Issue 93
April 2019

motor neurone disease association

Reading and West Berkshire

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News Letter

Inspired by the City of Spires!

Four of our team have been privileged to take a look under the microscope at the amazing research studies being done in a bid to create a world free of MND.

Gifts in wills help the Association to drive forward this vital work and it is urging supporters to consider remembering people with the disease in a legacy.

Committee member Paddy Lunn with her sister Sue Lunn and fundraiser Lin Jenkins and husband Paul were among a group of invited guests who were randomly selected from local branches to a presentation and guided tour of the John Radcliffe Hospital's research laboratories and facilities in Oxford on March 26th.

Here is Lin's account of the inspiring day:

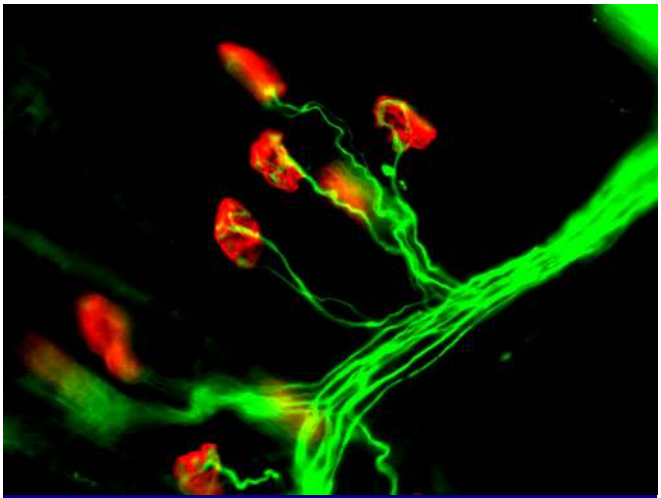
"We were welcomed with light refreshments before having very inspiring talks from Dr. Brian Dickie, the Association's Director of Research Development, Professor Kevin Talbot, Head of Clinical Neurology and Rachael Marsden, the Oxford MND Care and Research Centre Co-ordinator.

This was followed by a splendid buffet lunch before the final talk from Professor Martin Turner, Consultant Neurologist and co-director of the centre.

We were then split into four groups of eight or nine people and escorted around the research facilities where we had small presentations from staff actually working at their desks showing the different sections.

For me, the most exciting things were kept to last. We were able to view slides through one of the microscopes and then in another room view a VERY advanced new microscope recently donated by a single donation. It was so new the staff have not yet been trained how to use it.

Our visit culminated in another part of the hospital where a huge new scanner has been installed. This is two and a half to three times more powerful than the usual hospital scanners. It is magnetic and you cannot go into the outer room if you have a pacemaker. There are tapes on the floor which you must not cross unless ALL metal has been removed, and only very few people can cross this line. It is running 24/7 and has to have its own electricity sub-station just outside!



Using special staining with antibodies and high resolution microscopy scientists can visualise the connection between nerve (green) and muscle (red)

I have deliberately avoided trying to tell you any scientific data, because I would not do it justice. I am, personally, astounded that people with such high intellect are able to produce these talks in language that we, mere mortals, are able to understand.

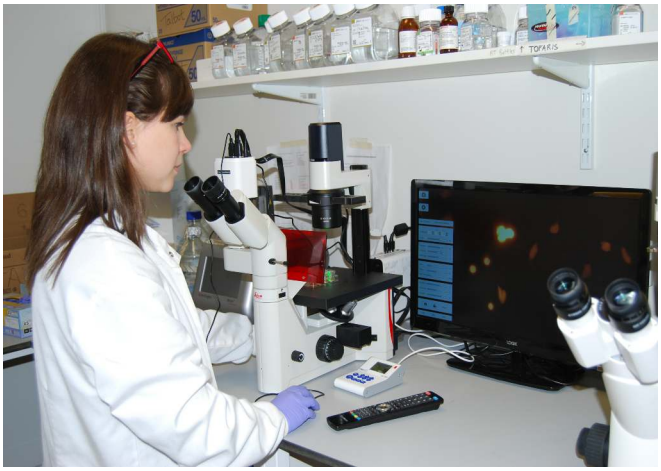
No – there is not a cure in sight. But, goodness me what great progress they have made in the last ten to 20 years. The work they can now do with DNA/genetic research is astounding and they are making huge advances.

When the tours finished we all met up for a final Q and A session, although we were encouraged to ask questions throughout the whole day, and learned so very much. The staff were truly wonderful, and we can't thank them enough.

Continued on next page

Inspired by the City of Spires! - cont

I am inspired and can't wait for "the season" to start. With the 40th anniversary this year I am hoping to try a few new ideas alongside my usual work. Here's to a good season – and thank you Oxford!"



The Association's Legacy Marketing Manager Emma Fellows said she hoped the group got a lot out of the day and that they felt reassured that the fight against MND continues with their support.

She added: "Thank you also to everyone who has pledged or is now considering remembering people with MND in their Will. Gifts in Wills help us drive forward research in the fight against MND and we are so glad to have you with us! "

If you would like more information about the research funded by the Association you can read the fact sheets on its website https://www.mndassociation.org/research/our-research/research-we-fund

How close are we to effective treatments for MND?

Scientists are now starting to understand how MND could eventually be treated precisely.

Professor Kevin Talbot described it as a step by step process in the laboratory to create a road map for the future.

"We are not dealing with one disease and that is where the problem begins," he told an intrigued audience at the branch's recent annual general meeting.

"In the clinic we have seen 2,000 people in the last 16 years and we realise how different everyone is.

"We need to understand why the person has the disease it has and then we will make progress."

Prof Talbot, of the Oxford MND Care and Research Centre, said Precision Medicine is based on:

- Understanding disease mechanism
- Screening and
- Stratification

The main aim of his research is to identify targets for therapy using motor neurones grown in a dish from patients' stem cells and to understand why they are affected by certain genetic mutations.

"If we can get to people with the genetic error before other steps appear we could stop the disease occurring," he said.

Testing of people living with the familial type of MND and their relatives is vital to the research work and could lead to gene editing which targets the precise mutation provided it proved to be safe.

Prof Talbot and his team are involved in the biomarker testing programme as well as the setting up of a MND Register of England, Wales and Northern Ireland.

This aims to collect information about every person with MND to help tell researchers more about what might be causing the disease. People with MND can take part in the study via the project website mndregister.ac.uk. They may also be invited to take part during an appointment at their MND clinic.

Prof Talbot concluded that he was very aware that the Association's Reading and West Berkshire branch is one of the most successful in the country.

"Keep it up," he told the audience. "It makes a massive difference."

Jane Gilbert

Runner Ellis romps home

Well done to young Ellis Narey who nailed the Sage Reading Half Marathon in an amazing time and smashed his fundraising target.

Ellis ran the 13-mile course in memory of Malcolm Findlay, who died of MND at his home in Sunninghill, last August, aged 78.

He said: "My step dad Andy lost his dad Malcolm to this terrible disease. Andy and all his family will sincerely appreciate your donation for the MND Association Reading and West Berkshire Branch, as they were very supportive to him and his family."

Ellis romped over the finish line on March 17th in a time of 1.37 to be greeted by his sister Jasmine, girlfriend Chira and his grandparents Janice and Peter Mann. His efforts have raised more than £700 to help local people living with MND.

Family friend Linda Green said: "We are all so proud of his amazing achievement. It means so much to his family and mine."

Andy Findlay said Malcolm was diagnosed with Motor Neurone Disease in February 2018 after suffering with mobility issues with his right leg for two years.

He said: "We would like to pay special thanks to all the motor neurone specialists that helped and advised us through the tough six months after diagnosis, it is a very difficult disease to live with for the patient and the family. To see our dad go from the strong man that he was to being very dependent on the nursing care provided was something we had never expected to experience."

Malcolm was married to his loving wife Dawn Findlay for 57 happy years and they had two sons and seven grandchildren.

He was a well known figure in Ascot where he worked as a landscape gardener into his seventies.

Andy said: "He was a hard worker and a perfectionist. He was also well known for his love of a good joke even in his last days.

"Whilst it was horrible to lose Dad so soon after diagnosis - six months - it also felt like a blessing in disguise to see his suffering end so peacefully at home surrounded by his family.

We can only hope that in the future more knowledge is gained about this killer disease. Thank you to all of those that helped us through the dark days of dad's suffering. We miss him but are pleased that he is now at peace. "

To boost Ellis' total for the branch visit his online fundraising page: https://localgiving.org/fundraising/ellisnarey/

Editors note: Next year's event is on April 5th 2020, and early bird entries are now open - http://www.readinghalfmarathon.com/index.htm - so dust off your running shoes and get training to help fight MND. By using https://localgiving.org/rwbmnda all online donations come directly to the branch. Let us know and we'll provide the running vest.

Jane Gilbert



Ellis (centre) with sister Jasmine, girlfriend Chira and grandparents Janice and Peter Mann

Garden Sale

I will be holding my Annual Sale at 261 Overdown Road, Tilehurst, RG31 6NX, on Friday 26th and Saturday 27th April, from 9am – 5pm. There is adequate parking in the road. I try to get as much of my stock as possible out on display and priced up. I use the whole of the downstairs annexe, gazebo and front drive. It never ceases to amaze people just how much stock I have. I usually take several hundreds of pounds over the two days. It also helps with local awareness and truly brings a great community spirit to our area. I do hope that lots of you can join us this year.

Lin Jenkins

Flowers and fond farewells



There were flowers and fond farewells for three of our superstars who stepped down at the recent AGM.

Dedicated volunteer Association Visitor Joanna Knott (centre) is retiring to Devon after 16 years of supporting innumerable people affected by MND and was given a photo book of memories to treasurer.

She also received a Certificate of Appreciation from the MND Association and a 15-year long service award.

Chair Margaret Moss told the meeting that the committee would especially miss Joanna's kind presence and high standards.

Bouquets were also given to Daphne Barker (left), who kept her pencil sharp during her seven years as Minutes Secretary, and to our inspirational Lady Hallifax , who may have left the committee but will keep on working behind the scenes to fight MND.

In her chair's report Margaret thanked the committee for all its sterling work during another busy and successful year.

She also praised the team of "super carer" Association Visitors and highlighted the need for more volunteers to take on this important role of supporting people living with MND (see separate story on page 6).

Treasurer Ed Gryglaszewski reported on a good solid year with income of £48,000 slightly up on the previous year. The branch had spent: £17,000 (care), £8,000 (operating costs) and £23,000 (mandatory transfer to national office funds).

He explained there were also various restricted funds, including a legacy, where cash had to be spent on projects determined by the donors.

Jane Gilbert

Your unwanted gifts could be our treasures

We all have those gifts that have remained unused, at the back of the drawer or on top of the wardrobe, for ages. Something that is in pristine condition but you got two of, or "just isn't you". Please let us take them off your hands to make a little money for the MND Association.

We need lots of items for our gift stalls over the summer and what you can donate will make someone else a lovely gift. The money it raises will help support local people with MND and their families.

Email Mary Kaye at ReadingMND@hotmail.com to arrange collection.

Mary Kaye



Joanna signs off . . . and how we will miss her

After nearly 43 years in Pangbourne, my husband and I are downsizing and moving to Devon to be near our eldest daughter and her family. This means that, sadly, I will be severing my links with the Reading & West Berkshire Branch of the MND Association which has been so much part of my life for the past, nearly, 16 years.

In the summer of 2003 I took early retirement from my job as a Speech and Language Therapist and was persuaded by the redoubtable Dr Monnica Stewart to train as an Association Visitor for the MND Association.



I didn't actually take much persuading because I wanted to volunteer for something and in my professional life, had always found the MND Association to be so responsive and supportive when I turned to them for advice and information. When Lightwriters were the only devices available to help people with speech problems, the Association could provide one within a fortnight when we speech therapists had to argue for them locally from the limited budget available for such things, and this could take months.

So it was by way of being a 'thank you' that I decided to put my volunteering effort into the service of the MND Association. I soon found that the local branch was vibrant and committed, led by the best chairman I have ever known, Margaret Moss. Our committee meetings are always lively and I have positively looked forward to them, even though they often end well after 10pm!

When I joined, Val Pearson was the Secretary and she was a huge help to me especially in organising and running the Drop Ins for so many years. Barry Clouting was the Treasurer and when he retired, Ed Gryglaszewski took over. It is remarkable that there have only been two treasurers in those 16 years and I think this has helped the stability of the branch and overseen its financial success.

The other person who has been a constant presence in my time with the branch has been Jane Gilbert without whom we would not have the profile that we do. She puts in a huge amount of work on the publicity front and in editing this Newsletter, often writing many of the articles. Mary Dodds, who was one of the original founders of the branch, rejoined some years ago and has injected extra energy and expertise into all that we do especially with different events and Facebook.

There are about 11 people on the Committee and they all contribute in various ways, making suggestions for improvements and producing new and innovative ideas for fund raising then volunteering to put them into practice, and all this happens under the wise and cheerful guidance of Margaret who is a very 'hands on' chairman.

It may sound odd when I say that it has been great fun to be associated with this committee when we are dealing with such a serious and horrible condition as MND, but if we didn't feel passionately about what we do to try and improve the lives of those living with MND then the Branch would not be the success that it is.

Becoming an Association Visitor was one of the best decisions I ever made. I have been privileged to meet many remarkable people and honoured to have been allowed into their lives at very, very difficult times for all of them. Although I hope I have been able to help in some small way, I think what I have received from the people I have visited and still visit, has been more than I could ever give them and I shall always be grateful.

At this point I would just like to say how enormously touched I was by Margaret's kind words at the recent AGM and to be given those wonderful flowers and the brilliant book of photographs covering my time with the branch. It is a lovely thing to have and will ensure that I will never forget any of you! So thank you.

And now it is on with the sorting, clearing (what would I have done without Lin Jenkins!) and packing and, hopefully, a smooth move to Budleigh Salterton by the end of April.

Have a heart - we need more AVs!

Our wonderful team of Association Visitors (AVs) are at the heart of everything we do to help families affected by MND.

"Having the support of an AV over the past few years has been wonderful, not just for the practical and emotional support but also because it has provided great friendship," said one young dad who is living with the disease.

His AV Jan Gryglaszewska says she finds her vital volunteer work with people in Berkshire very rewarding.

"After more than 10 years of being an AV, I'm still in awe of the strength and bravery of the people I support," said Jan who is pictured on the branch poster with another man she visits.

Branch chair Margaret Moss recently praised the work of our dedicated team of AVs. She called them "super carers" and appealed to branch supporters to consider the role. She said: "There is always something more to achieve."



Alan Parry with AV Jan Gryglaszewska

About the opportunity

Do you enjoy listening to and helping people?

Are you looking for a volunteering role where you can do just that and fit it in around your family, studies or other commitments?

By becoming an Association Visitor (AV), you can make a real difference to the lives of people affected by motor neurone disease (MND).

Visitors offer free and confidential emotional support which helps to reduce the sense of isolation many people affected by the disease experience. They also provide information about the Association and other services that helps people to make informed choices.

As an AV you will keep in regular contact with people with MND, their families and carers. This can be done either by phone, email or face-to-face visits, depending on what suits you and the person you are supporting.

Join our local team and make new friends; use your existing skills and learn new ones!
To find out more about becoming an Association Visitor please visit https://volunteering.mndassociation.org

For more information about the MND Association please see https://www.mndassociation.org/about-us/

What are they looking for?

Becoming an Association Visitor can be a rewarding, enriching experience. Those who train come from all walks of life, and all backgrounds. You don't need personal experience of MND – just the desire to make a difference.

As an AV you will need to:

· have good listening and communication skills
· be able to work as part of a team
· be able to develop and maintain supportive relationships with people with MND and their carers
· respect different lifestyles
· understand the need for confidentiality.

By giving as little as two to four hours a week you can have a huge impact on the lives of people affected by MND.

Practical considerations

Before getting started, all new Visitors take part in our initial learning programme including online learning and attendance at a two-day training course. You will also receive support and supervision from a member of staff. All reasonable out of pocket expenses will be reimbursed.

Still interested? If so, do talk to any of our AVs about their work or call in to one of the regular branch drop-in meetings to find out more in an informal setting.

Jane Gilbert

40th Anniversary Walk to d'feet MND

Forty years ago a small group of people with MND and their families got together to form the Motor Neurone Disease Association.

As a result, this branch and others can work towards A World Free of MND, raising awareness and supporting those affected by the disease.

Reading & West Berkshire Branch will mark this 40th Anniversary with a **Walk to d'feet MND** on Sunday 12th of May. It would be wonderful to have 40 people, marking 40 years, with 40 steps, or 40 yards, or for 40 minutes, maybe raising £40 or whatever you can do!

Will you join us? The walk is planned and organised and properly run by our friends in Newbury Rotary Club. It starts between 11 am and 12 noon near Greenham Common Control Tower and finishes there too. There's a choice of an eight-mile route or a shorter version that's wheelchair/buggy friendly. Maps, marshals and signposts make sure all goes well.

It would be great to see you on the day and if you let us know beforehand on 07760 854975 or by email to readingmnd@hotmail.com we can ensure that we have a T-shirt for you in your size. All together we'd make quite a splash for the media.

You can raise funds for the branch via https://localgiving.org/rwbmnda or just do it with friends to raise awareness by wearing your T-shirt and taking part in the photo.

Margaret Moss

For more details about the walk see

http://www.rotary-ribi.org/clubs/page.php?PgID=745118&ClubID=556

Art Cafe's sweet treats pile on the £s

Once again, the organisers of the popular Saturday morning Art Cafe in Whitchurch-on-Thames allowed us through their doors to help raise funds for the branch.

Our team of volunteers donned their MND aprons and got stuck in under the ever watchful and helpful eye of Jill who oversees the premises and makes sure we are all keeping to her high standards.

Cakes had been provided by our star bakers and extremely delicious they were too! So much so, that very few were left at the end of our 'shift' and it was a comical sight to see 'ladies' vying for which pieces they might purchase to take home for loved ones and partners.

The vibes in the cafe were amazing - visitors from the local area, some returning, some experiencing for the first time, a child's birthday celebration, you name it, it was all happening.

Busy is an understatement! The sound of joyful conversations, of laughter, of cheeky banter, all filtered throughout the building, culminating in an extremely profitable and profile raising exercise. A total of £305 was raised to help us support families affected by MND.

Many thanks to all who helped and to Mary Dodds for once again keeping us all in order.

A great time was had by all.

Brenda Rayner



Katie Cooper, Carol Coker and Mary Kaye relax before the crowds arrive.

Fangtastic fundraising!

These creepy looking characters came up with a spooktacular way of raising funds to help fight MND.

The team at automatic gate manufacturers FAAC UK , based in Basingstoke, choose a charity to support each year and the overwhelming response was to help the MND Association.

Sarah Cosby, who handles the marketing, explained: "We have a couple of staff members who have experience with this illness first hand and so we felt it was a great cause to back."

The team had some great fun getting competitive and held a Hallowe'en fancy dress competition for which the company generously donated an IPAD for the best costume. Can you spot our committee member Sue Hirdle (second left) who won, dressed as the creepy white haired witch?

Sarah said the team had also eaten many cakes through bake sales during the year but what made it really worthwhile was the company backing. The management team took every opportunity to help raise funds from donating £5 when a customer placed an order on a day in December to matching any money raised by staff.

Sarah added: " We've been proud to raise £440 for such a good cause and a happy bonus has been the staff camaraderie created from getting together to have some fun."

Jane Gilbert



Smart-ies way to raise funds



Lin Jenkins (second from left) hands out Smarties to Katie Cooper, Linda Green and Carol Coker

Here's a smart idea to raise cash for the MND Association – share out the sweets and fill the empty tube with £1 coins! Or maybe our young supporters might like to save their 20p coins in the tubes.

Branch fundraiser Lin Jenkins came up with the brain wave for the charity's 40th anniversary this year. Why not join her in asking stores to donate some packs of the sugar coated chocolates to share with friends and supporters this Easter? Lin reckons she can fit almost 40 coins into a tube of Smarties so our treasurer thinks it's an eggs-ellent way to raise funds and help fight MND.

Calling childhood philatelists

Many of you already know that Jill Gaisford collects used postage stamps and sells them on to raise funds for the Reading and West Berkshire Branch of the MND Association.

I always tell people I know about this and many of them save their stamps for me. However, I was quite surprised when, a few months back, one of them presented me with her childhood stamp collection to pass on to Jill.

I wasn't sure if she had a market for such items so went along to one of the branch Drop-Ins to have a chat to her. She gladly took the album (and the other stamps I took as well).

If you collected stamps as a child and your album is still lurking in the back of a cupboard somewhere then why not dig it out and pass it on to Jill. It all helps to raise some cash for the branch.

You can contact Jill by email jmg1520@gmail.com or by 'phone on 01635 868 834.

Mary Davidson

A warm welcome at our winter drop-in

During our drop-in session at St Luke's Church Hall in Theale on 29th January the weather was cold outside, but steaming hot inside!

There I was standing at the kitchen door with Margaret Moss and Paddy Lunn receiving my orders for table set up and assistance with wheelchair arrivals to and from the car park. Branch experts and Association Visitors were also deployed at each table chatting to our quests and carers who were enjoying the complimentary tea, coffee, juice drinks, sandwiches, cakes, fresh fruit and yoghurts.

I decided to take a few photos for the Branch Newsletter with the hope that my snapshots would reflect the popularity of our drop-ins, and how they provide a forum for patients and families living with MND, along with the opportunity to seek professional guidance on information gathering, medical research, patient communications, family welfare, equipment & support aids.

At the end of the two hour session further jobs were dished out and I threw myself into dish washing, clearing up and bag carrying to the car park, before returning to the church hall which was by that time "blissfully quiet".

Everyone I spoke to said that they had enjoyed our drop-in which was relaxing and full of laughter. But what really made my day was the quote from one regular visitor who admitted: "I ONLY COME FOR THE CHOCOLATE BROWNIES!"

Barry Dodds



Re-freshers' Fayre

We would really love to increase the numbers of younger supporters and, with this in mind, the Committee decided to take up an offer from University of Reading Student Union to exhibit at their Refreshers' Fayre on January 16th. This event is designed to kick-start the new year for undergraduate students and to remind them of the plethora of extra-curricula activities available to them. The event included a diverse mixture of sports clubs, societies and a few charities.

We were pleased to chat with a few students who were interested in finding out more about the MND Association and what our branch does to support local people living with MND. It was a great opportunity to raise awareness and encouraging to hear of plans for fund-raising activities. We hope to attend the Freshers' Fayre in the autumn and meet more potential supporters.

Jane Westwell

Waitrose Community Matters

We were lucky enough to be nominated for the scheme during December which must have brought us a better awareness opportunity than other months.

As the Oxford Road, Reading, branch is my local store, I was able to "encourage" my family, friends and neighbours to support us with their green tokens.

And, in the New Year, I was delighted to receive a telephone call with the news that a cheque for £340 was ready for collection.

We must extend our grateful thanks to everyone at Waitrose which also chose the Association as one of its good causes at its Woodley store in February.

Lin Jenkins

If you would like to change the way you receive newsletters (post or email) please contact Jane Westwell:
07449 176173 or secretary_rwbmnda@yahoo.com

Forthcoming Events

Wednesday 17th April, 7 for 7.30pm, A Charity Fashion Show at Leighton Park School

The Inner Wheel Club of Reading Maiden Erlegh invites you to a charity fashion show presented by John Lewis and Partners in aid of the Motor Neurone Disease Association and Arthritis UK. The show starts at 7.00 pm at Leighton Park School, RG2 7ED. Tickets which include a glass of wine cost £12 from Margaret Adams 0118 947 2237 (margaret-adams@virginmedia.com).

Friday/Saturday April 26th/27th from 9 am to 5 pm. Lin's Garden Sale - See page 3

Sunday 12th May, Walk to d'feet MND at Greenham Common - see page 7

Tuesday 14th May, 12.30 - 2.30 pm. Drop In at St Luke's Church, Theale, RG7 5AS

Everyone welcome. Come along and meet friends old and new.

Friday/Saturday/Sunday 24th/25th/26th May. Rokefest (nr Wallingford/Benson)

Raising money for the MND Association - see http://rokefest.com/

Saturday/Sunday 8th/9th June. Stoke Row Steam & Vintage Rally

Tuesday 2nd July,12.30 - 2.30 pm. Drop In at St Luke's Church, Theale, RG7 5AS

Everyone welcome. Come along and meet friends old and new.

Saturday 13th July. Caversham Rock 'n' Ale

Our amazing friends at Caversham Rock 'n' Ale Festival will be rocking for us again this year - What stars! Come along, let your hair down and know that you are supporting a great cause as the event is in support of the Motor Neurone Disease Association.
Once again the event will feature three great local bands, a full bar, hog roast and entertainment for the kids. Tickets are now on sale. Call PACK & SEND on 0118 958 4498 during office hours or visit We Got Tickets (https://www.wegottickets.com/event/463773) to buy online.

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Are you reading a borrowed copy of this newsletter? Or did someone pass it on to you?

If you are, and would like to receive your own copy in the future, please complete the *data consent form* at the back and let us know whether you would like to receive the newsletter by post or email.

If the form is no longer with the newsletter then please contact us to obtain one.

Jane Westwell

Email :- Secretary_rwbmnda@yahoo.com or phone 07449 176173

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MND Association Reading & West Berkshire Branch

Thank you for your interest in our Branch. Please read the privacy statement and complete the form below if you are happy for us to be in touch with you.

Privacy statement

We will record information about you, such as your contact details, to allow us to keep in touch with you as a supporter. We may occasionally share your information with appropriate staff and volunteers but be reassured that your data will be securely stored and not shared with anyone outside of the Association without your consent.

We will use your contact details to keep you informed about what is happening locally; sharing news, inviting you to events and providing opportunities for you, your friends and family to support us through volunteering, campaigning and financially via fundraising events and appeals.

For further information on how your data is collected and used, please use the link to see our full Privacy Policy www.mndassociation.org/privacy-policy

You can stop communication from this branch or change your preferences at any time by emailing us at secretary_rwbmnda@yahoo.com or phoning 07449 176173.

Cut along lines

Communication preferences

Please complete your details and tick the boxes below to indicate how you would like us to contact you. You may select as many options as you wish. If there is more than one person who would like us to keep in touch please include names and preferences for all people.

Name:

Address:

Postcode:

Please contact me by:

☐ Post (As Above)

☐ Email address:

☐ Phone No:

Please return the completed form by post to: Jane Westwell, 194 Silverdale Road, Earley, Reading, RG6 7NB or by email to secretary_rwbmnda@yahoo.com