Oxfordshire MNDA Branch Newsletter





Inside

- Oxfordshire Branch Walk
 - Fundraising news
 - Family and Friends Support Group
 - New Year event details

The Oxfordshire Branch Walk in October 2023 raised £4,781.55





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

www.mndassociation.org/support-and-information/local-support/branches/oxfordshire-branch/

The sun shone, the birds sang and we had an absolutely fantastic turn out, of over 150 blue t-shirt clad, walkers descending on Blenheim Palace grounds. The 2023 Oxfordshire Branch Walk 2 D'Feet was amazing, so firstly a HUGE Thank You once again to everyone who turned out to support this annual event. People came from all over to make new friends, remember past family and friends, and to simply enjoy the strong feeling of companionship and shared goals. So Thank You. Secondly, you all raised over £4000 to help local people and support the challenge to find a cure, so all pennies will be well spent.

And finally please pop the date in your diary - Saturday 5th October 2024 is the provisional date for the annual Branch Walk so hope to see you there.

If you are undertaking any charity events for MND over the next year and you would like some support please do get in touch and we will help in any way we will.

Jill Garner

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Many thanks to Jill for organising another very successful walk to boost branch funds that benefit people in Oxfordshire living with MND as well our branch contributions to research, care and support provided by the MND Association. Our thanks too for the practical support of members of the North Oxford Rotary Cub on the day and to all those who raised sponsorship for their walk.



New Year Event

The UK MND Research Institute: leading the way in collaborative research to speed up the search for treatments.

Saturday 27th January, 2.30 - 4.30pm at: Northcourt Community Centre, North Court Rd, Abingdon, OX14 1NS

Join us for a talk about developments in research with Professor Kevin Talbot, Head of Department of Clinical Neurosciences at Oxford University

Please contact lao.ogden@googlemail.com if you do not receive an invitation.



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

Fundraising news

The branch has been extremely lucky recently to be chosen for fundraising efforts by these amazing people among others . Huge thanks to you all and your funding will make a real difference to support people with those people and their families living with MND in Oxfordshire.

The branch contributes towards research into MND and the support given by the Association through our annual transfer of funds. All contributions large and small are very welcome and could be donated on our website.

Kelly and Anna's Heroes contributed £3,872 to branch funds

These cyclists are men who undertake epic events every other year to raise funds for local charities and in total have raised over £46,000 over the years. This year they chose our Oxfordshire MNDA branch and Helen and Douglas House children's hospice to benefit from the event . They cycled 316 miles from Liverpool football club to The Kasaam Stadium, Oxford United's football club in just 3 days, passing many other football clubs on the way which required a huge amount of effort and determination from the team .

Jill Garner went to receive a presentation cheque for £3,872 and meet some of the cyclists in Oxford. She reports "Despite many hills, lots of punctures and late nights they raised nearly £8000. They had fantastic help along the way



from their support team who provided hot meals, massages, and general wonderful moral support over the 3 days. A fantastic effort...such amazing wonderful people"

"Silver Lining" by Sandi Toksvig

A production of the play "Silver Lining" by Sandi Toksvig by the popular and accomplished Eynsham Bartholomew Players was a recent sell-out over four nights. Afterwards Denise Santilli (Publicity Officer) and Gareth Hammond (Chairman) of the Bartholomew Players presented a cheque for £1000 to the MNDA Oxfordshire Branch.

Denise says:

"The entire proceeds from the raffle, which raises funds for local community organisations, went this year to the Motor Neurone Disease Association Oxfordshire Branch in memory of our own very talented actor Gillian Somerscales who died this year from this awful disease.

Encouraged by the very generous raffle prizes on offer, including a family day-pass to Blenheim Palace worth £93, and a silent auction of an original oil painting by local artist (and Gillian's husband) John Somerscales, the generous audience were able to help us beat yet another record; we are delighted to be able to donate £1000 to the MNDA Oxfordshire branch and hope that this money will help local families affected by this debilitating disease."



A BIG thank you to all the Players and the audience and sponsors for their much appreciated donation.

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West Oxfordshire Levellers

The West Oxfordshire Levellers are a community Rugby League Club - ages 7 to adult, all genders and all abilities. September saw their inaugural Family Fun Day held at Wood Green School in Witney, it's normally an opportunity to generate funds for the club, this would be a charity fund-raiser.

Ian Ferry, committee member writes

"We're in the process of sourcing sponsors for our new kit and fulfilling an ambition to literally wear our hearts on our sleeves, by having a section of kit dedicated to a charity. MND continues to be in the spotlight for both codes of rugby and has actually brought us together. MNDA was the obvious choice and cause to rally behind; and will feature in the new kit design which we hope to show you soon."

The day was an outstanding success, raising £602 for the Oxfordshire MNDA branch with amazing examples of generosity from young and old alike. Whilst kids (and Mums) played on the inflatables, organisers explained why MNDA is important to the club and what the plans are going forward. The Levellers would like to thank all who attended, donated money and raffle prizes; and helped put this special day together. Here's to next year!

Anchor Court

The loyal branch supporters and residents living at Anchor Court, Oxford held various sales recently raising £447.

It was lovely to meet quite a few of them at the branch walk where they were thanked for raising a large amount in sponsorship for their walk as well. Not only that, but one of their number has trained to become a volunteer Association Visitor.

Their support is much appreciated.





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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Raising the roof – and funds for the MND Association, Oxfordshire Branch



I am a member of the Oxford Manchoir, a thriving community of men who enjoy the companionship of singing together, drinking tea and beer and eating cake, although not simultaneously. Manchoir has been going for the last ten years, ably led by our choirmaster, Philip Read. Mike Thomas, another member of Manchoir, had for some time wanted to organise a concert in St Mary Magdalene Church Woodstock, and this idea was made reality on the 18th November with the help of Nick Tonks, a fellow member of Manchoir and manager of Jerram's Brothers, a local business who generously offered to sponsor the event. With the kind permission of the vicar of Woodstock the church became the venue for a concert in aid of the MNDA and the church roof repair fund. There is a heightened awareness of MND in Woodstock as, sadly, two of our community, Gillian Somerscales and a local doctor, both died from it this year, and I am living with the disease.

There was a slight concern that, on a dank Saturday night in November, the church would only be half full, but locals, friends and relatives stepped up to support us and the event was a sell-out. The concert started with local duo Mandolirium playing on guitar and mandolin. They were followed by The Ponderosa who performed an eclectic mix of folk and acoustic songs accompanied by acoustic guitar, mandolin, violin, bass and drums. During their final number Manchoir joined them for a stirring rendition of Leonard Cohen's "Dance Me to the End of Love".

After the interval Manchoir took to the stage. Thirty-six men dressed all in black looked intently at Philip as he counted us in for our first song, "Caravan of Love". Unaccompanied singing without reference to lyrics or music sheets (not that many of us can read music) certainly concentrates the mind, but when it all comes together, with four-part harmonies and the rising crescendo of a rousing chorus, the satisfaction is immense. And when it's in front of an audience who seem to enjoy it and applaud at the end it is truly uplifting! We sang a variety of songs, from pop to traditional, interspersed with performances by two small groups from Manchoir and a poignant recital of a beautiful poem written by Gillian Somerscales. John Somerscales is putting together a book of Gillian's poems called "Secret Self" which will be published in the New Year to raise funds for the MNDA.

The concert was deemed a great success, with £1600 raised to be divided equally between the church and the MND Association. MNDA banners and information leaflets were made available to help raise awareness of the disease and what the MNDA does to assist sufferers and their families.

Huge thanks are due to the organisers and all those who performed, those who collected ticket money and dispensed the interval refreshments, the vicar and churchwarden, and of course all those who came to support us.

Tim Cairns

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

Family and Friends support groups

These continue to be held on alternate months in two venues. The group met again in the Lounge room at the Christ Church Centre, Abingdon in November and enjoyed getting together for friendly exchanges to share experiences and useful information with each other. Some who used communication devices compared their feelings about them and those in a caring role enjoyed getting together too. As the branch has been invited to a meeting of Oxford City Council to make a short presentation in January, some issues to put forward were mulled over. Thanks to our volunteers for making tempting homemade cakes and cups of welcome drinks.

Two support meetings have been arranged - one in October and then one in December by our smaller but growing group in **Banbury** hosted by Area Support Co-ordinator, Matthew Hollis. These are held at the pleasant clubhouse of Banbury Cricket Club who generously provide a room for us. Matthew would appreciate a volunteer to help him with refreshments.



Invitations are always sent out to members nearer the time and anyone interested is welcome to go to either venue.

The next meeting at the Cricket Club in Bodicote, Banbury will be held on Tuesday 13th February between 2 and 4pm. Contact matthew.hollis@mndassociation if you would like more details. After that the group will meet on Tuesday 26th March 2-4pm at Wytham House, Farmoor, Oxford.

Contact lao.ogden@googlemail.com if you are interested in more details. Lesley Ogden

Sincere apologies to Marion Dorrington for a misprint in her poem published in the last newsletter. Her book of poems has been offered for a donation to the branch on the website's Just Giving button and this has been much appreciated.

No One Knows What To Say

My brother came yesterday He hugged me so tight I couldn't breathe.

It's distressing that my illness makes my family distraught my friends shocked. No one knows what to say. Marion Dorrington has published a book of her poems recently. The cover is illustrated by one of her paintings. She is offering copies for a donation to the Oxfordshire branch at:

https://www.justgiving.com/fundraising/oxfordshirebranchmnda

She says that her writing was inspired by her poetry - loving mother and her daughter who started her writing her own poems after visiting a poetry class. "It was scary because we had to write a poem in the class. But I was reasonably successful and it took off from there. The poems reflect on my childhood in Rugby and my life in Oxford, including 35 years as a GP." The more recent ones about her diagnosis with MND has helped her come to terms with her illness she says.

Copies will be available at our meetings or through the branch contact email: lao.ogden@googlemail.com.

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Further Funding for Oxford MND Team's Clinical Psychologist

We're delighted to announce that Dr. Rachel Woolrich, Principal Clinical Psychologist at Oxford University Hospitals will continue to provide psychological care for people with MND at the Oxford MND Care and Research Centre from the beginning of January 2024 for a further two years with funding provided by the MND Association.

The Oxfordshire Branch identified psychological care as a priority for people with MND and were pleased to offer the first two years of funding to start the service from a generous legacy. Initially for one-day per week, the service has been so much in demand and proved so essential that it will be extended to three-days per week from January.

We know that for many people psychological care is invaluable in coming to terms with a diagnosis of MND. Over the past two years, 54 people with MND in Oxfordshire have been supported by Dr. Woolrich enabling them to adjust to life changes, cope with emotional challenges, consider treatment decisions and reduce anxiety about future care.

In a future edition of the newsletter, we'll talk more about the positive impact of psychological care and our plans to seek long-term sustainable funding from the NHS.

If you feel this service could help you, please speak to any member the Oxford MND Team at the John Radcliffe Hospital about a referral to Dr. Woolrich.

Chris Bennett, MNDA Head Regional Care Partnerships - Central and West

Recently the branch has funded things such as...

Support grants assessed by health and social care professionals applied for through support services at national office for:

Wash dry toilets; chair adaptations; contributions to a wheel chair accessible vehicle and shower equipment

Quality of Life grants application to the branch for contributions towards respite breaks; a cup holder; equipment for cooking and cleaning; removal costs

Carers Grants and Young person's grants application to the branch for contributions for instance to short breaks, well-being therapies; driving lessons.

Forms and information available from the MNDA website www.mndassociation.org or contact Lesley Ogden lao.ogden@googlemail.com or Matthew Hollis matthew.hollis@mndassociation.org

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