mnda
motor neurone disease
association

Summer 2025

Oxfordshire Branch Newsletter

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.... and more!

Branch New Year Event
‘How do we prevent MND?’

On 25th January this year, we were delighted to welcome Associate Professor & Honorary Consultant Neurologist, Dr Alex Thompson to speak at our New Year event. Dr Thompson was joined by DPhil Student, Beatrix Cardus, both of whom delivered thoroughly engaging, thought-provoking and above all, inspiring presentations, under the banner, **How do we prevent MND?**

Dr Thompson started the session by outlining the key questions needing to be answered, such as why does MND happen, who is at most risk and why?

MND is a rare disease but there are things we do know about why the disease happens. The causes are complex and, although we do know that genetics are a key factor in some people, they are not the whole story. He went on to talk about a range of other factors, such as cardiovascular health, metabolism eg. cholesterol, lower BMI, physical activity and tissue damage. Understanding all of these things will help work out who is at risk.

Research is hard but studying gene carriers will further help understand causes. The ACORN National Study is helping do that. An alteration in the C9orf72 gene, known as a repeat expansion, is the most common genetic cause of MND. The C9orf72 National Register and Cohort (ACORN) is a UK national cohort of people with or at risk of C9orf72. Samples of spinal fluid and blood, along with MRI scans with 1 to 2 yearly follow-ups, are taken.

ACORN
A C9ORF72 National Study

Beatrix then went into more detail about understanding C9orf72, using a recipe analogy.

“Imagine a gene as a recipe for a protein. A repeat expansion is a bit like having a recipe that repeats an ingredient over and over. If you’re making a cake, having this many eggs is going to ruin the final output, you’re going to make a lot fewer good cakes, and having that many eggs in the kitchen will interfere with other cooking processes”.

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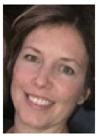
...continued - ‘How do we prevent MND?’

Beatrix went on to explain how when the DNA in your body’s cells are altered, it can lead to mistakes in the recipe, which change how proteins are made, leading to disease. 9 out of 10 people with MND will have no known genetic cause of their disease. However, 1 in 10 people will have an altered gene known to cause MND. The hope is that, by understanding genetic forms of MND, we will unlock knowledge which could lead to better prediction, prevention, and treatment for everyone with MND.

Essentially, measuring the length of the C9orf72 repeat expansion could help answer questions about C9orf72 MND. Also, looking at the length of the C9orf72 repeat expansion in different parts of the body and cell types, might shed light on how this gene alteration causes MND, and whether anything can be done to prevent it or slow it down.This project would not be possible without the hugely valuable contributions of people who have the genetic alteration in C9orf72 and their family members, who take part in the ACORN study.

Heartfelt thanks to our inspiring guest speakers and to those who came along to this event. As always, lunch and lively discussion was accompanied by the usual selection of delicious treats, baked by our branch volunteers.

Check-in with Rachel Woolrich



A brief update from me as Clinical Psychologist within the Oxford MND Care Centre. One thing I am finding very helpful is when I’m working closely alongside colleagues within the team, often providing joint appointments or approaches.

In our new patient clinic, I try to join one of my nursing or OT colleagues (Rachael Marsden, Jessica Newman or Phillippa Sharpe), after patients have seen one of the consultant neurologists for diagnosis. This allows us to attend to raw emotions at the time as well as give holistic guidance and support for those first few months.

It’s also an opportunity to signal how patients/families can access psychological support in the future. Alongside this, I am struck by the benefit of working jointly with colleagues to tackle a problem from different angles. For example, Phillippa Sharpe (OT) and I might work together to support a patient to access more meaningful and purposeful activity that has become more challenging. While Phillippa might support with practical adaptations, problem solving and work-arounds, I might support via thinking through psychological barriers, managing anxiety and developing clarity of values. Together it feels like we can make a much more effective impact on quality of life.

Colleagues in Sheffield are just writing up a research project looking at the role of clinical psychology within the multidisciplinary team working with MND so this will be a fantastic contribution to making a case for ongoing funding of the role.

Wishing you all a peaceful and warm summer ahead.

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‘Meet the Researchers’ – a Legacy Event

By Margaret Wright, Association Visitor

I attended the Meet the Researchers Day at the John Radcliffe Hospital on Friday February 28th.

It was an excellent event, organised by the MNDA legacy team, with an impressive line up of the John Radcliffe neurologists and their research team.

Professor Kevin Talbot spoke about the MND register. The creation of this database provides information about the characteristics and lifestyle of people with MND. What kind of people get MND? What is their life history? Where do they live? What do they eat? The register enables everyone with MND to contribute to the data.

Two of the younger researchers, who have grants enabling them to carry out their amazing projects, discussed their work and their findings. I was struck by the cohesiveness of the team at the John Radcliffe, and by how supportive and encouraging the neurologists are of their younger research colleagues.
Dr Beatrix Cardus described her research which uses new DNA sequencing techniques to look at hereditary MND. She is specifically investigating a gene called C9ovf72. This gene is the most common genetic element of MND. It provides instructions for making proteins, particularly in the motor neurones.

Dr Björn Vahsen talked about how he uses stem cells grown in a dish to model MND. He is specifically looking at brain cells called microglia and their involvement in MND.

A highlight of the event was the visit to the research laboratories on the top floor [from where there is a wonderful view over Oxford!]. We were taken to two laboratories where the technicians and researchers demonstrated their work, fascinating and at times, bewildering in complexity!

Afterwards there was a panel including Professors Talbot and Turner, Dr Alexander Thompson Consultant Neurologist, Dr Brian Dickie (Chief Scientist MNDA), Dr Nick Coleman (Head of Research at the MNDA), and Drs Cardus and Vahsen. Included in the questions afterwards were discussions about repurposing drugs for use in treatment of MND. In these studies, everyone takes the drug, there are no controls or placebos.

There was also much discussion about neurofilaments (NFLs). These are structural proteins within cells. When cell damage occurs, as in MND, their number is raised, and this serves as a biomarker showing the extent and progression of the damage. A short film was shown at the end in which Dr Brian Dickie commented on the great advances made over the last 25 years in MND research and knowledge. They have moved on from asking: “What’s going on here?” to “Now what can we do about it?”. It was an optimistic note on which to end the day.

Oxfordshire Fundraising

Elizabeth's Walk for MND

By Maureen Sears

Elizabeth is my daughter who sadly died last May with MND. She was a great walker and lived in London, close to the Thames. She liked nothing more than walking the local area with her dog, Olive. To pay tribute to Elizabeth's life, I am intending to walk the Thames Path from the Barrier to the source, accompanied by friends along the way. I am hoping to raise £3,000 for MND research and also to contribute to the MND Association, to help local branches who offer advice and support to people living with MND.

I intend to walk two days a week and will follow the sections advised in the Thames Path Walk book, hopefully achieving approximately 20 miles per week. I will log my progress and let people know where I am each week, inviting walkers to join me. I will also alert walkers to the sections that are wheelchair friendly and accessible for everyone.

This information will be found on the 'Just Giving' page - the aim is to make this venture a 'community' project, open to walkers with two or four legs, plus wheels who are keen to make a difference. The purpose of Elizabeth's walk is to raise money to enhance the lives of people living with MND and to succeed in the aim of the Association to FIND A CURE. Any donations would be very welcome.

Link: Maureen Sears Just Giving page

'Love Me Do' Concert for MND

One April evening in Kennington, a concert entitled 'Love Me Do' was held in support of the Motor Neurone Disease Association, and was thoroughly enjoyed by a group of generous supporters. The branch is pleased to publish this acknowledgement from the organisers.

Nicola and I just wanted to say a **huge thank you** to everyone who came along on Saturday night - and to those who donated from afar. It was an absolutely incredible evening and we were truly overwhelmed by all the love, support and generosity in the room. Thanks to your kindness, we raised **over £4,000 for the Motor Neurone Disease Association,** through ticket sales, donations, the bar and the raffle (thanks Jill Garner!). An amazing total that will support the vital work for those affected by MND.

We really hope those who joined us, enjoyed the music and the atmosphere as much as we did. It meant the world to do this in memory of my Mum and Luke's Mum. We feel so lucky to have been able to do something with all your help. With heartfelt thanks.

Laura O'Mahony & Nicola Taylor

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

Family & Friends Support Groups welcome you

These groups are held on alternate months in Abingdon and Banbury and provide a chance for those affected by MND to get together informally, to share information and experiences with others in a similar situation and also the knowledgeable volunteers. It is an opportunity, as well, to share many other unrelated topics of interest which arise.

At our March meeting in Abingdon a fairly recently diagnosed lady came with her daughter who cares for her. Although she had speech difficulties, she told us she was so pleased to finally meet someone else who is facing the same struggles as her. She agreed to and really enjoyed a massage for her uncomfortable legs by therapist, Amanda, who was attending that day. Her daughter learned more about MNDA Quality of Life grants, Carers and the Cost-of-Living grants that are available and how to apply for them. Another carer really appreciated a shoulder massage.

Former carer Maureen told us about her planned fundraising walk along the Thames Path. Everyone finds a warm welcome, enjoyable refreshments and often friendship, whether they come along early in their MND experience or whether they decide to try out these gatherings later on.

You are more than welcome to join us, please get in touch with our branch contact Lesley Ogden (details shown at the foot of this page).

Our next dates are:
- Tuesday 22nd April 2- 4pm will be at the Cricket Club in Banbury
- Wednesday 16th July 2 - 4.30 pm A visit to Millets Farm and Garden Centre, Marcham
- Tuesday 23rd September 2- 4pm will be in the Christ Church Lounge Room, Abingdon

A Trishaw Trip around Blenheim Palace Park

By Susan Brayton

If this is an outing that might appeal to you, please get in touch with Janet at fudge3484@aol.com, who can tell you more about Cycling Without Age, a charity that runs these trips.

My friend, Sue, sent me a WhatsApp message to ask me if I fancied going for a ride on a Trishaw. Now here I must tell you that she has been trying to get me to travel on a bus for the last year or so! I know what a bus is but I had no idea what a Trishaw was! Apparently, her friend, Janet, had offered to take me. "Are you coming too? " I replied nervously! She wrote back to say that she was, so, thinking, I'm game for anything, I accepted the invitation. I was nearing my 80th birthday and have a rare form of MND which affects my mobility and speech. We wrapped up warmly and even wore matching red hats (!) because it was a very cold but sunny day. Janet was waiting on her drive for us, and there it was - a TRISHAW, complete with a red lap cover to match our hats! Fortunately, the footrest on it lowered and Sue and Janet helped me to sit comfortably on the seat. Wrapped up against the cold, off we went with me clutching my Yorkshire terrier, Ella. I was pleased that the 'machine' was turbocharged otherwise Janet would have had trouble peddling two well-fed old ladies forward! My friend said "It was so exciting and exhilarating to feel the wind and sun on my face." We stopped near the lake and drank tea and ate cake. A few passers by stopped to admire the trishaw and ask questions about it, which Janet expertly explained. I think we will be featured on several Japanese tourists' holiday photo albums, as well!

New Chair for the Oxfordshire MNDA Branch

The branch would like to announce that Martin McLeman has stepped down as Chair after 3 years at the helm. Huge thanks from us all, for his leadership and inspiration. He will be greatly missed.

We are delighted to announce Sue Butler as our new Chair. Sue has been a hugely valued volunteer and committee member for our branch for more than 10 years and is a truly accomplished fundraiser! Please join us in congratulating Sue on her new role.

This newsletter is published by Oxfordshire Branch of MND Association. The views expressed (in the newsletter) are not necessarily those of the MND Association or the branch. The products and services mentioned or promoted should not be taken as recommendations by the Association or branch, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact Lesley.Ogden@mndassociation.org or write to Oxfordshire Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ

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Oxfordshire Branch
Summer Event and Lunch

Saturday 17 May 2025

in The Barn, Christ Church Abingdon,
Northcourt Road, Abingdon, OX14 1PL

(Easily accessed from the A34 Abingdon, with plenty of parking and good disabled access)

12 midday to 3.30pm

This summer's guest speaker will be
Colin Capper, MNDA's Senior Head of Integrated Services & Delivery
This is an excellent chance for our members, fundraisers, supporters and volunteers to get together to hear about the branch's activities and to socialise over lunch with homemade cakes.

Please reply to **cathy.burch@mndassociation.org by 8th May**,
so that we can ensure there is plenty of lunch for everyone!

Oxfordshire Branch
Walk to D'Feet MND 2025

Save the date!

The Oxfordshire Branch Walk in Blenheim Palace Park
Saturday 4th October 2025

A very popular annual fundraising and awareness event for families, friends and supporters to join together to walk a 2 mile or a 5 mile route on wheelchair accessible paths in these famous attractive grounds.

For more details and registration contact: jill.garner@mndassociation.org

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