OXFORDSHIRE MNDA
BRANCH NEWSLETTER

AUTUMN 2022

A message from the Branch Chair, Martin McLeman

A very warm welcome to our latest newsletter which is packed full of news, information about future events and inspirational stories from amazing fundraisers and volunteers.

It seems that MND is always in the news at the moment whether it is National Fundraising Challenges such as Kevin Sinfield in Yorkshire, Research Funding Challenges as highlighted by our National Association or the efforts of more local fundraisers such as Susan Fletcher-Watts.

Indeed much of this newsletter is quite rightly given over to the achievements of Susan. For not only did she complete an incredible challenge, raise an amazing sum of money, present a truly inspirational talk at our Oxfordshire Summer Event but was then voted on to the MNDA Board as a Trustee. All of us at Oxfordshire MNDA send our warmest congratulations on everything Susan has achieved and we deeply appreciate her commitment to ensuring that the voice of people with MND is clearly heard at Board level.

I am sure that you will enjoy reading about Susan's incredible challenge in this newsletter and I hope that her commitment to doing all she can to support the MNDA will also inspire you to consider volunteering for the Oxfordshire Branch. We are always in need of volunteers and in particular we are in urgent need of people to become Association Volunteers who could spare some time visiting and supporting people with MND. If you feel you could give up a few hours every month please do not hesitate to contact myself, Lesley Ogden our Branch Secretary or any member of the Committee.

I want to take this opportunity to thank everyone who has given their time and effort over the past year to support the Oxfordshire Branch including all our volunteers and fundraisers who give so many of their hours to support people with MND. Talking of fundraising , I still have flashbacks and panic attacks about losing on the human fruit machine at the Upper Thames Caravan Club! A huge thank you to Lisa and her team for their efforts!

The North Oxford Rotary Club are raising funds for the MNDA Oxfordshire branch with this talk by a well - known personality from the Antique Roadshow. We hope that it will be well supported.

Beyond the Roadshow

An evening with BBC TV's Antique Roadshow
Andy McConnell, world renowned glass specialist

Exeter Hall, Kidlington - 17th September 2022
Doors open 6:30px- Starts at 7pm

Tickets can be purchased at: www.eventbrite.co.uk/e/andy-mcconnell-tickets-377755596157

Oxfordshire Branch Summer Event

We were delighted to be able to host our Oxfordshire Branch Summer event on Saturday 28th May 2022 at the Christ Church Barn, Abingdon.

The event was very well attended and the highlight of the afternoon was an absolutely fascinating and inspirational talk by Susan Fletcher-Watts about her Pennine Way Challenge. You can read more about this later in the newsletter.

The meeting was a great opportunity for volunteers, fundraisers and officers of the Committee to come together and spend some time together rather than at the end of a fibre optic cable. The benefits of online meetings have been plain for all to see during the pandemic but you can't beat sitting down next to someone and having a good chat. This wasn't quite the first face-to-face meeting we had arranged after the pandemic but it was certainly the most popular and I hope that everyone who attended felt that it was worthwhile.

Before we heard from Susan, I was able to give a brief summary of activities we had been involved in over the previous 12 months, give a brief financial overview of the state of the Oxfordshire Branch, update everyone on developments at the Clinic as well as at a National Level.

There was also a call to action on four areas close to our hearts and attendees were asked to double their efforts on the areas of Campaigning , Supporting, Volunteering and Fundraising. The MNDA is at a critical point in its development where major research funding has been agreed by the Government to facilitate research activity to help find a cure for MND. The process for using those funds has yet to be agreed and we need to continue our campaigning and support for the National Association.

Locally we continue to benefit in Oxfordshire from some amazing friends such as Susan, Lisa at Upper Thames CC, Stuart and Charlotte with their Spennylympics efforts and many others. The financial demands for support, however, continue to come in and I am sure that we will see the need beginning to rise. Fundraising remains such an important activity and one of the best ways of getting involved is by joining our walk on Saturday 8th October at Blenheim Palace. Details are to be found in this newsletter, Jill Garner, our Walk Organiser, will be delighted if you sign up for the Walk.

After the first half of the meeting we enjoyed a delicious lunch and it was great to be able to mingle and meet with so many people. A special thanks must go to Jane Finnerty and the volunteers for providing such a delicious spread.

Following lunch we were completely inspired by Susan Fletcher-Watts and her account of her Pennine Challenge. Everyone agreed that it was an amazing feat of skill, courage and determination as well as being a superb example of how friends, families and supporters rally around to help people achieve amazing goals. The final fundraising total was…..well you will have to read Susan's article further on in this newsletter to find out.

Everyone agreed that the venue at Christ Church Barn was excellent and we offer our thanks to them for their assistance. We are very much looking forward to the next one and hope to see you there.

Martin McLeman

Thanks to David Weeks for sharing his experience of communicating using Eye Gaze equipment


Hello!

Following our recent get together at the branch Summer event, I was surprised how few people use the Eye Gaze system. I was personally very sceptical about using the system however, I was mistaken and it has proven to be a life saver. Firstly, I would strongly recommend everyone 'banks' their own voice as quickly as possible. The process is very straightforward and only took around two hours. When you need it for your Eye Gaze there is normally a charge. The MND Association were kind enough to pay this for me.

When the new system arrived I was delighted with it as my hands had got weak and I had resorted to blinking, which was rather frustrating. The new system was extremely easy to use and it was smashing to have my own voice back. I could participate in group conversations and communication was easy again with my family, which I had missed greatly.

I was soon able to add lots of new features, mainly environmental controls to include television controls and also enabling me to adjust my profile bed and recliner chair myself. It also links with your phone enabling you to text, email and use spotify. The minor drawbacks are tired eyes and the difficulty of it not working in direct sunlight. Otherwise I would strongly recommend you try it out. If you have specific questions feel free to direct them to me via Lesley Ogden.

For more information about communication aids including voice banking for a person with MND contact the Oxford MND clinic for a referral to a Speech and Language Therapist.

Welcome to Jessica Newman, specialist nurse with the Oxford MND clinic team

I trained in Wales at Swansea University, then went straight into theatre recovery. A couple of years later, I then moved to Oxford after doing some travelling and started my job in neuro intensive care for 3 years. In June I made the big move to MND specialist nursing as I had an interest in MND and the ongoing research. I have a golden Labrador called Ruby, who loves to fill up all of my time and attention outside of work. Going for long walks with her and my partner are my favourite thing.

…and a warm welcome to our newest committee member, Safina Akhtar

Hi, I'm Safina! I have had a close family member who had suffered from MND and having gone through the anguish of losing them to MND - I desperately wanted to do something that could benefit others. Having not long moved to the Oxford area, I've come on board to MND Oxfordshire to help out as much as I can.

Please support the branch by joining us for the Annual Branch Walk on Saturday 8th October… and let your friends and family know too

A message from Jill Garner, the Branch Walk organiser: jill.garner@outlook.com

Last year despite the most horrendous weather, we had the most successful Walk EVER! A huge thank you once again to everyone that braved the storm... really hope you can come again this year. It is on the 8th October 2022 from 11:30am with a prompt start at 1pm. The event will comprise a 5 mile or 2 mile circular walk through the beautiful Blenheim Palace grounds, meet in the car park by the Pleasure Gardens, you will be directed by one of our helpful volunteers.

This family friendly walk is great fun for walkers, wheelchair users, dog walkers on a lead and children though based on previous experience we would recommend children who are walking only do the 2 mile event!.

Volunteers will be there on the day to help direct, support and push if needed. It is always a popular gathering of committed people with the aim of supporting and remembering those with MND and raising funds for the Oxfordshire Branch. Sponsorship is very welcome but not essential, and sponsorship forms are available from me or on a link on the branch website at www.mndassociation.org/support-and-information/localsupport/branches/oxfordshire-branch/

We ask that you register for the event so we can manage numbers and order enough t-shirts etc. So please fill in or request a registration form to be returned to me by 30th September.

Payments/ Donations can be made via a Just Giving Walk 2 D'Feet page

www.justgiving.com/Oxfordshire-Branch-MND-Association-Walk2DFeet-2022

All monies will go to the Oxfordshire Branch to support local people affected by MND as well as contributing towards the care, support and research provided by the MND Association.

We want to limit contact due to Covid controls so please ensure payment is made before the day. There will be additional measures in place on the day as well, to keep yourselves and us safe and secure. Costs are £12 for adults and free for children.

Please do come along and support a very worthwhile cause.

Dates for your diary for Family and Friends Support Group meetings

Unfortunately we chose the hottest day of the year for our July meeting at Millets Farm Centre and by common agreement we decided, unusually, to cancel this event. The next get togethers will be will on:

Wednesday 28th September 2pm in the Lounge Room, Christ Church, Abingdon for a friendly social gathering, refreshments and information updates. Do come and meet us if you haven't been before.

Tuesday 22nd November 2pm on Zoom a talk about how to set up an often recommended **Lasting Power of Attorney** covering both finance and health. This information could be useful to any of our members and their families so all welcome, especially those who find it difficult to come to meetings.

Saturday 8th October is the date for the **Branch Walk**. Of course we hope to see you and your family and friends there too.

Lesley Ogden

Susan's Pennine Way Walk raised over £67,000 for MND research

Back In January we reported that MND sufferer Susan Fletcher Watts was embarking on ambitious challenge to walk the 260 mile Pennine Way trail all in one go over 4 weeks. How did she get on?

"We made it!" exclaims Susan. "In doing so we have raised over £67,000 for the MND Association, far exceeding my original target of £10,000." Susan was joined by over 180 friends and family, and everyone was united in fundraising and spreading the word about the disease. Every week on the walk the team raised around £5,000. "Even passers-by stopped to say hello, curious about our bright green 'Susan' T-shirts and our striking home-knitted green and orange bobble hats, and generously donated" Susan adds.

Five hardy souls walked every inch of the way, with everybody else joining from anything from half a day to over 3 weeks. Susan had intended to be one of those hardy souls, but things didn't turn out quite as planned. About 2 months before the Walk she had begun to notice a slight stiffness and wobble in her legs. This did not greatly affect her training walks in the relatively smooth Oxfordshire countryside, but on Day 2 the trail path was rocky and Susan had a nasty fall resulting in 2 days in and out of A&E and 20 stitches above her left eye. After that she had to pace things a bit and benefit from a friendly supporting arm on the rocky bits. Even so she managed to walk 100 miles.

When asked with how she coped with such a physical challenge more than one year since onset of MND, Susan admits it was difficult at times. "Walking got more tiring so I popped off for late afternoon naps when I could. The ordinary jobs like packing and unpacking every few days was wearing as I am slow, and my fingers and arms don't work properly. It was frustrating not being able to join in all the banter, although my 'Synthy Sue' synthetic voice app on my iPad and phone were a great help."

"But I wouldn't have missed it for the world!" says a Cheshire-cat smiling Susan. "The fundraising was amazing, the countryside stunning, but most of all I was bowled over by the huge team spirit, warmth and support of all the walkers."

On 21st May the jubilant team crossed the finish line at Kirk Yetholm, just inside the Scottish border.

Fundraising at Southmoor Fete

On the 25th June 22 I with the help of our fundraiser Jill Garner had a stall at Southmoor village fete held in the gardens of lovely Kingston Bagpuize House. It was the first fete for 3 years and turned out to be a beautiful day although windy. I had requested through our village Facebook page donations of unwanted/ unused gifts and also from family and friends - I was amazed at the amount of jewellery, toiletries, books and Games that I received. Jill and I set up in a nice spot on the lawn. I asked for donations instead of pricing items, indeed buyers were very generous and we made a grand total of around £250. A very successful afternoon.

Sue Butler

Jill Garner was also invited back again this year to summer fetes at Childrey and Shrivenham after successful previous visits providing a stall and activities which raise funds and awareness for the branch – thank you Jill and Sue.

The Upper Thames Caravan Club raised over £1,400 at their rally

Over the weekend of 21st -25th July The Upper Thames Caravan Club celebrated their 70th anniversary, around 100 caravans and motorhomes came to join in the celebrations.

On Saturday afternoon Lisa Dymock Chair of the club organised an afternoon Fete and Grand Raffle with lots of prizes donated by local companies, all in aid of the MND Association and the Oxfordshire branch.

There were many exciting stalls run by volunteers and other fun things to do, including an inspirational human fruit machine.

Many thanks and congratulations to Lisa and her team for their stupendous efforts.

facebook.com/OxfordshireBranchMNDAssociation

Our branch covers a large area and needs more volunteers

I have been a volunteer Association Visitor for several years now, having first become interested in MND during my working life as a Speech and Language Therapist. I have found the MNDA to be an amazing source of a truly impressive range and depth of knowledge, expertise, and research into MND.

In addition, the Oxfordshire Branch has the advantage of close links with the John Radcliffe MND Care and Research Centre and its wonderful staff.

I consider it a privilege to be part of this Branch and to be able to get to know so many fantastic people. The bravery and fortitude of those living with MND and that of their families, is inspiring.

I would certainly encourage others to get involved.

Margaret Wright

Do you enjoy listening to and helping people?

Are you looking for a volunteering role where you can do just that, and it fits in around your family or other commitments? Or maybe you know someone who is interested in volunteering.

By becoming an **Association Visitor** and donating your time, energy and skills, you can make a real difference to the lives of people affected by MND. As an Association Visitor, you can:

- offer valuable individual support to people living with and affected by MND
- provide information to people living with MND, their carers and families
- help people living with MND make informed choices
- help people to access appropriate services / support
- develop relationships with the branch team and attend support meetings when possible

The time required is flexible but needs commitment. Support for people affected is offered in various ways including by a visit, email, phone or text. Excellent training and support for you is available from the MND Association and the branch team of AVs.

OR would you like be a Branch Support Volunteer?

We are looking for someone to support people affected by MND to have a smooth, positive and comfortable experience whilst attending clinic or events. This person would be reliable, warm and empathetic with some understanding of MND and its impact on families. As a branch volunteer you would be able to:

- provide a warm welcome and be a point of contact at our meetings
- help with the practicalities of the event such as helping to hand round refreshments.
- attend scheduled events for people affected by MND including our friendly Family and Friends support meetings held every other month.

OR Could you be a **Clinic Volunteer** once a month to meet and greet people as a receptionist for their appointments at the Monday MND clinic at the John Radcliffe hospital?

For further information or just for a chat about these worthwhile roles do get in touch:
Lesley Ogden: lao.ogden@googlemail.com or call 01235 850372.

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

Call: 0808 802 6262
Email: mndconnect@mndassociation.org