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mnda
motor neurone disease association

Reading and West Berkshire

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News Letter

Royal County of Berkshire Show 2016

The branch stand was a great success over the two day show on September 17th and 18th, promoting awareness of the MND Association, networking and advertising our Facebook details to our many visitors, Our tombola stall was as popular as ever with most of the 450 prizes being won by Sunday lunchtime. We continued throughout the afternoon with our Christmas card and merchandise sales, and overall we raised £978.37 for the branch funds.

One memorable moment over the weekend was seeing Alec Jenkins arriving alone in his wheelchair, with a big smile on his face. When asked what he had done with his wife, Chris, he laughingly replied that he had decided to explore the trade exhibit stands without her permission or knowledge, and that he had simply "done a runner". It takes a brave man to get away with this prank, and the look on his face said it all ..... FREEDOM!!!

Thanks to Ed Gryglaszewski for his help putting up the stand and dismantling it, for his supervisory skills and great courage when telling his lovely wife and other female colleagues on how to do things his preferred way, ... and for GETTING AWAY WITH IT TOO!!!!

Special thanks to Gill Selby for the 17 bottles of wine, to Bob, Linda & Peter at JUST Newbury Ltd for their generous prizes, stand grass cutting and continuous support to the MND Association, and to everyone for their tombola donations.

Finally, a huge thank you to all of "Team MND" for their hard work, and to our many supporters who make this branch event a lot of fun, and very worthwhile.

Barry Dodds

More from the show on page 2



Ed Gryglaszewski hard at work

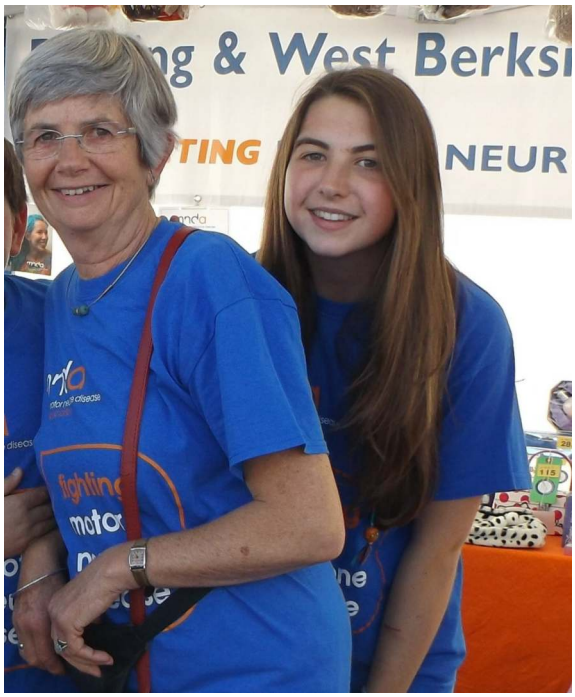


Brenda Rayner mans the tombola while Alec Jenkins, Asha Munissi, Chloe Hawkins and Barry Dodds look on

What do our younger supporters think of the show?



Chloe Hawkins and Asha Munissi



Ella Wright with grandma Paddy Lunn

Mary Dodds writes "It was refreshingly different this year in having some young people helping out on the stand, and what a super job they all did."

"I had a wonderful time helping out on the stand."

Melissa Rideout

"We both enjoyed our day at the Newbury show and it was a pleasure to help out on the MND Association stand. We hope that the tombola raised lots of money and that more people are aware of the disease and the charity. We would love to come and do it again!"

Chloe Hawkins and Asha Munissi

"Once again I was delighted to be helping out on the MND Association stall at the Royal County of Berkshire Show. It's always lovely to see everybody on the team and all the friendly faces that visit the stall. As usual, the showground was buzzing with thousands of families eager to explore the vast variety of food, crafts and activity stalls the show has to offer. The favourite, obviously being the MND Association stall, holding its famous raffle.

The wonderful obscurity of the prizes fascinates me every time. From cuddly toys to bottles of booze nobody is left disappointed with their prize. We were all kept busy frantically searching for the 0/5 prizes amongst a sea of coloured tickets. By the end of the day the prize table had almost cleared, proving its inevitable popularity amongst the get-lucky show-grounders.

We finished the day with a wander around the show to see the farm animals and the giant fruit and veg on display. Everything was washed down with a deliciously cooling cup of lemonade for me and a cup of coffee for grandma (and a giant almond twist). Yet again I had a great time."

Ella Wright

If you would like to receive newsletters by email please contact Val Pearson:
Valerie.a.pearson@btinternet.com

Please also contact Val if you know of anyone else who would like to receive a copy of the newsletter by post or email

Mutiny on the Rebecca

A gentle cruise along the Kennet and Avon Canal was just the tonic for this happy crew in September until . . . . their craft came to a grinding halt and they decided to abandon ship!

The cause of the mutiny was an old makeshift fender which had got snarled up in 61- foot-long Rebecca's rudder about a mile and a half from the end of the day's voyage from Newbury to Woolhampton.

While the gallant Newbury Rotary Club hosts were up to their armpits in muddy water trying to free the fender our intrepid women volunteers decided to set off along the tow path to find their parked cars for the earlier than planned journey home.

Massive thanks to the Rotarians for having us on board once again and for getting one of our wheelchair-bound guests safely off before pushing him along the tow path up a steep incline onto the road to a waiting car.

It was an enjoyable and very eventful day, we all agreed.

For the record, the Rotarians eventually got Rebecca going again with the help of an engineer from boat owners The Bruce Trust which runs boat holidays for disabled people. - www.brucetrust.org.uk

Jane Gilbert



Happy smiling faces…



Now the problems start…



… and we abandon ship

Congratulations on 50 golden years



Many congratulations to Anne and David Smith who have recently celebrated their golden wedding anniversary.

Anne, pictured with Carol Allen and friend Christine Gascoyne, has been living with MND for many years and is a regular guest at branch events. She writes: "Would you believe it . . . where have the years gone?"

She and David celebrated by taking a group of their friends to dinner and playing 60s music.

Fundraiser Lin turns trash into treasure

Fundraiser Lin Jenkins has endless ways of turning trash into treasure to raise funds for the MND Association.

This Summer she again joined the salvage team cleaning up after Reading Festival and collected anything from discarded cans of beer to muddy welly boots and sleeping bags. Soon they were cleaned up and looking good as new on her stall at car boot sales and fairs around the county.

The amazing mum from Tilehurst works tirelessly and never fails to spot the latest gimmick or hot seller. Her knitted Pokemon balls have been flying off the shelves at £2 a time and she says people now come looking for the MND Association stall at events.

"I cannot stress how much interest there is out there," says Lin who recently was given a cash donation at a car boot sale. "That happens a lot at fetes but never at a car boot sale when people are out for a bargain. I am getting so much satisfaction out of it."

Lin's tireless work is supported by her husband Paul, son Ross and sister Ruth as well as other family members who turn out to help her with the stall.

Together they have raised an amazing £7,015 this year and would like the branch to spend their hard-earned cash on equipment to help people living with MND. Their inspiration is Paul's brother Alec Jenkins, from Newbury, who now features with his wife Chris on the new branch poster.



Lin (left) is pictured presenting her cheque to Chair Margaret Moss with Association Visitor Jan Gryglaszewska and Minutes Secretary Daphne Baker in front of the branch poster featuring Lin's brother-in-law Alec Jenkins and his wife Chris

In the last three years the Jenkins family has also given six "cough assist" machines to the respiratory department at the Royal Berkshire Hospital.

So look out for Lin at one of our future events – you'll be amazed at what she has come up with next!

Jane Gilbert

What a year!

I have been very lucky with the weather this summer, and have not lost many events due to rain. I have, therefore, made a grand profit of £7,015 this last year. Some cheques having gone straight to The Treasurer, I was able to hand over £6,665.00 at the last committee meeting.

I am mostly supported by my family, friends and neighbours, but also receive items from my "MND Association family" – so a big thank you to you all.

When my brother-in-law Alec was diagnosed with MND it hit us hard. Over the years, with Paul & Ross doing all their walks and runs, and me doing the family stall at all local fetes, fayres, car boots etc, it has turned a negative into a positive for us all. Bringing us all together, bringing happiness instead of sadness. Perhaps we should thank MND for this!



My latest venture is Pokémon Go Balls. It started with Ross producing a black and white picture, saying "Knit these mum – they will be popular". I found out the colours, designed a knitting pattern, and have now sold well over 100 of them. Not only is the money good, but people are seeking out the MND Association lady who knits them, so lots of awareness! They are £2 each if anyone wants one.

I am now preparing for Autumn and Christmas events, and will keep you all posted via Facebook etc.

Lin Jenkins

Jaqui's tips for tickling the tastebuds

Dad Richard Warbey worked as a product technologist for Sainsbury's and completed 29 years service before he took ill health retirement last year.

Now his journey with MND has made eating more difficult his wife Jaqui is determined to cook up a host of tasty treats that he can still enjoy.

Here Jaqui, who works in Newbury, shares some of her mouth-watering ideas with other families affected by this debilitating condition.



Richard and Jaqui Warbey are pictured on their mini-break in July this year at Revitalise in Southampton

"Richard, aged 56, was diagnosed with MND 18 months ago. In the beginning the MND affected his arms and legs so although I have been helping to feed him for the last year it is only in the last couple of months that he has started to find chewing hard work.

He had a feeding tube inserted in June but by adapting his diet he has managed to continue eating orally. His portions are much smaller and the "little and often" approach works best as he tires when chewing.

Richard has always been a fussy eater with a long list of things that he didn't like (yoghurt, eggs, soup (except for Heinz Tomato), gravy, custard, etc) and strangely, there seems to be a high correlation between the foods suggested by his dietician and his dislikes!

Determined that Richard will be able to enjoy the taste of foods he does like for as long as possible I wracked my brains to come up with meals he can enjoy and which keep his calorie intake up. Out came the ice cream maker, the blender and the food processor.

Breakfast is usually a Nesquik milkshake or a slice of toast with butter and marmalade, although on Saturdays, Richard still enjoys a small cooked breakfast in town. I just have to cut his rasher of bacon into smaller pieces and the hash brown provides essential lubrication.

Sandwiches are a no go area now so lunch is often a jacket potato with cheese, Tomato soup (with croutons of bread) or a bag of Wotsits followed by a chocolate mousse or jelly. I made some cheese and onion mini potato bites for a recent lunch with friends and that meant everyone could enjoy the same food.

Mashed potato is almost a must for dinner - even if he has a few chips or a roast potato with it. We continue to have a Sunday roast but Richard's meat is minced up in the blender with a little gravy and the vegetables have to be cooked so that they are soft. On weekdays it is often some variation of minced meat or fish and it is easy to freeze a portion so the rest of the family can enjoy a more varied diet. We have even given Richard his dinner and then ordered in pizza for the rest of the family only to find he is up for a couple of slices - it is amazing how much easier it is to eat a treat than a meal!

Puddings are perhaps the easiest: homemade ice cream made with double cream is a favourite for the whole family - we have five different flavours in the freezer at the moment!

Profiteroles go down quite well - the choux pastry is not too "doughy" and the whipped cream and chocolate sauce provide the lubrication. Homemade pavlova even with puréed fruit seems to work well. I have also made trifle using jelly, sponge fingers, diced peaches, chocolate or strawberry blancmange(he doesn't like custard) and cream. If this is all too fancy, puréed stewed apples or puréed tinned peaches also work well.

We don't know when Richard will find it too difficult to eat but we will know that we have continued to provide a normal and varied diet for as long as possible."





Jaqui's pavlova and profiteroles - what more can you ask for?

Let them eat cake!

At your service! Meet our committee members modelling smart new Association aprons for the pop-up Art Cafe at Whitchurch-on-Thames near Pangbourne.

The community cafe serves tea, coffee, home-made cakes and a splash of original artwork every Saturday from 10am until 12.30pm.

Organiser Gill Williamson invited us back on October 8th to sell our delicious bakes on behalf of the Association while visitors browsed the arts and crafts on display. The morning's work, which included a raffle, donated £280 to the branch coffers and spread the word about MND.

For the next month visitors to The Old Rectory Stables will be able to bid in a silent auction for this lovely oil painting kindly donated to the branch by artist Peter Webb.

Peter, who lives at Buckhold, near Pangbourne, gets much of his inspiration from trips to Cornwall and is keen to support our fundraising work.

To place a bid for Rocky Shore, which has a £150 reserve, please email Gill Williamson: gill@artcafe.co.uk

Jane Gilbert



Jane Gilbert, Paddy Lunn, Mary Dodds, Daphne Baker and Joanna Knott



Rocky Shore



Peter Webb

Sensory garden: a new possibility near Woolhampton

An opportunity has arisen to develop a sensory garden project near Woolhampton, thanks to an existing garden having been offered by its owner who is no longer able to maintain the land. The existing garden has toilet and other facilities suitable for disabled people. The idea should be able to lift off if there is someone who wants to take a coordinating role that would allow the idea to develop momentum to create an attractive option for disabled people interested in an organised gardening project. Several local groups have gardening projects and may welcome the opportunity to operate in collaboration near Woolhampton.

This is to canvass if there is any interest. Please forward your initial responses to John Holt at johnmholtbsc@aol.com following which a site visit can be arranged if there is sufficient interest.

John Holt

All the fun of the fayre

Our amazing volunteers turned out in force to help run stalls at this year's successful 20th Chapel Row Fayre at Bucklebury, near Reading.

A few weeks later branch chair Margaret Moss went along to a presentation evening at the village's Bladebone Inn and received the fruits of their labours – a cheque for £2,300!

The Association was one of four charities to each receive this magnificent amount from the event in August which featured sheep racing among its many attractions.

Our team was kept busy selling raffle tickets while branch fundraiser Lin Jenkins did a good trade with her popular Lucky Bag game in the Association's marquee.

Many thanks to the fayre organisers for supporting our work – we'd love to be asked back again next year!

Jane Gilbert



Team MND ready for action at Chapel Row Fayre

Christmas is coming…

Just a reminder with Christmas just around the corner …

… you can buy MND Christmas Cards through the branch. **The branch benefits from every item sold.**





Contact - Mary Dodds on 0118 941 4956 or MaryDodds@mndrwb.org

If you want to view the full range of Christmas merchandise which is available see:

https://shop.mndassociation.org/product-category/christmas/

And don't forget that you can also benefit the branch by saving your used postage stamps! See back page for details.

Hungerford Christmas Fair

Get a head start on your festive gift shopping in Hungerford on Friday, 28th and Saturday, 29th October to boost the funds of the MND Association and other charities.

The £2 entrance fee and raffle proceeds at the event in the Town Hall and Corn Exchange are in aid of the branch so please tell your friends. There will be lots of unusual stalls as well as a cafe at the fair which runs from 10am – 4pm on both days.

Our cheery team of volunteers hope to see you!



Music at heart

Royal Berkshire Hospital cardiologist Dr Will Orr will be swapping the surgery for the stage to conduct singers at a Christmas concert in Yattendon Church on December 1st.

The Oxford Collutorium Choir returns for another delightful evening of music and readings followed by wine and canapés in aid of the MND Association and Yattendon and Frilsham churches.

Tickets for the event, which starts at 7.30pm, cost £15 and are available from Yattendon Stores or Association Visitor Joanna Knott, tel. 0118 984 4495.

Do you know used postage stamps still have a value?

Two of our members have buyers for used postage stamps and so raise funds for the branch. If you would like to help, remove the stamp from the envelope with about 1cm around it thus providing an undamaged stamp for the collector.

Jill Gaisford collects ALL stamps - tel 01635 868834 or email jmg1520@gmail.com to arrange delivery.

Mary Dodds collects ONLY second class stamps - contact her on 0118 941 4956, by email to MaryDodds@mndrwb.org or see stamp book to the left for postal address.

Alternatively give your stamps to any committee member who will ensure they get to the correct person.

Thatcham Christmas Lights and Fair

Friday 2nd December from 5.00 - 7.15 pm

Come along and see what Lin Jenkins has managed to conjure up for her stall at this event!

She may even have some of her famous Pokémon Go balls

Branch Contacts

Chair
Margaret Moss
0118 9470871

Branch Contact
07760 854975
ReadingMND@hotmail.com

Secretary
Val Pearson
0118 9789063
valerie.a.pearson@btinternet.com

Treasurer
Ed Gryglaszewski
0118 9789069

RCDA
Kathy Hymas

Events Coordinator
Gill Selby

Publicity
Jane Gilbert
0118 9714172

Newsletter
Mary Davidson
mary@rfdg.org.uk

Website
Jan Williams
p-jbrown@msn.com