oxford MND Care and Research Centre**. The focus of his work is establishing biomarkers of disease activity for people living with MND, to more efficiently assess possible therapies. He also studies pre-symptomatic changes to the nervous system in carriers of genetic forms of MND with the longer-term aim of eventual primary prevention.

There has been a lot of publicity recently in the press about possible drugs for MND. Professor Turner was able to explain the challenges of drug trials and a view on some of drugs that have been making the headlines. He first explained that a diagnosis of MND can take a long time as there is no one specific test and it presents in different ways. He highlighted the value of the MNDA's work in making GPs and other health professionals more aware of key symptoms so that delay in referral to a neurologist is reduced.

He then discussed a concept new to most of us, an emerging biomarker for neurological disorders called neurofilament light chain. It can be detected in a blood test and its level gives an approximate indication of the speed at which a person's MND is advancing. Professor Turner pointed out there are a lot of drugs being tried for use with MND in various countries but the whole process takes a long time. Taken as a group level, neurofilament light chain offers the potential to use lowering of this marker as an early sign of benefit in a drug trial.

He then went on to discuss some drugs that are being discussed in relation to MND at the present time. The MNDA also gives detailed information about drug trials on its website.

MND Connect is available 9am to 5pm and  
7pm to 10.30pm Mondays to Fridays.

**0800 802 6262**

## Amylyx Pharmaceuticals

Amylyx Pharmaceuticals drug **Relyvrio** was developed in the USA and recently given a provisional licence by the FDA for use in MND. Professor Turner feels it has so far shown a very small theoretical clinical benefit over a very short study time and that it is unlikely to be approved by NICE, the UK equivalent. He felt this is a similar outcome to **Edavarone**, sold under the brand name Radcava, which is another drug licensed for use in MND in the USA, Canada and Japan on the basis of very limited evidence of beneficial effects.

## TUDCA

TUDCA is one of the main ingredients of the recent Amylyx Pharmaceuticals drug and is being independently tested in a clinical trial across Europe. The **TUDCA-ALS Phase 3 clinical trial** will look at the safety and efficacy of taking TUDCA in combination with riluzole over a longer period of time (18 months). This study should report its results later this year. Professor Turner added a warning against purchasing drugs online that have not completed clinical trials.

## Tofersen

**Tofersen** is drug that has recently received a lot of press coverage. It specifically targets cases of familial MND linked to changes in the SOD1 gene. This means it is only useful for about 2% of all cases of MND overall. There are some encouraging results, including reduction in the neurofilament light chain biomarker. The FDA will be considering it for approval in the USA very soon.

## MIROCALS study

Finally, the **MIROCALS study (Modifying Immune Response and Outcomes in ALS)** involved 12 different centres across the UK and continental Europe to assess the safety and efficacy of a drug interleukin-2 (IL-2) given subcutaneously for 5 days every 4 weeks. The headline results were presented at the recent MNDA International Symposium. They look positive but with a large caveat that the analysis is statistically 'adjusted' and Professor Turner advised waiting for publication of the full data in the coming weeks before drawing any firm conclusions.

He ended his very interesting and informative talk with a plea for a broader approach to treatment, including eventually giving people a combination of drugs, and studying future risk biomarkers in the wider population.

*Jackie Reeves (Association Visitor)*

## In appreciation of psychological support, Marion Dorrington writes...

I was diagnosed with ALS MND in October. **I am a recipient of support from the psychologist Rachel Woolrich.** I write in appreciation of the generous legacy and fundraisers who enabled her post. The effort and cooperation required between the Oxford MND Care and Research team, the JR psychology team and the MNDA in setting up this part time post for 2 years should not be forgotten.

I first met Rachael when the diagnosis was new and I was struggling with overwhelming emotion. It was wonderful to be able to talk with someone who understood the challenges of MND. Through our discussion, and her recommendation of an excellent book called the Reality Slap by Russ Harris, I learned remarkably good strategies for coping which I use every day.

So a big thank you to all you donors and fundraisers!

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

[facebook.com/OxfordshireBranchMNDAssociation](https://facebook.com/OxfordshireBranchMNDAssociation)

## Fundraising news

The branch is so grateful to those who get in touch with offers to raise funds for the branch both large and small which support people locally, provides grants for them and contributes to the work of the national association for research and care by our annual transfer of funds to the central office.

Many thanks go to .....

### Drayton Golf Club Ladies Team for raising £3,062

Teresa Browne, Ladies Team Captain at Drayton Golf Club for 2022 says that sadly a member of the ladies team was diagnosed with MND which inspired her to choose the Oxfordshire branch for her charity fundraising over the past year. They organised several events including sponsored local walks which raised over £1,000 on the MNDA just giving page. Over £3,000 came from raffles and competitions and they had a lot of fun in all these activities.



### Upper Thames Caravan and Camping Club to date have raised £1,760

Lisa Dymock has chosen to raise funds for the branch with the club members over the three years in her role as Chair. The latest donation came from one of their members who requested gifts for his birthday be directed to this funding which added to the amazing total so far. They are looking forward to the summer season to continue their efforts to support the branch.

### A Fete at Anchor Court

A Fete at Anchor Court, Oxford raised £869 for branch funds.....many thanks to resident organisers Rose Morgan and Elaine Catt who were helped by branch fundraiser, Jill Garner.

### Oxford in Camera

Stephen Church has donated proceeds to branch funds from his Oxford camera book which feature his stunning photos of Oxford. This is still available through this link:

<https://www.blurb.co.uk/b/11359517-oxford-in-camera-photography-by-stephen-church-ol?>

Ever creative and innovative Stephen has designed a novel solution to his head drop with the assistance of the Remap organisation who will make equipment for disabled people. This involves a strong magnet sewn into his colourful hat which attaches to another strong magnet on his wheelchair headrest so while wearing it keeps his head back. Otherwise he becomes the invisible man as his photo shows!



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## Dorchester on Thames fundraising evening at the White Hart hotel

On Sunday 29th January the White Hart Hotel at Dorchester on Thames hosted a Bingo evening together with an auction in support of Matt Husband, my son, and the wider Motor Neurone Disease (MND) family in Oxfordshire. The White Hart was buzzing with a full house and over a hundred people from the village and surrounding areas joining in the bingo and then bidding enthusiastically for the array of fabulous gifts which were generously donated by hotel suppliers, local businesses as well as many individuals. It was great fun and a fantastic success with £1700 being raised for the Oxfordshire branch of MND.

Shaun, the hotel manager generously hosted the event and proved himself not only to be a brilliant bingo caller but also a splendid auctioneer. Thanks too to others for working so tirelessly in preparation for the occasion as well as to all the staff at the White Hart for their support and enthusiasm in making this such a memorable evening for us all.

Matt and April first came to live in Dorchester on Thames in 1995 where they ran the post office for several years. Matt developed MND three years ago and, although he is now wheelchair bound, the White Hart has become his second home with its warm and friendly atmosphere. So a huge thank you to everyone who has generously supported Matt and our local Oxfordshire MND Association. Janet Husband



## Introducing new Association Visitor, Louise Groves

Hello, I'm Louise and I live with my husband and two children aged 7 and 10 in West Oxfordshire. In my free time I enjoy spending time with friends and family, cooking and walks with my dog Daisy.

My background is in nursing and at the moment I am training to be a counsellor. I am drawn to volunteering as an Association Visitor as I think I'm a good listener and enjoy working with people to support them. I feel privileged to have this opportunity to work with people living with MND and their carer's and am really looking forward to getting started.

If you are interested in having individual support from an Association Visitor please contact:  
[matthew.hollis@mndassociation.org](mailto:matthew.hollis@mndassociation.org)  
or Lesley Ogden [lao.ogden@googlemail.com](mailto:lao.ogden@googlemail.com)



## Grateful for grants

Having enjoyed years of uninterrupted care from Jane, my long-suffering wife, it came as a shock when last year she proved to be human after all. She was struck by a recurrent gut problem which in the end would have to be operated on, meaning seven weeks in all off caring duties. Well, she had earned a break! Our family are all in work and have their own lives to live, and so we would not call on them. The operation turned out to be a rushed job as the problem became acute.

So we had to find and fund carers to look after me while Jane was out of action. We explored very local firms and also emailed Rachael at the MND Centre. She put us onto the George Springall Homecare Partnership. In fact it's named after the elderly man with MND whom the partners, Dominic and Roxane Lane, cared for until his death. They are based in Abingdon, and have experience with MND clients. They proved to be just what we needed. As long as we were prepared to be flexible, they fitted me into their schedule at three days' notice, and so a nicely varied team of equally efficient carers came in to get me up in the morning and get me to bed in the evening. They were not only efficient but also interesting and interested. Local friends filled in during the day when needed.

So that was the finding sorted. But what about the funding? George Springall gave us a quote for the six weeks. As others will know, care is not cheap. I enquired at the MNDA who put us in touch with the Benefits Advice Service about possible benefits

<https://www.mndassociation.org/support-and-information/our-services/benefits-advice/>

No joy there. I'd also asked Lesley for advice. "Let me explore possible grants," she said. In the end she sent us information for two grants from the MND Association. Before long they were approved, and money appeared in our bank account. It didn't meet the full account, but it certainly was a great help to get some funding from the local branch. We are very grateful. Thanks a lot, Committee.'

**Jane writes:** 'One of the grants we received was a Carer's Grant, which was for me. It meant that I didn't have to worry about Michael's care, while I was out of action putting my feet up - on doctor's orders! Come to think of it, it was my first substantial break from caring for Michael with MND for twenty years.... However, to be honest, I wouldn't want to get used to it - well, not that way! Anyway, thank you very much.'

PS Happily, Jane's operation was successful, and she's now back in charge!

*Michael Wenham*

## Would a grant help you?

Quality of Life grants, Carers grants and Young Persons grants can be applied for directly to the branch or from the MNDA. Support grants covering things that have to be assessed by health and social care professionals have to be applied for through Support Services at the MND Association. Full details of grants and the appropriate application forms can be found on the MNDA website

<https://www.mndassociation.org/support-and-information/our-services/>

### Fundraising and awareness

Please let us know about any fundraising or awareness campaign and we will include your story or event in the next newsletter.

Information and photographs supplied to the branch secretary  
Lesley Ogden at: [lao.ogden@googlemail.com](mailto:lao.ogden@googlemail.com)

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## The Family and Friends Support Group....

...were made very welcome in March at **Wytham House** on the Eynsham Road near Oxford in extensive grounds which overlook Farmoor reservoir. Twenty of us met there and generous refreshments were provided in a very comfortable room. Information about travelling and accessible places to stay were exchanged, new friends were made and others we hadn't seen for a while reunited with each other while sharing experiences. We would like to take advantage of a repeat invitation to Wytham House later in the year.

A list of information gathered about accessible holidays and hiring equipment is available from Lesley the branch secretary. Information about travel and transport is on the MND Association website under useful organisations.

We would love to hear from you about holiday recommendations and experiences.



Our **Family and Friends Group** will visit **Millets Farm Centre** Frilford, Abingdon on 11th July at 2pm with refreshments provided in the Flower Market Café. Come and join us there for an afternoon out.

*Lesley Ogden*

## Banbury meetings are back

Dave Vale reports that the meeting held in April welcomed seven people to the cricket club venue in April and our Area Support Coordinator Matthew Hollis. Pete helped with refreshments and a lovely cake baked by his wife. There were some good conversations and sharing of information, added to which two or three people realised they knew each other before meeting here!

**Next Banbury meeting is Tuesday 27th June.** Contact: davevale30146@gmail.com T: 07309 446646

## You are all welcome to join us for lunch at our Summer Event

**Saturday 20th May 2023  
at 12-3.15pm**

Christ Church Suite  
Northcourt Road, Abingdon, OX14 1PL

Easily accessed from the A34 Abingdon. Plenty of parking and good disabled access.

A chance for all our members, supporters and volunteers to get together again to hear about all the branch activities, socialise and to find out information from each other and make new friends.

It will include a sandwich lunch with homemade cakes so it is important to let us know that you are coming by 17th May so that enough can be provided. After lunch there will be an inspiring talk about the MND Association.

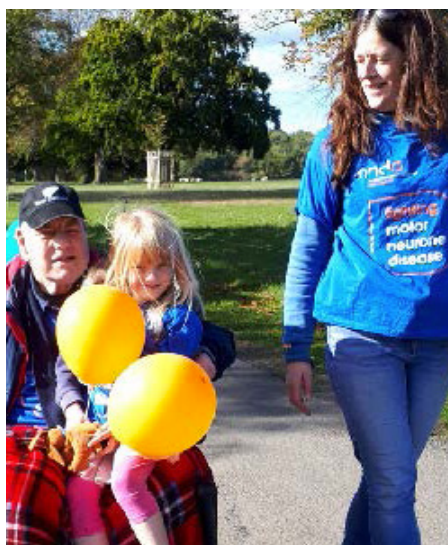
**Amanda Devlin our MND Regional Fundraiser**  
Fundraising projects, her role and the impact of MND  
featured in TV and film dramas

Please reply to: Lesley Ogden by 17th May so that enough lunch can be provided: lao.ogden@googlemail.com or call 01235 850372

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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# Save the date!



## The 12th Annual Oxfordshire Branch Walk in Blenheim Palace Park

Saturday 5th October  
1pm start

A popular fundraising event for families  
and friends to join with 2 mile or 5 mile  
routes on concrete paths.

For more details of registration contact:  
Jill Garner [jill.garner@outlook.com](mailto:jill.garner@outlook.com)



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