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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Sick Santa's no show at the Branch Christmas Tea Party!

The magnificent Long Gallery at Englefield House was thronged with branch members for a very special afternoon tea party in December.

Festive decorations added to the wonderful setting, which has featured in TVs The Crown, and with several new faces, there were many saying they had never been there before.

Sadly, this year, our very own Santa Claus was unable to come and distribute gifts as he has often done in the past. And being sick at the beginning of December, he was determined to get better for the children in time for Christmas Eve!

A sumptuous afternoon tea was served by our caterers to the great enjoyment of all. And, of course, a raffle, as ever, was held to help swell the branch funds.

However, mysteriously, the gifts did arrive and included an array of glorious cyclamen plants kindly donated by Glenvale Nurseries at Southend Bradfield. These were distributed to everyone before they headed for home as darkness descended.

We are very grateful to our Branch Patron, former Newbury MP Richard Benyon and his wife Zoe, who very generously allowed us to meet at Englefield House once again.

It was a very happy festive afternoon.

Margaret Moss



Association Visitor Carol Allen and Jo Fitchett



Helen Varley and Alison Pill





Juliet and Richard 'Tod' Halkes

Remembering a special friend

Friends of popular Woodley mum Mandy Wyeth have been remembering her in various inspiring ways to help fight motor neurone disease.

One group, pictured top right, went on holiday together recently and held a raffle at the dinner table to win a box of chocolates and a bottle of wine.

Close friend Mary Kaye was thrilled to say the proceeds of £75 went to the Association in memory of Mandy who died of MND, aged 58.

Mandy's former work colleagues, pictured on the right, also gave the branch a generous £70 gift instead of their usual Secret Santa presents to each other in December. They had all worked together at The Avenue School in Reading.

"She was a special lady", said Mary who joined the branch committee and regularly volunteers at events to help raise funds and awareness of MND. Mandy's daughter, Joanna Robertshaw, is also a valued part of our team working as Minutes Secretary at the monthly committee meetings.





And there was masses more goodwill from friends at Asda



Mary Davidson, Margaret Avenell, Jacqui Warbey and Mary Kaye, a few of the helpers at Asda

Volunteer Jacqui Warbey writes:

An awareness and fundraising day at the Asda store in Lower Earley raised a massive £1172 thanks to Mary Kaye's tenacity, hard work and attention to detail with support from other volunteers.

Mary had booked the 30th November slot a year in advance and Asda allowed us to have collection buckets at each entrance. We had a stall selling MND Association Christmas cards and various knitted and handcrafted items as well as some of the unwanted gifts that people had donated.

Margaret Avenell, another of Mandy Wyeth's friends, ran a tombola which was a big hit with the customers. It was a long day, but well worth it. It was wonderful to see how happy little children were to be given a sticker in return for a donation or to chat to someone who had a friend or relative affected by MND and were eager to donate.

SCRAP6MONTHS

Help us call on the Government to urgently prioritise the benefits review for terminally ill people.

In July 2019, the Department for Work and Pensions (DWP) announced a review into how the welfare benefits system supports terminally ill people.

Six months on we have seen little sign of progress on the review. In that time, more than 1,000 people will have died from MND, many struggling to access the benefits they desperately need.

We are calling on the DWP to urgently prioritise the review and ensure that it progresses as quickly as possible, so that all terminally ill people can access welfare benefits quickly and sensitively.

Please join us by sending an email to your MP today inviting them to attend a meeting in Parliament to discuss the DWP review and how they can ensure the review takes place as a matter of urgency.

Email my MP

Finally, we're looking for people living with MND to share their experience of claiming benefits as part of our #Scrap6Months campaign. We'd also like to hear from carers who have supported a person living with MND through the benefits process. If you have a story to tell, please take a look at this page on the Association website and get in touch.

www.mndassociation.org

We spied marvellous mince pies!

Florrie Varley, aged 9, (pictured) and her sister Lily (14) are star bakers when it comes to mince pies.

They made no less than 300 of them for a festive charity day at a garden centre in Southend Bradfield, near Reading, run by their parents.

The popular annual event in aid of four good causes was organised by big-hearted Helen and Duncan Varley at Glenvale Nurseries. More than 500 people went along to buy Christmas trees and to visit the charity stalls while enjoying free mulled wine and, of course, delicious mince pies.

Helen said Florrie and Lily tried really hard to make the day a success and also organised the raffle and children's games.

They were joined by three of their friends who had lost their granddad to MND and help at Glenvale Nurseries' Charity Day every year with their mum Alison Pill.

Helen said: "It was wonderful to see so many people supporting the charities which will share £800 from the day. We will donate £250 of that to the Association's Reading and West Berkshire branch and we're also collecting used postage stamps on its behalf.

"People are welcome to drop them off any time in our house mailbox at Oak Lodge even if the garden centre gates are closed."

Branch fundraiser Lin Jenkins also ran a stall selling her usual vast array of goods and raised £62.

She said:"This is one of my favorite events of the year with everyone working together and helping each other. We were regularly fed with hot sausage rolls and tea.

"I sold a lovely lot, but still came away with a car load as one of the other stall holders gave me all her leftover stock!"

Jane Gilbert



Always a warm welcome at the Art Cafe

Fundraiser Claire Maslen was delighted with the huge success of a coffee morning at the Art Cafe in Whitchurch on Thames as a tribute to her dear friend Helen Jay.

The get-together has been held annually in October to mark what would have been Mrs Jay's birthday. This time her friends and former work colleagues from Theale Green School generously donated £500 to branch funds.

Mrs Maslen said: "There was a great turn out yet again and some scrummy cakes got eaten all in memory of our lovely friend Helen, taken too soon but never forgotten".

On the cold and windy morning of Saturday 14th December Team MND also returned to run the Art Cafe at The Old Rectory Stables.

Volunteer Linda Green writes:

It's always a lovely event to attend in an idyllic setting on the other side of the River Thames Toll Bridge at Whitchurch.

The team got to work to get the coffee brewed and we set out our delicious cakes some of which were decorated for Christmas by Carol Coker.

After a slow start we had a steady flow of visitors and this time we made £71 on the raffle and £133 from the sale of coffee and cakes. We are extremely grateful for this boost to our funds and also to raise awareness of MND.



Katie Cooper, Lin Jenkins, Barry Dodds, Paddy Lunn, Linda Green, Carol Coker and Mary Kaye

We have an amazing team who always enjoy working together, although we missed Mary Dodds, who was ill, and were very grateful to her husband Barry who is a perfect washer-upper.

Thanks go to all our lovely volunteers for their constant help and support.

We'll be back at the Art Cafe, RG8 7DF, on March 28th, 10.30 – 12.30pm. Come and see us!

Jane Gilbert

Fancy a day out on the Jumbulance?

Last May we were fortunate enough to be invited to have a day out at Blenheim Palace with The Jumbulance Trust. (Branch Newsletter July 2019)

We'll be on board the specially adapted vehicle again on Monday, the 18th of May, and hope some of you will take up the offer.

A group of us will depart from West Berkshire (probably the Holiday Inn on the A4) and we'll go out for the day. Our destination is not yet decided but we are thinking about other large country houses.

This is for you to save the date and think about whether you would like to join the group. The Jumbulance can take wheelchairs either on board or, if you can transfer, stored underneath. There is room for several wheelchairs and also normal coach seating.

Invitations will be sent out in due course when more detail is known.

'If you get a chance to go on a trip on the Jumbulance, I can really recommend it', said Alec Jenkins pictured on the last outing.

So save the date - MAY 18th!

For more details about The Jumbulance Trust charity visit: jumbulance.org.uk/



Tandem WoW are unstoppable!



Remember the two awesome women who set off from Oxford last Summer on a pink tandem in a record breaking bid to circumnavigate the globe? Well, they are doing amazingly well and, as the Newsletter went to press, they had reached the USA and Mexico via Europe, the Far East, Australia and New Zealand!

Cat and Raz, aka Catherine Dixon and Rachael Marsden, the Specialist Nurse and Care Co-ordinator at the Oxford MND Care and Research Centre, have now been pedalling for more than 200 days.

They are aiming to set a new world record for being the fastest women to circumnavigate the world on a tandem. So far they have cycled through every type of terrain and battled against extreme weather conditions and hazardous drivers often camping in the middle of nowhere or sleeping in shabby hostels.

They say:"We will be cycling about 100 miles a day for over 18,000 miles, unsupported, which means carrying our own stuff. The route will take us through more than 20 countries and over 5 continents."

"If you'd like to sponsor us for a day, we will dedicate that day to the person of your choosing. It can be in memory or in celebration of the person you love. Find out more and we would be so grateful if you can donate."

The adventurous duo are aiming to raise £18,000 for the MND Association and Oxfam – a pound a mile! Cat and Raz have their own website where you can find links to follow and sponsor them: tandemwow.com/

Jane Gilbert

STOP PRESS: THEY HAVE ALREADY EXCEEDED THEIR £18,000 TARGET. WELL DONE CAT AND RAZ!

Burghfield May Fayre - Sunday, May 10th

This year marks the fayre's 30th year and coincides with the special VE Day Bank Holiday weekend.

Many of you will know that I salvage several hundreds of pounds worth of camping equipment from Reading Festival each year.

This will all be on display at Burghfield for people to stock up on a range of items including tents, folding chairs, camping mats, sleeping bags, pillows, blankets, wellies, pots and pans, plastic plates, cups and water carriers etc.

In fact, everything you could need – either for festivals or just camping holidays.

Please spread the word, and encourage people to come and see our stock for sale at very reasonable prices.

Lin Jenkins

What's on?

Drop-ins with refreshments are scheduled for January 29th and April 1st at St Luke's Church Hall, Englefield Road, Theale, RG7 5AS from 12.30-2.30pm. All welcome. Come along and meet friends old and new and have a chat.

If you have any queries please contact the Reading and West Berkshire branch on 07760 854 975 or email readingmnd@hotmail.com.

The branch AGM is being held on March 18th at 7.30pm at Holiday Inn Reading West, Bath Road, Padworth, Reading, RG7 5HT.

Dr Kirsten Kelly, the Association's Research Programmes and Partnership Manager, will be giving a talk entitled "Research isn't just for researchers."

Singing for fun is music to our ears



The Sing for Fun Community Choir had a wonderful evening on December 14th in the Majendie Hall, Speen, near Newbury, singing a wide range of popular festive songs.

As if raising everyone's spirits with joyful singing wasn't enough, the choir's enthusiasm encouraged the audience to donate more than £200 to the Association's Reading and West Berkshire Branch.

The choir chose the charity as one of its members is living with MND and is no longer able to sing with his friends, although he is still a committed supporter.

When Jane Dunton created Sing for Fun in 2004, she wanted to encourage people to find the voice that she believes everyone has by singing popular songs with other enthusiastic people without any pressure. She never expected that this would lead to charitable giving that has totalled more than £900 for the Association's funds this year.

Jane said: "We love singing, and having the audience show their appreciation with such generosity is an added bonus.

"The £900 came through audience donations at my Newbury choir's end of term performances, as well as at this Christmas concert, one in April when we were joined by a wonderful French gospel choir, contributions from refreshments supplied at my Basingstoke choir, and additional payments made by one of our singer's customers.

"Thank you to everyone who has taken part this year, and especially to everyone who has donated to this charity, which is very close to my heart."

The Sing for Fun term starts again in January, and the singers look forward to learning new songs, welcoming new friends, and spreading the joy of singing.

For further information, please contact Jane Dunton of Sing for Fun on jane@singforfun.co.uk

Jane Gilbert

Cards, cakes and chutney for Christmas



Having set the date for a sale in November the weeks before flash by in a whirl of cake making, choosing which of Rod's paintings to get printed for cards and gathering raffle prizes from generous donors. Jars of marmalade and chutney sold well last year, so another batch was waiting. with Christmas in mind, to be gift wrapped for the occasion.

It's always a fun afternoon with my daughters Sara and Jo to help serve tea and sell cakes and raffle tickets. Each year I see new faces who haven't been before as well as faithful supporters who return.

Grandson Jack, who also enjoys helping at our stand at the Royal County of Berkshire Show, always gets back from school in time to 'count up the money' after the raffle has been drawn.

This year we made £450 on the day which crept up to £550 by the end of the following week from further donations and requests for more marmalade or Rod's Christmas cards.

A big 'Thank you' to all who came on the day to support and swell the funds for our MND Association branch.

Paddy Lunn

Do you know that you can bank your voice?

Most people living with MND do not bank their voice

Most people living with MND don't know that they can bank their voice

Most people living with MND don't know that the Motor Neurone Disease Association will cover all the costs of banking their voice

So what's involved and what exactly is voice banking?

It really is a very simple process. The name voice banking might appear a little confusing and perhaps even intimidating. All that is involved is for you to record online 350 simple sentences, which are displayed one by one on the computer screen. The recordings are then processed using a combination of computer wizardry (something called a deep neural network) and a touch of magic. The end result is a realistic digital computer generated version of your voice that can then be used with any of the available computer aids, including the Tobii eye gaze and even an ipad using an app called Predictable. Your digital voice can be used to say anything at all. It's cleverly not just limited to the words that you have recorded in the 350 sentences. From these words the system builds up your digital voice that is then capable of saying any word or sentence that you need.

The MND Association can support you to bank your voice in a number of ways. We can provide email and online video support, telephone support as well as the option of logging remotely into your computer to provide practical help – with your permission! We also have volunteers who have been trained in voice banking who can visit if more help is needed than can be provided remotely. After a test recording of a few sentences, the balance of the 350 can be recorded at a time that fits in with you. Once completed your finished voice is stored online ready to be downloaded.



Your computer needs to be running the latest version of Windows or Mac software and there must be a good internet connection. The association even has laptops that you can borrow should you not have a suitable computer. The recording process is very easy and can be completed by anyone with basic computer skills, and now that the number of sentences has been cut back to 350, the whole project can even be completed in an afternoon if you are feeling very keen.

Some links that might be useful are shown below but please note that they are there just for information. You do not need to study or prepare as the voice banking volunteer will have all that is necessary. It is a simple process and is no more difficult that talking on the phone.

Your local voice banking volunteer is **Michael Morrison** (Email: ReadingMND@hotmail.com or Tel: 0776 085 4975) who would be pleased to discuss voice banking and then be happy arrange to visit you to help record your voice. Remember, it is very easy to get started and the MND Association will cover all the costs

Acapela - My Own Voice - mov.acapela-group.com This is the company who process the recording to generate the digital version of your voice.

MND Association online application form - mndassociation.org/support-and-information/our-services/communication-aids-service/voice-banking-volunteer-support-application-form/

Michael is also very happy to assist with the application process.

We can help in so many ways. . . .

We are the Reading and West Berkshire branch of the Motor Neurone Disease Association, and we are your local point of contact. You might be surprised at how we can help you and people living with MND, their families and carers. We do a lot more than just providing voice banking, fundraising and organising the social events you read about in this newsletter.

We are all volunteers and most of us have had a close connection with MND. We work with professional health care providers to try and ensure people living with MND get the best possible care and advice. We also have a few hard working trained volunteer Association Visitors who can offer guidance and support.

Don't be shy, use the contact details so we can discuss with you how we might be able to help.

Email: ReadingMND@hotmail.com **Tel: 07760 854975**

Could you be the next Branch Chair?

Some months ago I told the committee of my decision to stand down as branch chair at the next AGM in March 2020.

It's almost 20 years since I agreed to take it on (I can't believe it, maybe you can!) and I really do think it's time to bring some new energy to the role.

So there's a vacancy, could you fill it? I'm asking you, yes you, to consider if you could be the next branch chair.

You would need to plan and chair committee meetings, reach decisions as and when required, support branch activities and events, doing it your way, always remembering it's part of a bigger organisation.

If so, please get in touch with me. If not, please think about people you know who might be right for the role. No knowledge of MND is required, rather the personality to work with the current, great committee. Induction and training are provided and travel expenses are paid.

It has been a rewarding and interesting role for me with this very effective and successful branch. We have a great team supporting those who are living with MND, their families and friends. Team MND and the branch works well; the role of chair (there is a job description) can be as you make it.

I will be staying involved and even on the committee if that's helpful – I don't intend to disappear!



We look forward to continuing the vital work of the Reading and West Berkshire branch of the Motor Neurone Disease Association.

Margaret Moss

Branch Events Co-ordinator

As you might imagine, any event the branch runs needs to be planned and organised - whether it's the venue, the t-shirts, balloons, the tablecloths, invitations or the myriad other things!

In order that the event actually happens, all this needs someone to mastermind it. Not to **do** it all but to organise and delegate the separate items to individuals - either the committee or supporters.

Those of you who were at the Summer Tea Party or the Thank You Lunch will appreciate the work done by our dedicated team. We are very grateful for all that everybody does but things could be so much better if we had an Events Co-ordinator.

As the branch has only occasional events, this is not a full-time job! Nor would it require attendance at the monthly committee meeting; it only requires a person with a tidy and organised mind who wants things to go well.

Could you or someone you know be this person?

The branch has been without an events coordinator for some time now and it would make for the smoother running of events if we could now fill this role.

For further information contact any of the committee on the branch phone 07760 854975 or email readingmnd@hotmail.com

We look forward to hearing from you!

Margaret Moss, Branch Chair

If you would like to change the way you receive newsletters (post or email) or if you do not currently receive your own copy and would like to be added to our mailing list (post or email)

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