

Oxfordshire MNDA

Branch Newsletter

Summer 2024



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Motor Neurone Disease: is there a cure?



Professor Kevin Talbot, Head of Department of Clinical Neurosciences at Oxford University, kindly gave up his valuable time to talk to us at the Oxfordshire Branch's New Year event in January.

We were delighted to welcome Professor Talbot at the event which took place at the Northcourt Community Centre in Abingdon, this year. With more than 30 people in the audience, we were keen to hear how the UK MND Research Institute is leading the way in collaborative research to speed up the search for treatments.

Professor Talbot took the audience through an inspiring and positive presentation, the title of which was *Motor Neurone Disease: is there a cure?* He kicked off by acknowledging Doddie Weir, Scotland rugby player (1970-2022) whose foundation has gone on to fund research projects across the UK and donated generously to the MND Association's support grant programme.

Professor Talbot gave the audience a reminder of the nature of Motor Neurone Disease and then went on to highlight the key problems which need to be solved, referring to the Epidemiologic Trends of Amyotrophic Lateral Sclerosis (ALS) in Ireland, 1996–2021 study which showed that survival of ALS is not changing over time and that its incidence is increasing as the population ages.

What was clear from what he said is that we need to stop the disease progressing at the earliest stage possible. We need to establish when the disease really starts, define a way to identify damage at a time when there is possibly no awareness of symptoms, and ultimately start treatment at this stage. Earlier diagnosis is crucial but diagnostic delay has not changed. Currently the order in which things go wrong is very unclear and we don't understand why the disease progresses rapidly in some and slowly in others – there has been no change in survival rates and available drugs have minimal impact.

Professor Talbot also talked about the 'United to End MND' campaign, which began in 2019 involving people with MND, neurologists and charities joining force for the first time. With research into MND progressing faster than ever and with a concerted effort, treatments which have a significant impact could be found in years rather than decades.

He also talked about the 'UK MND Research Institute' and its vision to accelerate drug discovery from laboratory science to phase 3 clinical trials, to make MND a more treatable condition. He cited the ACORN study which aims to identify and characterise people with MND and asymptomatic family members who carry the C9orf72 gene mutation, and create a national register of this cohort, facilitating further research and study participation.

We thank Professor Talbot again, for sparing his time to enlighten the audience about the work that's happening to address the important question of whether, or not there could be a cure for MND. All in all, he gave the audience confidence that, thanks to him and his colleagues, we are heading in a positive direction in the search for a cure for this devastating disease.

The usual refreshments, which included a delicious array of cakes baked by our talented volunteers, were on offer after the talk and we were delighted that Professor Talbot could join us for this too, and to answer questions people in the audience had.

Keith Bird

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

0808 802 6262

Rachel Woolrich gives us an update on her clinical psychologist post at the Oxford MND Care & Research Centre

I was thrilled to be appointed to continue in my role from January 2024 with 3 days a week dedicated to the role for 2 years.

It is fantastic that the MNDA is able to financially support the post - we all hope that the NHS will be able to take this on in due course. The renewed and augmented post has allowed me to provide some continuity to patients I was already working with and also to consider how I can improve what I offer to the team as a whole. The first development has been to join the team for new patient clinics on a Monday afternoon. After a diagnostic appointment with one of the consultants, our new patients come through to see Rachael Marsden, Jessica Newman or Phillipa Sharpe alongside myself to take stock and think about priorities for the first few weeks after diagnosis. This has allowed me to share some psychological information about what to expect, managing strong emotions, telling others the news, as well as introducing them to the ongoing support I am able to provide alongside the team. This model allows me to offer a planned follow up quickly and patients have shared that this has felt reassuring and comforting at a time when life feels flipped upside down. As a team we are also reviewing and developing our new patient information booklet and I will be providing an outline of what to expect and how to cope in the first few weeks post diagnosis. In addition to this, my increased capacity has meant I can offer to see patients more frequently when appropriate.



Alongside the clinical work, I am also establishing a few other initiatives that contribute to the team. Firstly we are aiming to offer online peer reflective supervision to clinicians across the region working with patients living with MND. We are fortunate in Oxford to have a fantastic team to support each other, but others working out in the community can be working in isolation. This space hopes to provide a regular opportunity to share expertise, discuss complex cases and support each other's wellbeing. More recently Phillippa Sharpe (OT) and I have started to draw up a research project proposal to investigate the experience of living with Primary Lateral Sclerosis and we hope to share more at the PLS patient/carers day being organised for the autumn. This is a really exciting opportunity to contribute to improving understanding and ultimately care.

Sometimes people ask me how psychological approaches can help people who are facing MND. It's important to remind ourselves that overwhelming emotions are a normal response in this situation and learning how to make space for these is key. As human beings we instinctively want to push strong negative emotion away as it is so painful. However this locks us in an additional battle, using up our precious energy, taking us away from other important experiences. And the bottom line is that avoidance doesn't work - the pain doesn't go away. By learning to relate to our pain in a different way, we can see that it shines a light on what truly matters, and is an important part of validating the life we lead and the suffering faced. My role, and that of the whole team, is to be alongside people in their suffering, to help them spot mental traps we all fall into as we try to cope and to connect to living meaningfully even when facing loss. I am regularly humbled by the lessons I learn from patients in this regard.

Rachel Woolrich

The Oxfordshire branch committee are pleased to have agreed to allocate £5,000 towards maintaining this very valuable post having received many reports of how much it is appreciated by local people living with MND and also others who are supported by the Oxford MND team.

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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Introducing new branch volunteers who have recently joined our team

A very warm welcome to Cathy Burch and Keith Bird who joined the committee late in 2023.....



Cathy sadly lost her brother, Jimmy, to MND in May 2020. She wants to support others with MND, and to help in any way she can to finding a cure. Cathy has two teenage children and a dog, and currently works in teacher training at the University of Gloucestershire. In her spare time, she enjoys running and playing music.

Keith lost his younger brother, Ben, to MND in May 2010, aged 39. Having recently retired, he's keen to play a part in ensuring that people facing MND receive the vital support and highest quality care they need and to support MNDA's mission to find a cure for this devastating disease. Keith is married and has three adult children. He lives in central Witney with his wife and little dachshund Arthur. From a career perspective, Keith is a marketing and communications professional, the last 15 years being in senior leadership roles in the education sector. In his spare time he's trying to get fit!

.....and **Michael Curran** a new **Association Visitor** to join 5 others in the branch AV support team

Michael was originally from Belfast and apart from a year, teaching English as a foreign language in Venice, he has lived in Oxford since 1982. He was posted to Africa for a while as an Assistant Medical Records Officer where he served in the Voluntary Services Organisation. He has also been a professional actor in many stage productions although now, more occasionally. His hobbies are swimming and tennis. He became interested in supporting people with MND when a neighbour and a tennis partner were affected by MND. He has been involved with the fundraising efforts which were held where he lives.

If you or your family would like to find out about support on an individual basis by a trained branch Association Visitor please get in touch with matthew.hollis@mndassociation.org or lesley.ogden@mndassociation.org.

Time for a change!

After gathering and compiling all the articles for the branch newsletter since 2012 and working with Matthew Jones who produces the newsletter in this attractive and eye catching format, I am pleased to tell you that we now have a new newsletter editor in well qualified **Keith Bird**. You will read his interesting articles contributed to this edition and we look forward to his new ideas and a new look in the future. He will welcome your articles to include in the September issue keith.bird@mndassociation.org.

Very welcome too is **Cathy Burch** whose impressive enthusiasm and perceptive approach has led her to take over a number of secretarial activities from me after my 20 rewarding years of being on the committee.

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Raising funds for the branch

The branch is always pleased to be nominated for charity fundraising by organisations often keen to support local charities while enjoying their activities. The recent efforts and publicity around Doddie Weir, Rob Burrows, Kevin Sinfield and the MNDA, not to mention the Coronation Street coverage, have led to more approaches from clubs, workplaces and other organisations which are very welcome.

The Branch received £2,166 from rural and countryside sporting events

Thanks to Jeff Paybody, and friends Andrew Holt, Charles Gowling, James Linnell and Richard Wright from Northamptonshire who decided to raise money at a number of local rural and countryside sporting events they are involved with in Northamptonshire and Leicestershire over the winter period. Jeff has a very good friend who farms in Oxfordshire who has MND and suggested the Oxfordshire Branch as the benefactor for the money raised.

He says “I was amazed by the generosity of friends and guests at these events who gladly offered to support MND and the work it does to fight this terrible condition and we hope to continue to raise much needed funds for MND going forward”

Former Oxfordshire branch committee members John and Stella Waterer.... organised a concert which featured a piano recital in St Kenelm’s Church in Enstone on 3rd March

Stella, a greatly valued former Association Visitor Co-ordinator, says.....

“ I was on the PCC and knew our church was looking for a grand piano. David Marriott, a talented pianist and friend of our daughter, was aware of this and contacted me. The price was right, transport was organised and St Kenelm’s had a lovely piano. David offered to do a recital in honour of this if we would organise it. We went ahead and then thought any proceeds could go to the MNDA Oxfordshire Branch.

David chose an excellent programme featuring the music of Brahms, Schubert, Clara Schumann and Robert Schumann and introduced each piece before he played. Everyone who was there thoroughly enjoyed it. We had many appreciative comments. We took over £300 and when a fee was paid to the church the balance of £230 was donated to the MNDA through the Oxfordshire Branch”



Thanks to all our supporters who raise funds in large or small ways which enable us to support people living with MND locally. Also the branch contributes funds to the important support and care activities of the MND Association and the research that they commission. Donations can be made using the donate button on the branch website. Or contact the branch treasurer roger.payne@mndassociation.org

A member of the Oxfordshire Branch records his thanks

Receiving a grant has made a difference because it has helped us to install a wash and dry toilet in the downstairs bathroom. My physical abilities are declining and although I am currently able to use the toilet unaided, there will come a time when I will need one that can wash and dry me automatically. This will mean that I can retain some independence and dignity when I will increasingly be relying on my wife Linda to do things for me.

Thank you so much for this generous grant – it is reassuring to know that the MNDA and My Name’s Doddie Foundation are there for us and can provide practical help as we attempt to overcome the many challenges that MND brings.

News from the Family and Friends Support meetings

The March meeting in Abingdon saw us back at the Lounge room at Christ Church when we welcomed two visitors to join us there. Chris Bennet Head of Regional Partnerships for Central and West for the MNDA came to introduce himself and to congratulate the branch for their part in funding the psychologist's post with the Oxford MND team.

He was pleased to report that the success of the post would mean it was to continue for the next two years for 3 days a week funded by the MNDA in the hopes of making it more permanent in the future. He then spent time chatting to everyone individually to hear about their experiences and views while they enjoyed the refreshments and home made cakes provided by the volunteers.

We were lucky in also having a visit from qualified massage therapist Amanda Munday who offered hand, shoulder and even leg or foot massage to all those who requested it. You could see their smiles of appreciation after the relaxing treatment she gave and the caring, knowledgeable advice she offered them.

Lesley Ogden



At the first Banbury drop in meeting for 2024, held in February, we welcomed the largest turnout of attendees since the support group was reintroduced in 2023. Nine attendees, two volunteers and myself braved the downpours to meet at Banbury Cricket Club and enjoy each other's company, and plenty of cups of tea and coffee while we discussed everything from Christmas to Pancake Day, while also touching on the latest research news and sharing knowledge of living with MND and caring for someone.

More recently in April we had a smaller turnout of 5 people, but the two hours still flew by as we updated each other on the last two months and also discovered that at least one attendee has broken a Guinness World Record not just once, but twice! It is a lovely informal setting and we always try to enjoy the time we have together communicating about many different topics, and of course supporting each other as best as we can.

Matthew Hollis, MNDA Area Support Co-ordinator

Congratulations to Matthew who has raised £2,798 for the MND Association in April by his challenge to drive from the easternmost point of England to the westernmost point of Ireland, without using a map or sat nav, and only using B roads.

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Save the date!

The Oxfordshire Branch Walk in Blenheim Palace Park

**Saturday 5th October
1pm start**

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@outlook.com



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

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Committee member Safina Akhtar has been working hard in the last few months to help one of our members who had a few issues and she has established a useful relationship with the Oxford City Council

Since being involved with MND Oxfordshire Branch, I have looked into a couple of different matters. One of them is trying to help out a person with MND as they had some issues with the local Council. I have been in contact with the City Council and am working with them on car parking issues and suitable toilet facilities particularly in the city centre.

This has led me to start building good relationships with the City Council and alongside fellow committee member Sue Butler, we recently delivered a presentation to them so that Council workers can try to understand the needs of a person with MND and how their policies impact people with MND. We reminded them that the Council undertook the MND Charter back in 2013 and for them to reaffirm their commitment to it so that we can see some positive changes in their decision making. Whilst this presentation was a short one, we mentioned the crucial need for suitable housing as well as getting fast tracked in the social care system with the difficulty that can be found in navigating through all the paperwork and procedural side of things. Hopefully we can see some ease of these difficulties for people with MND and their community.

Safina Akhtar

Summer Event and Lunch Saturday 22nd June at 12-3.30pm

Christ Church Suite Northcourt Road Abingdon OX14 1PL

All welcome to meet Tanya Curry CEO of the MND Association who will be the speaker after lunch to give a talk about her first year in post and then look forward to strategy and next steps ahead.

Reflections and Next Steps

A chance for all our members, fundraisers, supporters and volunteers to get together again to hear about the branch's activities and to socialise during a sandwich lunch with homemade cakes. Please reply to lao.ogden@googlemail.com by 19th June to estimate for catering.



Branch Committee Members

Chair	Martin McLeman	martin.mcleman@mndassociation.com	07909 117848
Treasurer	Roger Payne	roger.payne@mndassociation.org	01844 351959
Branch Secretary	Lesley Ogden	lao.ogden@googlemail.com	01235 850372
Committee member	Sue Butler	david.butler212@aol.com	
Website	Dave Little	david.little@mndassociation.org	
Committee member	Safina Akhtar	safinaakhtar@hotmail.com	
Committee member	Keith Bird	keith.bird@mndassociation.org	
Committee member	Cathy Burch	cathy.burch@mndassociation.org	

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