Issue 88
October 2017

mnda motor neurone disease association

Reading and West Berkshire

www.mndrwb.org

Tweet to @MND_RWB

Join us on Facebook -
MND Association Reading & West Berkshire

localgiving.org/charity/rwbmnda



News Letter

Team MND's tombola wows the crowds

Your Team MND was kept very busy at this year's two-day Royal County of Berkshire Show raising vital funds to support people living with the condition. Most importantly, we were there to boost awareness of MND at the huge crowd-pulling event.

I have so many people to thank for all the help we received. We are very lucky to have a most generous sponsor who pays for our site at the show each year. Our sincere thanks go to her.

During the course of the year many items were donated to the branch so that we were able to run a very successful tombola raising £804. Thank you all.

Paddy Lunn and I started preparing the prizes that you donated as far back as April this year and we have had plenty of help. Paddy even roped in her two granddaughters Ella and Tilly to help with the final wrapping of gifts. I don't know what the girls were up to but there was a lot of laughter going on!

Our amazing Team MND was wonderfully supportive over what is, for us, a six-day event. We had twenty three people to help us at different times - collecting the tent from storage, setting it up and stocking it on the Friday; meeting and greeting all our loyal supporters over the Saturday and Sunday; dismantling the tent on Sunday evening, then finally on Monday taking it back to storage.



Michael Morrison and Ed Gryglaszewski taking a rest after lifting all the heavy tombola prizes from their cars

Without a team such as yourselves, willing to give up your time to support the branch, we would not be in the strong position we are in at the moment. As a result, we are able to help people living with MND and their families, financially, practically and emotionally.

Many, many thanks!

Have you ever been to the Royal County of Berkshire Show? If so, you will know that it is a really good event, with so much to see and do. For the gourmets among you, there were seventy or more stalls in the food tent, some of whom offered tasting sessions. This was a really good reason to sample anything on offer with the excuse (to yourself) that you were a connoisseur, sampling their wares. It had nothing to do with being weak-willed and giving in to temptation!

The craft tent was also a pleasure to visit, with eighty original craftsmen displaying their skills. The patience necessary to produce some of these items was remarkable. Gardeners among you were not forgotten with a fabulous display of plants and flowers to admire. I came out of the tent, having made a resolution to get my own garden in order. How long that promise will last is yet to be seen!

The events in the main arena ended with a spectacular display of hot air balloons taking off into the sky. I can remember many years ago driving home along the M4, seeing the balloons drifting along in the evening sunlight. It was a beautiful sight.

Mary Dodds

Registered Charity No 294354

More news and views from 'The Show'

Fun and frolics were again in evidence at our stand at the Newbury Showground and we were delighted to see our loyal supporters and children who visit us each year.

This year there was a notable increase in the number of people who wanted a chat with our branch experts, and from the passing crowds who were drawn to our popular tombola stall, excellent prizes, book sales, MND Association merchandise and Christmas cards.

A big thank you to our fantastic team of volunteers who helped to set up and run the stand over the two-day period, and as you will see elsewhere in this newsletter, a few of our young supporters wanted to share their views and experiences with our readers for this very worthwhile MND awareness event.

Barry Dodds



Ella & Jack Wight, Paddy Lunn, Val Pearson, Alec Jenkins, Netta Thorne, Jill Gaisford and Barry Dodds

Once again the MND Association stand proved to be an absolute hit at this year's Royal County of Berkshire Show.

Compared to the mountain of prizes I encountered last year when I worked on the first day of the show, I was shocked when I arrived to work on the Sunday this year to find an almost empty table. Clearly the locals couldn't resist a good old-fashion tombola and had almost cleared the stall clean of prizes. Still, I was kept on my toes scanning and searching for the famous five/nought tickets and their attached treasures to present to the lucky winners.

Approaching the stall I spotted Barry, bucket in hand, awaiting the approaching show-goers. This attracted a lot of sweet-toothed customers, myself included. Everybody who visited the stall departed with a lolly in their mouth or a raffle prize in hand. Throughout the day this treat bucket served us all as we re-fuelled ourselves with refreshers, love hearts and lollies.

It was wonderful to see how fate seemed to allocate the perfect prize to each individual. Children giggled with delight to discover they'd won a cuddly toy, replicating the same hysteria of adults who'd noticed that they'd won a bottle of wine! Nobody was left out. Mary was at the ready with her 'bottom-lip-basket' full of prizes for the not so fortunate little ones. Thankfully, in the end everyone was a winner.

Seeing my grandad's cards for sale reminded me of why I was there that day. Having a memory of him present with me through the shift made me value the event even more. I felt proud to be a part of the team for the day and it was lovely to see everybody's friendly faces again. Every second was a joy to me, even in the rain.

Ella Wright, aged 17



Ella, left, and Tilly making up prizes for the show

Before spending the day helping wrap and create tombola prizes I didn't realise at all how much work went into preparing for fundraising events such as the Royal County of Berkshire Show.

Pieces were collected all year round and gift wrapping started months in advance. Mary and my grandma Paddy have been in the office since April making masses of gift sets: beauty sets, china sets and many more.

There are boxes filled with potential prizes and each must be sorted; the care that goes into sorting them is extraordinary.

My cousin Ella and I volunteered to help with our grandma. We spent the day gift wrapping and making sets such as jelly bean jars, which I must admit took a lot of self-control to finish.

I really enjoyed being able to help out - it's a very personal charity and I am always thrilled at any chance I get to help. It was amazing to see the work that goes into these events and I hope to be able to help again soon.

Tilly Lawson, aged 16

More news and views from 'The Show' - continued



Chloe, on the left with friend Amy Cogden

My friend Amy and I really enjoyed our day out at the Royal County of Berkshire Show on Saturday 16th September.

We spent some time working on the MND Association stall with a few others from the branch and we thoroughly enjoyed every minute.

It was lovely to see a number of people making generous donations and participating in the tombola with its wide selection of wonderful prizes which had been donated to the charity for this event.

Once again, it was a truly successful day. We hope that awareness of the branch continues to grow and that we raised lots of money for the charity on both days.

Chloe Hawkins, aged 15



Margaret Moss, Sophie Dimond, Daphne Barker and Barry Dodds

After finding out that my father was diagnosed with the disease over a year ago now I decided it would be a productive use of my gap year to help with fund-raising and raising awareness for the Association.

I thought that helping out at the Royal County of Berkshire Show would be a good start and meant that I was able to meet some of the volunteers from the West Berkshire branch.

We raised money by setting up a tombola which seemed to be popular with people of all ages! Our grand total for the event was £804 which is a huge amount and I feel very privileged to have been part of such a successful event.

It was so lovely to meet all the amazing volunteers working with the branch and hear how they got involved with the Association.

It really inspired me to continue helping out and raising more money for such an important cause.

Sophie Dimond, aged 18



This pack of Christmas cards features a Christmas present bursting at the seams with lots of decorations. On the present tag are the words 'Merry Christmas'. Pack of 10 cards with envelopes. Gold foil blocked.

Message inside: Best Wishes for Christmas and the New Year.

£4.00 per pack. Other designs are available.

Contact Mary Dodds for a brochure.

Contact MaryDodds@mndrwb.org or Tel: 0118 9414956

A passion for pedal power

A grandad with a passion for pedaling has just clocked up an epic 1000-mile trip to raise money for the MND Association.

Bob Wearn, aged 67, from Old Windsor, chose the charity to benefit from his endurance ride after hearing that dear friend and former colleague Peter Colvin is living with the disease.

Now all the £1,570 proceeds from the Land's End to John O'Groats ride will give a boost to the Reading and West Berkshire branch which is supporting Peter and his family.

Bob, who worked in sales for BT with Peter, set off on the group trip in September and rode 70 miles a day continuously for 14 days.

When he finally reached John O'Groats Bob declared: "Job done!

"The last four days were pretty tough going with some testing hills, occasional torrential downpours and a stiff breeze in your face a lot of the time.

"No more punctures though (three on tour - I got the prize for most!) and the bike performed well. The scenery was pretty amazing and visibility reasonable most days. Heading south now and back to 'reality'!"

Bob also thanked everyone who supported him especially his " long-suffering wife, Moira, who allowed me to go off on this jaunt with her blessing."

If you would like to donate please go to:

justgiving.com/fundraising/bob-wearn1



Jane Gilbert

'Cheque in' at the Art Café



Paddy receives the cheque from Gill Williamson and Alison Livesey

Usually when I go to the Art Café at Whitchurch-on-Thames on a designated Saturday morning I am behind the hatch serving with the rest of the MND Association team but, this time in August, Mary Dodds and I were sitting 'out front' with our coffee and cake chatting with other visitors to this popular venue.

We were there to receive a cheque for £200.83 on behalf of the Reading and West Berkshire branch which was donated by the Thames Pathway Together Community Art Project.

The project raised £4,920 over two weeks in May when Whitchurch Bridge was adorned with more than 100 pieces of knitted artwork inspired by the Thames Path.

I passed the amazing display as I returned from our branch's 30th anniversary celebrations at Englefield not knowing we would also be benefiting from this 'yarn bombing' which was enjoyed by so many people who showed their appreciation with their generous donations.

Paddy Lunn

Brolly boating weather

The drizzle didn't dampen the spirits of this happy crew who went canal cruising with Newbury Rotary Club in September.

Huge thanks to hard-working hosts Tim and Julia Barton, Eddie Webb and Carl Smith for keeping us safely on the straight and narrow.

All was calm and tranquil as Tim, Julia and Carl manned the locks while Eddie steadily steered Rebecca along the Kennet and Avon Canal from Woolhampton.

Then just east of Aldermaston Lock the 30-feet long boat was forced to turn around due to a power failure at the swing bridge. We were beginning to think we were jinxed after last year's evacuation when the boat broke down!

Thankfully, we escaped being stuck the other side of the bridge for the return journey to Woolhampton and were kept entertained by Tim's baffling card tricks.

We are very grateful to Newbury Rotarians for again choosing the Association as one of the charities to benefit from the club's week-long hire of The Bruce Trust's specially adapted boat Rebecca.



Ken Eggleton, Viv and Colin Wilkes brave the weather

"We so enjoyed our day despite the disappointing weather," said one of our delighted guests, Tony Martin, afterwards.

Jane Gilbert

Dragon boaters are all stars!



Association Visitor Jan Gryglaszewska receiving the cheque from Swindon Phoenix Rotary Club president Nigel Causton with (left) Kristy Gardiner and Maxine Connolly of AECOM.

Staff at a global engineering company really pushed the boat out in support of popular and talented colleague Robert Andrew, aged 55, of Finchampstead, who is now living with MND.

The 20-strong AECOM Allstars paddled like fury in a dragon boat race this Summer organised by Swindon Phoenix Rotary Club and raised £870 for the Association.

Robert's colleague Maxine Connolly said: "Bob was one of the most amazingly experienced signal design engineers and he worked here for 15 years before getting this awful disease. We picked this Charity as we all wanted to do something for Bob to show we care. "

The AECOM staff at Swindon also organised a game of 'guess how many sweets in the jar', a cake bake and an Easter egg raffle to bring in the cash.

Robert's Association Visitor Jan Gryglaszewska went along to receive the cheque at a presentation evening for all the charities supported by the dragon boat race. She was joined by Kristy Gardiner and Maxine Connolly from AECOM.

Maxine said: "It was a truly inspiring event and highlighted the importance of raising money for the wonderful people who do so much for these charities."

Jane Gilbert



Clearing up after the festival goers

Undaunted by previous years, I signed up for my fourth year as part of the Reading Festival Salvage team. Various family members have helped in the past, but it really is outside of most people's comfort zone – therefore it was just Paul (who joined me for one trip) and myself.

You just have to forget any normal standards of hygiene, put yourself "into the zone" and wear sturdy shoes, long trousers and a good pair of gloves.

Luckily there was no rain, therefore no mud, this year, but boy was it hot! Following two very hot fetes on Saturday and Sunday the heat at the festival site was just unrelenting. I wimped out at lunchtime on the Tuesday, just too hot and tired to collect any more. Mind you, the house and garden were full by now, so it took a week to get it all clean and sorted.

We are able to get on site from 3 – 8pm on Bank Holiday Monday, and 8am – 8pm on Tuesday, having previously supplied all relevant details and car registration numbers.

I first had to attend a Heath & Safety lecture, then signed on the dotted line, and gradually we formed a convoy behind one of their vehicles.

You get taken right round, and through, the whole festival site, before ending up in one of the colour coded camp sites. This journey, in itself, is quite an experience!

Once you arrive at the first campsite it becomes a free for all. Many of the charities/groups have a lot of people and use vans, trailers etc. but I was alone on the first trip, with Paul joining me on the second.

You will have seen the sites on TV and in the newspapers, but nothing prepares you for the reality.

The festival goers simply walk away at the end, leaving EVERYTHING behind. Lots of homeless and refugee charities with larger vehicles target the tents etc.

I have learned to "specialise". I do collect some tents, but I go for sleeping bags, camping mats, duvets, pillows, wellies, blankets, picnic rugs, folding chairs, trolleys, BBQs, pots and pans, unopened food and drink, coats, hats, unused toiletries. I "guestimate" that my haul was worth about £650 - £700 this year.

Despite it all – I will be back!

Lin Jenkins

Sixty sparkling years sealed with a kiss



Diamond wedding couple Tony and Jenny Martin have revealed their recipe for 60 years of wedded bliss - they always say good night with a kiss and say that they love each other.

"We never go to sleep on an unresolved argument," added Tony, aged 86, who is living with MND.

He and Jenny, aged 82, were married on 21st September 1957 by the Bishop of Gibraltar at the chapel belonging to Dulwich College.

They now live in Woodley, near Reading, and regularly attend the branch's drop-in meetings and special events.

Tony and Jenny celebrated their long and happy married life with a dinner at Sonning Golf Club attended by all the family including their three children, six grand-children and three great-grandchildren.

Many congratulations from us all at Reading and West Berkshire branch of the MND Association!

Jane Gilbert

Chapel Row Fayre was everyone's cup of tea

Team MND did such a wonderful job serving teas at the crowd-pulling Chapel Row Fayre that it has been invited back next year!

Jubilant organisers have now shared out the fayre's £11,000 proceeds to five charities and the Association received a magnificent £2,500 slice at a presentation evening on October 16th.

Committee member Mary Dodds and her team were kept busy serving cream teas and cakes on a scorching August day as families enjoyed an astonishing array of entertainment at the traditional day out in Bucklebury, near Reading.

Association Visitor Bridget Foden, who was one of ten volunteers helping in the tea tent, said afterwards: " I thought the hard work and effort put into today's Chapel Row Fayre was amazing!

"Everyone worked so hard and for such a long time to raise funds for the MND Association. It was wonderful to see! Never mind all the cake baking and scone making that preceded the event!

"As ever, it is a pleasure to know and volunteer with you all."

The annual charity fundraiser on the village green draws in the crowds every August Bank Holiday weekend with sheep and ferret racing, a dog show, vintage funfair and cars as well as displays and stalls.

Save the date in your diary for next year on Saturday August 25th, 2018!

Jane Gilbert





Cheque presentation showing Charlie Plank, Steve Ruddick, Lynette Maja, Graham Plank, Mary Dodds, Lin Jenkins and Caroline Lafferty

Fantastic fundraising

The Jenkins family stall has been busy all year. We attend fetes, fayres, water fest, beer fest - you name it we turn up! When there is nothing else on I go to car boot sales. I also sell privately, have the odd garden sale, and also take some items to the local auction houses.

I'm afraid we were down on last year's figure, but we still managed a grand total of £6,156 when we closed the book at the end of the summer events. We have again requested that this money be used for equipment etc for people living with MND.

I have thoroughly enjoyed my year mixing with the general public, and "spreading the word" as well as raising funds.

Some of the stories I hear are truly heart warming, but sometimes heart wrenching. I often have to disappear behind my tent to shed a few tears, before putting on the smile and going back out.

I was recently asked to give a talk to a seniors group in Compton. These wonderful people then had a collection, and another £56 was added to the pot. What lovely people there are out there.

I am now busy planning for the Christmas events. Hopefully the next few months will be considerably less busy than the last few, and I can use the time making and preparing things for next summer. I have many "projects" planned for the coming months.

I would like to publicly thank all my family, friends and neighbours for their continuing support. (Mysterious deliveries appear on my doorstep all the time!) Without them this simply would not be possible.

Lin Jenkins and family

Nikayla is our star baker



Nikayla with brother Elijah and parents Nicholas and Lisa

Eleven-year-old Nikayla Charles has the perfect recipe for cooking up an amazing £400 to help support people living with MND.

The young star baker, who attends Highdown School in Caversham, Reading, arranged several very successful cake sales.

Her mum Lisa said Nikayla wanted to raise some funds for the branch which supports her grandma Marjorie Moore, who is living with MND.

She said: "Nikayla arranged cake sales - at her previous school, Caversham Park Primary, her cousin's workplace, 3 Chairs & A Barber in Basingstoke Road, Reading, and at my netball club in Maidenhead.

"A lovely cake was also donated to raffle."

Jane Gilbert

Nikayla's mum Lisa said her daughter is very excited to appear in the Newsletter which she plans to share with Highdown and Caversham Park schools.

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

The Reading & West Berkshire and Oxfordshire Branches of the MND Association

invite you to

Afternoon Tea

in the day room at Sue Ryder – Nettlebed Hospice

Joyce Grove, Nettlebed, Nr Henley on Thames, Oxfordshire, RG9 5DF

Thursday 2nd November 17 at 2.00- 4.00 pm

All carers and cared for welcome!

Sue Ryder provides specialist palliative care in people's own homes, in day therapy and clinic setting as well as an inpatient service.

You will receive a warm welcome and have a very pleasant afternoon in lovely surroundings with friendly people. Aromatherapy hand massage will also be available.

Nettlebed has been providing care for 35 years and is based in a lovely grade two-listed building . If you have not been before please think about coming . It is an opportunity to meet those experiencing similar difficulties and find out information from professionals.

Save the date!

Christmas Charity Day at Glenvale Nurseries

Hungerford Lane
Bradfield Southend
RG7 6HJ



Sunday 3rd December 12-4pm

Huge range of Christmas trees

Many stalls & a raffle



Complimentary mulled wine & mince pie

Wander round to choose your perfect Christmas tree, wreath & gifts, with a cup of mulled wine - the perfect way to get into the Christmas spirit!

10% of the profits on the day go to our charities.

In aid of

MS, Diabetes UK, & Motor Neurone Disease Association

Please tell the car park men if you need a disabled parking space when you arrive

Stamps for the MND Association

One of our members, Jill Gaisford, has buyers for **used** postage stamps and so raises funds for the branch. If you would like to help please remove the stamp from the envelope with about 1cm around it thus providing an undamaged stamp for the collector.

Jill collects ALL stamps - contact her on 01635 868 834 or by email to jmg1520@gmail.com

Asda tokens

The Reading and West Berkshire Branch of the MND Association has been nominated by Asda of Tilehurst, for its green token scheme during October, November and December.

Please ask your friends to join you in doing as much shopping there as possible during these months. Should they forget to give you your token please do ask them, as every one will count.

The machine is on the wall on your right, just before you enter the two sets of doors to leave the store.

The winner will receive £500, with the runner up getting £250. We are up against stiff opposition, so every token really will count.

Local Giving

The Reading and West Berkshire branch of the MND Association has set up its own Local Giving page which enables you to very easily donate money to the branch, by running a fund-raising activity or simply making a regular or one-off donation.

See our page at

localgiving.org/charity/rwbmnda

If you forget this web address google 'localgiving' and then use the site's search box to find our page. As with any online search the more specific you can be the better. If you get too may hits you can reduce them by opting for 'charities-only'.

Voice Banking Volunteer

As part of a new initiative the MND Association is investigating 'voice banking' which could enable people living with MND to bank their voice for future use with speech-generating devices when they are no longer able to use their own voices.

They are running some pilot schemes and Berkshire has been selected to participate in the pilot. Could you be one of our voice banking volunteers?

What does this role involve?

- Providing support to people living with MND, their families and carers, to enable them to access voice banking facilities and equipment.
- Supporting people to understand and undertake the process involved in voice banking.

This role is important as you will be supporting people living with MND to record a set list of phrases with their own voice, while they still have the ability to do so. You will be working as part of a team of local and regional staff to provide to pilot the voice banking support service for the Association.

Ideally we are looking for someone who can give approximately 2 - 4 hours per week to provide support, planning and correspondence time.

Full training and induction will be provided and travel expenses will be reimbursed.

If you would like more information about please contact:

Jo Campbell (Volunteering Development Co-ordinator) either by email jo.campbell@mndassociation.org or by phone on 03453 751839 .

Dates for your diary

MND has a stand of each of these events

Saturday 28th October - Pangbourne Christmas Fayre. 10am - 4pm in the village hall. Crafts, charity Stalls, cakes, tombola, refreshments. MND Christmas cards will be available to buy.

Friday 1st December – Thatcham Christmas Fayre and Lights. Broadway, Thatcham. Open 5.00 – 7.15pm Usually a wonderful evening. They have live donkeys!

Saturday 2nd December – Theale Christmas Fayre and Lights. Open from 3.00 – 7.00pm.

2nd Saturday of each month
Bradfield Market - 10 - 11.30am
Beenham Market - 1.30 - 3pm

WANTED - foreign coins

How many of you have been left with a selection of foreign coins after an exotic holiday?

I am busy trying to develop a "game" that I will be able to use at fund raising events. I will need coins from as many different parts of the world as possible.

Usually coins have very little actual monetary value, so would you consider passing them on to me? Once I start to get a decent supply, I can see which areas of the world they are coming from, and can finalise the game from there! Watch this space.

Lin Jenkins

MND Association pocket diary for 2018 is set out in week to week format, with space to input all those important dates.

Size: 16 x 8.9cm Cost £3.00

To order please contact:
MaryDodds@mndrwb.org or Tel: 0118 941 4956

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

Publicity
Jane Gilbert
0118 9714172

Newsletter
Mary Davidson
mary@rfdg.org.uk

Website
Jan Williams
p-jbrown@msn.com