Issue 94
July 2019

motor neurone disease association

Reading and West Berkshire

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News Letter

Will you help us #Scrap6Months?

Branch chair Margaret Moss and fundraiser Lin Jenkins were at the forefront of the MND Association's latest call for a change in the current 'demeaning' benefits system.

They joined Association campaigners who shared their stories with MPs and peers from across the country at the Parliamentary Drop-In held at Westminster on July 3rd.



Television and radio presenter and MND Association Patron Jeremy Vine was also there to listen to moving speeches from chair of the All Party Parliamentary Group Drew Hendry MP and Madeleine Moon MP, who is the chair of the APPG on MND.

The drop-in was held on the same day that Good Morning Britain presenter Charlotte Hawkins, whose father died from MND, **appeared on Lorraine** to urge people to sign the Association's **Scrap 6 Months petition** calling for a change in the law so everyone with a terminal illness can use the fast track process to access the benefits to which they are entitled.

Lin said she "totally agreed" with the campaign. "People with terminal illnesses are suffering enough as it is," she said. "I think it is quite degrading that they have to justify themselves every six months."

Margaret and Lin had both written to their MPs urging them to attend the Westminster drop-in. "Unfortunately neither the MP for Reading West Alok Sharma nor the MP for Reading East Matt Rodda attended," said Margaret. "We did manage to speak to several MPs and also members of branches far-flung across the country – Wales, Cornwall, Northumberland, Kent, Surrey, amongst others."

More than 60 MPs and Peers accepted an invitation to meet people with MND, Association volunteers and health and social care professionals at the parliamentary drop-in focusing attention on a new report which found the current benefits system for dying people is 'not fit for purpose'.

The report by the All Party Parliamentary Group (APPG) on Terminal Illness found that the current rule that only people with a life expectancy of six months or less can get fast access to benefits is 'outdated, overly time consuming and demeaning'.

The report adds further weight to the Association's **Scrap 6 Months campaign** being run alongside Marie Curie which maintains that people living with a terminal illness such as MND should be able to claim benefits without having to fill in a long form, attend a face-to-face assessment, or wait weeks for their benefits to arrive.

It says all people with MND should be able to access benefits quickly using the Special Rules for Terminal Illness (SRTI). This is a fast-track process for claiming benefits, meaning people do not have to go through a long and stressful assessment process. However, the SRTI requires a 'reasonable expectation of death within six months', which excludes many people with an unpredictable terminal illness like MND. The Association would like to see the Government change the law, **as Scotland has recently done**, to move away from the six months definition towards a decision made by a clinician.

Margaret added: "It was heartening for us to see so many others as committed as we all are in Reading and West Berkshire working towards a world free of MND.

I signed the Petition, will you sign it too?
https://e-activist.com/page/33936/petition/1

Go on! You do care!"

Jane Gilbert

Our jolly day out on the Jumbulance



Alec Jenkins being helped off the Jumbulance by driver Brendan Kelly

My wife (whose name continues to elude me) and I joined a group from the Association's Reading and West Berkshire branch as guests of The Jumbulance Trust on a visit to Blenheim Palace in one of their two Jumbulances.

I can already hear you asking "What's a Jumbulance?," No, it's not a fearsome animal with sharp claws and long teeth from a story by children's author Julia Donaldson. That's a Gruffalo!

Well, a Jumbulance is basically a big coach converted to take able bodied and disabled passengers. As the conversion is done in Belgium it is left-hand drive.

The Jumbulance Trust has two of these vehicles which have two rows of luxury reclining seats down the left hand side for both the able-bodied passengers and those who can transfer from their wheelchairs. The right hand side can take up to six wheelchairs or four stretcher-beds or a combination of both secured with restraints at the front and back. There is ample storage underneath for wheelchairs. It has a fully equipped kitchen for the preparation of small meals, a wheelchair-friendly toilet and access for those who cannot transfer from wheelchairs is via a large lift at the rear.

On the way we were served coffee and Jaffa Cakes and when we arrived we were ushered in through an ill-timed shower to a private room where a delightful lunch was served.

After lunch we were free to explore the house and/or the grounds which we were able to do in the dry. At about 3.30pm we boarded the Jumbulance for the journey home and were again served coffee and Jaffa Cakes. The whole day was an absolute delight thanks to the friendly, helpful staff at Blenheim Palace and the kindness and attention to detail of the Jumbulance driver and helper. If you get a chance to go on a trip in a Jumbulance I can really recommend it.

Alec Jenkins

It was so nice to receive an invitation from the Reading and West Berkshire MND Association to join a trip to Blenheim Palace on May 8th.

The invitation was for me and a guest. I took my son Wayne and we both had looked forward to our day out. We had no idea what a Jumbulance was. It was an amazing experience just seeing how the lift worked and how the wheelchairs are anchored in the wheelchair and trolley beds. We were shown around the coach where there is a good sized kitchen and a toilet that accommodates wheelchairs.

On arrival at Blenheim Palace we were led to a private room which was laid out with a welcoming buffet and drinks. A very enjoyable lunch was had by all.

We made our way to the Winston Churchill exhibition and also viewed the section of the house that Churchill lived in. We then visited parts of the vast and very beautiful grounds. It did just manage to stay dry for us during this time. Upon seeing the restaurant we decided to have a cup of tea and within minutes the heavens opened and people were running for shelter, umbrellas aloft!

In spite of the rain a great day was enjoyed by all. We assembled with all of our friends for a group photo before boarding the Jumbulance for our trip home.

Carol Coker



L-R Ajay Rideout, Carol Coker (sunglasses) Wayne Coker, Lady Hallifax, Margaret Moss, Val Pearson, Barry Dodds and Margaret Bowman

Another Jumbulance picture on the next page

Stoke Row Steam and Vintage Rally was hardly a snooze for Lin



Lin (right) with helpers Katie Cooper, Lara Cooper, aged 12, and her grandma Carol Coker

Amazing fundraiser Lin Jenkins, pictured below right at her stall, can be forgiven for sleeping on the job at this year's big two-day Stoke Row Steam and Vintage Rally.

She is so dedicated to raising funds for the MND Association that she bedded down for a stormy night in a tent next to her retro stall on the field at Hill Bottom, Whitchurch Hill, near Reading.

The rain poured, the wind howled, and Lin kept her nerve in preparation for her biggest and most successful fund-raising event of the year in June.

She explained:"Paul and I put up two tents in the pouring rain and wind on the Friday morning. We spent the rest of the day relaying seven more car loads of stock up there. (I feel like I'm sponsoring Whitchurch Toll Bridge).

" I worked until it got dark then spent the night in the tent with my stock. There is a lovely party laid on for all the stall holders and steam fraternity with a live Hill Billy band and a bar.

"This went on until well into the night but I retired at about 11.45pm. I'm not sure why because I could still hear music from my tent. I got woken at 4.30 am by the creaking of my gazebo as the latest storm was moving in. I got up at 5.30 am and started to set my stall out doing the best I could with the wind and the rain."

By about 9.30am the rain started to ease but the wind got worse during the day. Lin tied the tent to the fence and her car although she still had to hang on during the heaviest gusts. Finally the wind started to ease by late afternoon and she went home to bed for a more comfortable night.

Despite the forecasted rain Lin had a lovely day on the Sunday.

She said: "This meant we could display our items so much better. I had the most wonderful selection of items this year and people just kept coming back again and again. "As everything is donated I never charge much so people can get some really good buys. My motto is to send people away with a smile on their faces! We took even more today - £248 which made a total of £448 for the weekend.

"I would like to thank Sam Morgan, Carol Coker, Katie Cooper and Mary Dodds for coming to help me. This gave me a bit of a chance to have a sit down and a comfort break, but much more important was their company and support."

Undeterred by her ordeal plucky Lin is already booked in for next year's steam rally.

She added: "Do come and visit. You will not regret it. It is a superb event, and getting bigger every year."



Pictured (L to R) are: Margaret Moss, Brendan Kelly (Jumbulance driver) and Chris Chisholm who organises Jumbulance outings.



Pictured (right) is Lin with some of her wares

Committee says 'farewell' to Joanna

Lady Hallifax hosted a spring lunch party for branch colleagues to say "farewell" to Joanna Knott who retired in April after nearly 16 years of stellar work supporting countless people living with MND.

Joanna, who says becoming an Association Visitor was one of the best decisions she ever made, is pictured seated (front left) with Lady Hallifax (centre) and branch chair Margaret Moss.

She is now living in Budleigh Salterton, Devon, with her husband Tom and plans to get in touch with the Association's nearest branch when she has settled into her new home.



TandemWoW – Two Women, Two Wheels, One World Record



The crowds gathered in Oxford to cheer the redoubtable pair, Raz and Cat, off on their daunting (to most of us) challenge to break the record for two women on two wheels to circumnavigate the world.

Raz, better known as neuro nurse Rachael Marsden, and Cat, aka Catherine Dixon, are cycling about 100 miles a day for more than 18,000 miles, unsupported, which means they are carrying their own kit. Their route will cover more than 20 countries over five continents and they are aiming to raise more than £18,000 for the MND Association and Oxfam.

Friends of ours from the Oxfordshire Branch joined me to wave them off on June 29th as well as our wonderful specialists – professors Kevin Talbot and Martin Turner from the Oxford MND Care and Research Centre where Rachael is the co-ordinator and specialist nurse. Another familiar face who sent her love to all in the Reading and West Berkshire Branch was Fiona Turner, a former Association Visitor.

I also met Kumi Okamura who is taking Rachael's place while she is away - she said how fortunate she has been to be appointed and is looking forward to meeting everyone.

The sun shone, the photos were taken, there were smiles, words of encouragement and thanks to supporters with a countdown led by Professor Kevin Talbot and they were off amid the cheers! I heard one person asking about the exit from that part of Oxford being told: "by the time you turn round you'll never catch them!"

Good luck and happy travels to Rachael and Catherine!

You can watch their progress on https://www.followmychallenge.com/live/tandemwow/

and donate funds by visiting: https://www.tandemwow.com/

Margaret Moss

Postage Paid

Our thanks to an anonymous donor for the 2nd class postage stamps. Your generosity has helped us post out this issue of our branch Newsletter.

Mary Dodds



Thank you Waitrose & Partners!

Committee member Mary Kaye is pictured collecting a £350 cheque on behalf of MND Association Reading and West Berkshire from Sue Gill, at Waitrose & Partners in Woodley.

The generous donation in April was the result of the store's Community Matters green token collection from shoppers who supported our work.

Mary said: "We are very grateful to Waitrose for facilitating the collection and to local shoppers for helping to raise such a worthwhile amount."

Shoppers at Waitrose in Thatcham also gave the branch the thumbs up with their green tokens in May. At the time of the Newsletter going to press branch publicity officer Jane Gilbert was waiting to hear how much cash was being donated by the store.

*Don't forget to pick up a form and nominate the branch at your local store or at any of the other supermarkets which run similar schemes.



Mary Kaye picks up a cheque from Waitrose's Sue Gill

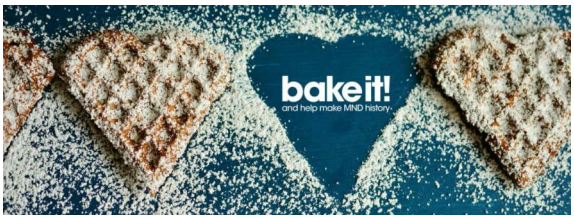


Have you eaten your Smarties?
And have you filled the empty tube with your £1 coins?

If so please do not forget to return it to Lin Jenkins
Tel: 0118 941 2738 or email: rlp.jenkins@tiscali.co.uk



Bakeit! and help make MND history





Jane Turner, Association Visitor Wendy Gouldthorpe, Chris Gray and her daughter Jules Pomfret-Gray

Pensioner Chris Gray organised a successful coffee morning and cake sale at her home in Woodley on July 4th in a bid to help other people living with MND.

Chris is very appreciative that the branch funds massage therapy for her on a regular basis and this is her way of thanking us.

"I want to give something back to the wonderful branch that has supported me and to help other people," says Chris who was diagnosed with MND in 2011. "You are all wonderful – it is like a little family and I like meeting all the friends."

Her Bakeit! event was held in the main reception area of the Independent Living home where she lives. She also ran a small raffle and sold some tasty treats to raise a wonderful £390 for branch funds.

Jane Gilbert

Barry's big birthday bonus

Grandad Barry Webb decided to throw a party to celebrate his 85th birthday and asked his guests for donations to the MND Association in lieu of gifts.

Afterwards his grand-daughter Joanna Robertshaw, the new branch Minutes Secretary, was naturally delighted to go and receive a cheque for £600.

She recently joined the committee after watching her mum and best friend Mandy Wyeth's "inspirational but devastating fight with this awful disease".

Joanna says the branch was invaluable with the support and expertise, as well as funding for therapy sessions, it provided to Mandy, from Woodley, who died aged 58.

She added: "One of the best things about being on the committee is hearing about people's fundraising ideas and this month I am pleased to share my family story."



Walking to d'feet MND with a taste of the past to help others in the future

About 30 supporters and their four-legged friends stepped out from the iconic Greenham Common Control Tower near Newbury to mark the Association's 40th anniversary this year.

The former US airbase looked glorious in the spring sunshine compared to its war-time and later Cruise Missile era when peace women dared to dread.

These happy walkers chose scenic routes from five to eight miles organised for various charities by Newbury Rotary Club.

The group shone out wearing the Association's bright blue tee shirts, raising awareness as well as vital funds for Reading and West Berkshire branch.

Here newsletter reader and regular walker Mike Scott writes of his experience:

On Sunday 12th May a few of us went for a walk around Greenham Common to raise funds and awareness of Motor Neurone Disease (MND).

The event, which is held every year at various venues, was organised by the Newbury Rotary Club. They always invite local charities to take advantage of their organising skills to raise money for something dear to their hearts. This year my walking friend Mary Dodds asked a few friends, along with other MND supporters to take part as well.

We all met up at the café in the old Control Tower for a warm drink and a few stretching exercises to get ourselves ready for a five-mile walk around the common. There was an option of an 8 mile walk but that was left for the more serious walkers.

After a short discussion we agreed on where to start our walk from and set off with a lot of other groups and two 'packs' of dogs. Within the first 50 yards we came across





a herd of cattle with young calves; the mums being very wary of the dogs!

We carried on along a level stony path under a blue sky with a few white clouds floating about. We all walked at our own pace with one or two getting quite ahead of the rest of us but we soon caught them up.

We walked past some interesting waterways on which we saw a few ducks and geese. Unfortunately, we hadn't come prepared to feed them or we'd eaten what we had started with.

The navigator then made a wrong choice at one of the crossroads and we found ourselves walking back along the path we had started on although we cleverly found a route to get us back on track. It was at this point we came across a couple who had planned to do the eight mile walk but had walked out the wrong gate from the car park at the Control Tower!

We then stopped for a well earned drink of water and a 5 minute rest after which, feeling refreshed, we strode on towards the end.

This is where we came across a bit of the history of the common, where the nuclear bunkers were – an area also used in the Star War films. Just past here we could see the control tower in the distance but realised that we needed to walk away from it before turning back towards it.

The last mile took a lot longer than the first although we all finished in high spirits and pleased that we had achieved what we set out to do: increase awareness of MND and raise money for a deserving charity.

Pictured left are Derek and Jane Gilbert, Priscilla Bennell, Mike Scott, Yvette Campbell and Mary Dodds

Golfers teed up a winning round to help fight MND

When one of the popular players at a Berkshire golf club was diagnosed with MND his friends were determined to show their support.

One of them ran the London Marathon raising £2,900 and the others gave generous donations to the Association at the annual Captain's Day.

Wokefield Park's Simon Rogers said: "The main reason for choosing the MND Association for my captain's charity this year is due to the fact that one of our key members was diagnosed with MND about 12 months ago and we wanted to support Micky Denny during this time. It was also to help raise awareness as well as funds."

Micky, who has had to give up playing golf, was presented with an honorary membership at the prize giving on the Captain's Day in June and Aaron Mata was congratulated on his marathon run.

Afterwards an auction for a set of golf irons raised £600 and a bucket collection totalled an impressive £263.88.

Association Visitor Wendy Gouldthorpe and committee member Mary Kaye turned up in their Association tee shirts to help with the collection at the club near Mortimer.

Wendy said: "Most of the bucket money was raised by Mary and me sitting by the tee for the twelfth hole handing out bottles of cold beer in return for a donation!"

Captain Simon Rogers said the annual event was meant to be a fun day out for all members who play on the day.



Mary Kaye, Micky Denny, Wendy Gouldthorpe and Simon Rogers

"This year was not different and we started teeing off at 7.20am in teams of four, stopping on the 6th tee for breakfast. For the last four holes we had the Captain's Challenge which included the One Club Challenge, Two Flag Challenge, Beat the Pro with a Nearest the Pin and the Green Keeper's Revenge on the 18th."

There were also prizes for the overall winner and runners up followed by lunch served on the patio.

Jane Gilbert

Amazing £5k gift from generous inner wheelers

Branch chair Margaret Moss was thrilled to receive a giant £5,000 cheque from members of the Inner Wheel Club of Reading Maiden Erlegh.

Club president Valerie Coughlin chose the Association as one of her two charities of the past year in memory of her late brother Peter, who lived in Ireland.



She said: "It's a cruel disease with no cure or treatment." Mrs Coughlin would like the money to be spent on supporting people living with MND in Reading and West Berkshire and to fund vital research work.

One of the biggest events during her term of office was a very successful fashion show held in April at Leighton Park School in Reading where Inner Wheel Club members braved the catwalk in outfits provided by John Lewis and Partners.

The club also raised £1,500 during the year for Arthritis UK, another cause close to Mrs Coughlin's heart.

Margaret Moss is pictured (left) receiving the cheque from Mrs Coughlin on June 13th at her last dinner as the club's president.

VIP visit lifted Lin's spirits



Luckily the weather held on the first day of Lin's annual spring garden sale and she was delighted to see about a hundred people flock through her garden gate.

"I took a wonderful £185 that day and should have closed at 5.00pm but people kept coming, so I did not finish until 6.15pm.

By the second day strong winds did battle with the gazebo and Lin was forced to store a lot of the sale goods inside her home in Tilehurst. A visit from Reading West MP Alok Sharma lifted her spirits as Storm Hannah threatened to wreck the second day of her sale.

She said: "Just when my spirits were at the lowest ebb, our MP Alok Sharma arrived. We had a lovely chat and a photo session. This really cheered me."

Mr Sharma, who is the current Work and Pensions Minister, was happy to oblige when Lin sent him an invitation to her popular fundraising event.

She said: "People trickled in all day, with takings of £130.00. At 5.00pm hubby and I hurriedly took the gazebo down, throwing the contents wherever, before the rain came. We shut the door on it, and had a meal! "

"Not only is this about sales on the day, but it is a lovely community event bringing neighbours together who rarely see each other. On top of that, I reach a whole new group of people to make them aware of our work.

"I was exhausted but it was so very rewarding. Thank you to everyone who supported me."

CARDS FOR GOOD CAUSES

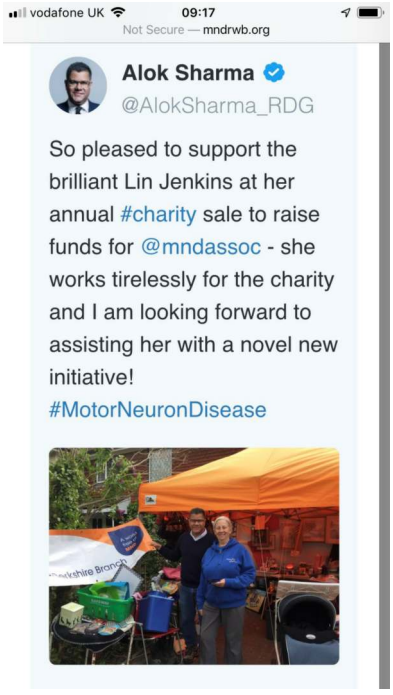
It's difficult to think of Christmas in the middle of summer but have you ever thought of helping at one of the Cards for Good Causes venues?

Volunteers are always needed to help sell the Charity Christmas cards at the local shops that appear in the run up to Christmas. Locally there are venues in Reading, Newbury, Henley and Wokingham.

It is a fun way to spend a few hours and to meet new people you work alongside. There is always someone on hand for advice if you hit the wrong key on the till! - and all the while you are knowing that you are helping to raise funds for the MND Association as well as the many other charities whose cards are on sale.

Cards for Good Causes can be contacted on 01264 361555 who will put you in touch with your local organiser .

Paddy Lunn



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

Please also contact Jane if you do not currently receive our newsletters and would like to be added to our mailing list (post or email).

Grand designs and glorious gardens for the Association's 40th anniversary





The MND Association held a "thank you" garden party at Boughton House (pictured left) in Northamptonshire, the Duke of Buccleuch's stateley home, on Friday 21st June.

I was fortunate to accompany Lady Hallifax to this event as her driver and companion. We were joined by Association Visitor Wendy Gouldthorpe and Alec and Chris Jenkins from Newbury who were among representatives from branches all over the country. There were some celebrities too - Dr Jane Hawking, Dr Lucy Hawking, four Association founders and many who give their time and commitment to the charity.

After a welcome by our host the Duke, we were shown around the ground floor of the house, followed by a talk about MND and research by Prof Ammar Al-Chalabi and then a tour of the garden. The duke was so pleased to show his lovely garden (and gardeners) to us all.

It was such a lovely afternoon with afternoon tea in the marquee and speeches – and on the first good-weather day we'd had, on midsummer day!

Thank you Your Grace for inviting us!

Margaret Moss

Roll up, roll up - get your camping gear here

I tried something very different this year at Burghfield May Fayre on Sunday, May 12th. Instead of my usual fete stall I took masses of camping equipment which was mainly salvaged from last year's Reading Festival.

I had signs up inviting people to stock up for this year's camping and music events and was selling tents, folding chairs, sleeping bags, air beds, wellies, pots and pans, washing up bowls, and BBQs. There were also lots of other small items needed by campers such as torches, lamps, battery fans, basic "toilet facilities for the night", ponchos, camping mats, and water carriers.

Obviously some families bought things for their own camping holidays as well.

It was extremely well received with many people stopping by and commenting what a good idea it was. I would like to make this an annual event whereby people can knowingly come along and stock up for the coming season. Can you please spread the word to friends and family who might be looking for camping items.

I met some lovely people throughout the day, quite a few who have been touched by MND in their lives. I also had a lovely long chat with an ex soldier who was suffering from Combat Stress. We had the most wonderful conversation, a hug, and some tears (when I thought no-one was looking). You get to meet such wonderful people at these events, not only our own MND family!



Lin Jenkins



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You shop. Amazon gives.

Sign up to AmazonSmile and you can support the MND Association as you shop, at no extra cost to yourself.

The Association is excited to partner with AmazonSmile. By signing up to shop via AmazonSmile, you'll still be able to enjoy the same range of products and prices just like you can with a regular Amazon account.

However, you'll now be able to select the association as your chosen charity – which means that 0.5 percent of the price of every eligible product that you buy will be donated to the association. This will have no effect on the price that you pay.

Shop and support the MND Association today:

Sign up for AmazonSmile via smile.amazon.co.uk

Search for the 'Motor Neurone Disease Association' via the charity lookup

Select us as your AmazonSmile charity of choice

Look out for products which are marked as "AmazonSmile eligible"

Enjoy your shopping

Yattendon & Frilsham Fete

For those of you who have never attended this event on a Spring Bank Holiday Monday, it is quite unique.

The picturesque village square is closed to traffic and there are many traditional stalls such as a maypole, morris dancers, choirs and bands down the street, in the church, village hall, social club and ancient tithe barn. Continue to the Manor Square where you can find the MND Association stall (it's bright orange so not easy to miss).



There are all the usual stalls, of course, but obviously, being Yattendon, which is famous for its festive foliage, there is also a Christmas Tree Throwing Competition!

This is always a lovely day out and the village where my husband Paul and his family come from so it is where our journey with MND started! Paul and I have attended this event for quite a few years now. We know lots of local people who always come and support us. We had lovely weather this year on May 27th but in the past, even if it rains, people still attend. "It's just tradition" they will say, if asked, "somewhere to come and catch up with friends".

We had a really successful day with the biggest takings so far this year.

Do make a note in your calendar for next Year!

Lin Jenkins

Forthcoming Events

Thursday August 1st 2.30 pm to 4.30 pm **Summer Tea Party**
Burghfield Sailing Club, Hangar Road, Theale, RG7 4AP

RSVP: ReadingMND@hotmail.com or call 07760 854975

Saturday August 10th from 10 am - 12 noon **Whitchurch Art Cafe**
The Old Rectory Stables, RG8 7DF

Pop in and enjoy tea, coffee and delicious homemade cake
Meet up with friends and browse the works of art (www.artcafe.co.uk/)

Saturday 24th August from 1 pm **Chapel Row Fayre**
on the green, opposite the Bladebone pub, Chapel Row, Bucklebury RG7 6PD

A great family day out as well as raising money for local charities, including the MND Association. See page 5 for more details.

Are you a cake baker? Would you be willing to donate a home baked cake to our tea tent at the Chapel Row Fayre.
Contact Mary Dodds.
Tel: 0118 941 4956

Saturday 24th August from 7 pm - 11 pm **Summer Party**
The Sonning Club, Pearson Road, RG4 6UL

An evening of disco in aid of Reading and West Berkshire branch of the MND Association and Duchess of Kent House. Tickets are £10 from Chris on 0118 987 6559 or by email sonningsummerparty@gmail.com.

See page 11 for more details.

Saturday 21st and Sunday 22nd September **Royal County of Berkshire Show**
Newbury Showground, Priors Court Road, Hermitage, RG18 9QZ

For the past few years we have had a very successful tombola stall at the show, which is great fun to do and helps with awareness raising.

We need people who can help at the show, could you spare 2 hours on any of the two days? If yes, please **contact** Mary Dodds.

Tel: 0118 941 4956 Email: MaryDodds@mndrwb.org

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