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motor neurone disease association

Reading and West Berkshire

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# News Letter

## 40 years on - we thank our amazing supporters



One table of happy guests - Paul Clough (Team Dean), Jane Gilbert, Richard Jones, Rev Clive Jones, Pippa Jones, Chris Warbey, Jacqui Warbey and Chris Brown (Team Dean)

A big-hearted Thank You Lunch marked the day the MND Association was founded by a group of volunteers who wanted to help others affected by this devastating disease.

More than 60 of the Reading and West Berkshire branch's amazing supporters and friends shared their inspiring stories at Basildon Village Hall, Upper Basildon, on October 6th.

Chair Margaret Moss told guests: "Without your funds we could not do as much as we do and every one of you has contributed so much."

West Berkshire Council's chair Graham Pask also paid tribute to the "exemplary" work of the branch saying it had taught him a lot about motor neurone disease.

He told fundraisers, volunteers and campaigners: "You are incredible in the work that you do. I applaud you. Keep it up – you are doing a grand job."

Every two years the branch honours its supporters and friends at a special lunch party for invited guests and dignitaries. Many of you will remember the former branch treasurer Barry Clouting and his wife Carolyn who were unable to come but sent their warm good wishes for the continuing strength of the branch.

Those attending said they were humbled to hear of the awesome fundraising challenges undertaken to help fight MND – a freefall skydive, a global online gaming marathon and gruelling endurance cycle rides and runs to name but a few.

Before lunch special prayers were said by the Rev. Clive Jones giving thanks for the work of the MND Association, its volunteers, fundraisers and researchers who are working to find the cause of MND and a cure.

On October 6th, 1979, a group of families affected by motor neurone disease came together for the first time. With little information, co-ordinated care or support available they felt 'isolated' and 'helpless'.

The time, hard work and dedication of those founding members created a charity which, thanks to four decades of energy and expertise given by thousands of volunteers, supporters and staff, is now looking to the future with a fresh optimism that we will deliver our vision of a world free from MND.

**Jane Gilbert**




Councillor Graham Pask with Colin Moss, Alec Jenkins, Margaret Moss and John Burton

# Energy firm's powerful support for popular colleague

We are over the moon to get a massive £5,373 boost from very generous staff at energy firm SSE's Thatcham and Reading offices.

They were devastated when they heard that MND had affected their popular colleague Mike Denny, who was a keen golfer and footballer. He is the inspiration for what proved to be their biggest ever charity fundraising campaign.

Organiser, Sarah O'Rourke, said. "It's good to think the money raised will be supporting him and helping other people too."

Sarah said generous colleagues had bought raffle tickets and donated prizes, sold cakes, and held a silent auction. Six of them completed the tough Snowdon Horseshoe Challenge over a weekend supporting SSE's Be the Difference initiative where employees can use one day to benefit their local community.

The firm's donation includes cash from De Vere Wokefield Estate Golf Club near Mortimer where Mike is now an honorary member since he is unable to play due to his illness. The annual Captain's Day at the club in June was also held in aid of the MND Association's Reading and West Berkshire Branch while one of Mike's friends ran the London Marathon to show his support.

Delighted volunteers from the branch - Wendy Gouldthorpe, Mary Kaye and Jane Gilbert - went along to the golf club with Mike on August 7th and were handed the massive cheque which included a £2,000 match-funding contribution from SSE.




(L to R) Sarah O'Rourke and MND Association volunteers, Wendy Gouldthorpe, Jane Gilbert, and Mary Kaye, SSE's Mike Denny, Darren Dodd, Paul Kimber, and Sanjay Sethi with Jamie Anton from De Vere Wokefield Estate Golf Club




The SSE team - Mark Mason, Darren Dodd, Rob Martin, Keith Hird, Paul Kimber and Sanjay Sethi (kneeling) on their Snowdon Challenge

Branch publicity officer Jane Gilbert said: "We were surprised and thrilled to receive this very generous donation to help our vital work supporting people in Berkshire living with this devastating disease. It was a pleasure to meet such an enthusiastic and caring group of people and we are very grateful to them."

Dad Mike, from Earley, is still working and praised his colleagues and SSE bosses for all their support to him.

"They are a great bunch to work with," he said. "It was well appreciated when they said this year's fundraising would be for the MND Association."

Thanks also to Sanjay Sethi from Lick Unlimited in Reading for kindly donating £110 from the sale of delicious cupcakes at SSE's offices in The Forbury.

**Jane Gilbert**

# Our star volunteers dazzle at the Royal Berks Show - come rain or shine




Jane Westwell, Graham Green, Joanna and Paul Robertshaw, Linda Green

Where in the world can you experience the following in one weekend?

**Weather** - on the first day at the Newbury showground on September 21st we experienced beautiful, scorching hot sunshine requiring sun screen, hats, glasses and copious bottles of water for rehydration.

On the second day we braved torrential rain needing rain hats, wellies and cups of coffee to keep out the chill! No two days could have been so completely different.

**Tombola stall** - yet again this was a fantastic sell-out of 1000 prizes all lovingly and very professionally prepared by Mary Dodds and her team. When the stand was first set up full of prizes, it looked absolutely amazing. Clearly, it was irresistible to the public and to our supporters!

**Crowds of people** - once again, there were very generous people not only entering into the spirit of the tombola, but also giving happily to the cause by using the MND Association charity box as well.

**Freebies** - who could ignore volunteer Barry Dodds who was out in the sun on the first day giving sweets to the children, having asked the parents' permission of course! Being the gentleman that he is, he very kindly held the umbrella for branch chair Margaret Moss to do the same on the second day.

**The unexpected** - we were involved in a minor drama when a young girl managed to lock herself in the ladies toilets opposite our stand. With a panicking father and two other children fretting outside, the females of the group went in to try and calm the girl down whilst Barry ran to seek some practical help.

Needless to say, the problem was soon resolved to our relief and, with the help of the sweetie treats again, happiness was restored. Well done the team!

**Laughter** - well, there was certainly much laughter throughout the weekend. One particular instance was when Mary was bringing out boxes of books to place on the table for the third or fourth time between heavy showers. The book titles were upside down so Mary started to pick each one up and turn it round - until someone calmly pointed out that all she needed to do was turn the box itself round! I think by this time, we were fast approaching 'tired, hysterical laughter time'.

**Congratulations** - once again, a special thank you to Mary and Barry Dodds for ' making it happen'. The setting up and taking down of the stand alone is no mean feat.

**Thanks** - to all the volunteers who gave their precious time and energy to make this year's event such a great success.

For me, personally, I would not miss it for the world. Yes, it was a tiring weekend but the awareness shared with so many people is a great way to improve the knowledge needed to fight MND!

Brenda Rayner



Still smiling - Brenda Rayner and Toni Kearsey

# Rock 'n' Ale says - Don't Stop Believin'



*Supporter Sam Morgan went along to join in the fun at this year's seventh and hugely successful Caversham Rock'n'Ale Festival.*

*Here she writes about the popular event run by the friends of inspirational mum-of-four Mrs Angela Fung who died of MND in December 2012:*

Who would have thought that tucked away within a quiet residential area in Caversham there was a toe-tapping, head-nodding, jumping, music and beer event being held?

On approaching the playing fields of Our Lady and St Anne's Primary School in July I began to doubt that I was at my correct destination but, all became completely clear, as soon as I entered the gates.

Children bursting with energy and atmosphere were bouncing to the beats of the bands on Space Hoppers. The four bands Forbury, Jadey, The Skandal and Dino's were on top form. The sun was shining, The Purple Turtle bar was open, the hog roast was rotating and the vegetable chilli was sizzling.

This event, which raised more than £2,000 for the MND Association, was filled with vibes, food and family fun for everyone.

Every year this festival has become bigger and better, but the last song on the playlist 'wrapped up' the real reason for why we were all there - Dino's version of "Don't Stop Believin" by Journey.

We cannot give in to MND and we have to keep believing that we can find a cure and help to make lives better.

Huge thanks to event sponsor, the Parish of Our Lady and St Anne's, the primary school, along with the various local businesses, bands and organisers involved in making this once again a successful evening for this very important cause.

## Angela's son has his sights set on developing therapies for MND

Student Luciano Fung, one of Angela and Daniel Fung's four sons, is progressing in his journey to become a neuroscience researcher.

The bright 23-year-old gained a First in his undergraduate degree at the University of Essex where he received the John Gorrod Prize awarded to the student with the most outstanding final year project in BSc Biomedical Science.

Now he is due to start a year-long MSc course at the University of Sheffield where he will be working and attending lectures in SITraN (Sheffield Institute for Translational Neuroscience).

He said: "I would describe translational neuroscience as applying the scientific research and knowledge that is currently available to develop new therapies for patients with neurological diseases. Furthermore, translational neuroscience also uses the current scientific knowledge to construct new medical procedures.

The topic of my final year project was testing a new antibody for TDP-43 in the diagnosis of ALS, as MND is known in the USA, and ALS-FTLD. In brief, we were testing an antibody for TDP-43 because in many ALS patients' neuronal cytoplasmic inclusions of TDP-43 are a common (but not definitive) neuropathological feature of ALS.

It is important that I give a special appreciation to the Cambridge Brain Bank and the Neuropathology Lab at Addenbrooke's Hospital for providing the brain tissue that was essential for this project.

Overall, I very much look forward to progressing in my journey to become a scientific researcher. "



Daniel, Luciano and Matteo Fung

# Plucky Vicar's MND skydive tribute




A retired vicar from Compton, near Newbury, hopes to have raised an amazing £7,000 from his awesome skydive in aid of the MND Association.

The Rev Clive Jones, aged 78, made the tandem jump over Salisbury Plain in memory of 47-year-old Jonathan Edwards, who lost his battle with the disease in July.

Clive descended from a height of 15,000 ft, free-falling for about a mile before releasing his parachute.

Afterwards he declared: "It was tremendous. I'd like to do another one when I'm 90 or perhaps a wing-walk!"

Clive got the idea of a skydive from his 16-year-old grandson and thought it would be a great way of raising funds for the Association.

His daughter-in-law Pippa Jones who was watching the jump said he was truly amazing adding: "Whilst other, much younger people, were noticeably nervous he was totally relaxed."

She said that out of 32 people who jumped that day, he was one of only two who took on the challenge from as high as 15,000 ft.

Now the retired vicar is delighted with the response he has had to his fundraising appeal.

He said: "I am amazed and thrilled at the amount of money that is being given for this very worthwhile appeal. All the money raised will go to our local Reading and West Berkshire Motor Neurone Disease Association who were so helpful and kind to Jonathan and his family during his illness."

He regularly visited Jonathan at his Compton home when he could no longer get to church and was able to tell him about his skydiving plans to help fight MND.

Clive still helps at seven churches in the Hermitage ministry team and he appealed to all the worshippers to sponsor him for his skydive.

He told them: "Unfortunately we hear very little about Motor Neurone Disease and its terrible effect on the individual and their family. My mission is to make people aware of this illness, and to raise money for the Motor Neurone Disease Association."

**Jane Gilbert**

**You can still donate via Clive's Justgiving page: www.justgiving.com/fundraising/clive-jones10-skydive**

**More photos at mediaroom.goskydive.com/jump/26-09-2019-913159**
**We are grateful to Pippa and Richard Jones for making these photos available to us. If you want to keep any please download them now as the online copies will get deleted after a certain time.**

# 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 recent 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**

# Chapel Row Charity Fayre











Mary Kaye above with some of her pretty hats

Jacqui Warbey is on the right with Boris the Bear




It is such a wonderful feeling to wake up on a sunny morning knowing that you are going to spend the day with friends in a pretty environment and raise money for a project that matters to you.

As you can tell from that, I am a great fan of Chapel Row Charity Fayre, an annual event on The Green in Bucklebury, that the branch has attended for several years. A group of us served tea and cake to the hungry hordes who made a bee-line for **the** tent as soon as we were up-and-running.

We have some very talented supporters, so that by the time I arrived, they had already smothered the tea tent in fresh flowers. Bedecked is the only word to describe it! It looked so pretty, drawing crowds to the tent from the moment they entered the field.

Even more of an attraction were the cakes – big ones, small ones, some as big as your head – you know the old song! Some of the cakes along with some of our team of great volunteers are pictured on the left.

Lin and her team also had a stall, selling books and other goods like hot cakes. (Hope you noticed the pun!). Mary Kaye was busy on her craft stall and Jacqui Warbey kept the children entertained with a hunt for MND Association teddy bears hidden around the fayre.

On this occasion we were one of five worthy causes that benefitted from the proceeds, while enjoying ourselves with good company in the sunshine at the same time. What could be better?

We are very grateful to Nina Sethi (pictured fifth from left in the top picture) and her great team from CDK Global (UK) Ltd in Hungerford who put up all the tents at Chapel Row Charity Fayre as part of the firm's volunteering day initiative.

A big thank you to all involved for making a successful day for the branch so enjoyable.

Some weeks later we were thrilled to receive a fantastic cheque for £2,150 as our slice of the proceeds from this year's scorching Chapel Row Charity Fayre.

Thank you to all our amazing volunteers who poured cuppas in the tea tent to swell the coffers and to the hard-working fayre committee for its incredible support once again. A total of £10,750 was handed out to the five worthy charities.

Fayre chair Lynette Maja is pictured at the presentation evening on October 7th at The Bladebone Inn, Bucklebury, with Association volunteers Lin Jenkins, Mary Dodds and Jane Gilbert.

**Val Pearson**

# Do you know that you can bank your voice?

***Most people living with MND don't 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 but all you have to do is 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 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 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 several ways:

- email and online video support
- telephone support
- with your permission somebody can access your computer remotely to provide practical help.

.

We also have volunteers, trained in voice banking, who can visit if more help is needed.

After a test recording of a few sentences, the balance of the 350 can be recorded at a time that suits you. Once completed your finished voice is stored online ready to be downloaded when needed.

Your computer needs to be running the latest version of Windows or Mac software and there must be a good internet connection. If you do not have a suitable computer the association can lend you a laptop to enable you to complete your recording.

The recording process is very easy and can be completed by anyone with basic computer skills. Now that the number of sentences to be recorded has been reduced to 350 , the whole project can be completed in an afternoon if you are feeling very keen.

You do not need to study or prepare anything in advance as the voice banking volunteer will have all that is necessary. It is a simple process and is no more difficult than talking on the phone.

Your local voice banking volunteer Michael Morrison (Email: ReadingMND@hotmail.com or Tel: 07760 854975) would be pleased to discuss voice banking with you and then visit you to help you record your voice. Remember, it is very easy to get started and the MND Association will cover all the costs. Do contact Michael if you would like to know more.

Further information can be found on the Acapela website at https://mov.acapela-group.com .

**Michael Morrison**

## *Glenvale Christmas Charity Event*
## Hungerford Lane, Bradfield Southend, RG7 6JH
## *Sunday 1st December 12-4pm*

There will be complimentary mulled wine, a huge selection of Christmas trees & holly wreaths and lots of stalls to look around.

This year, we are supporting:
**MS Society, Motor Neurone Disease Association, Diabetes and Parkinsons**.

We'd love to see you, please tell your friends & neighbours, the more the merrier.

It'd be great if you could let us know if you can pop along, then we'll know how many bottles of mulled wine to buy & how many 100's of mince pies to make!

Tel: Dunc - 07818 452851, Hel - 07766 903685 or Email helvarley@btinternet.com

## *Drop-ins*

Drop-Ins are scheduled for the following dates at **St Luke's Church Hall , Englefield Road, Theale, RG7 5AS** from 12.30 - 2.30 pm. All welcome. Come along and meet friends old and new and have a chat.

**6th November 2019**

**29th January 2020**

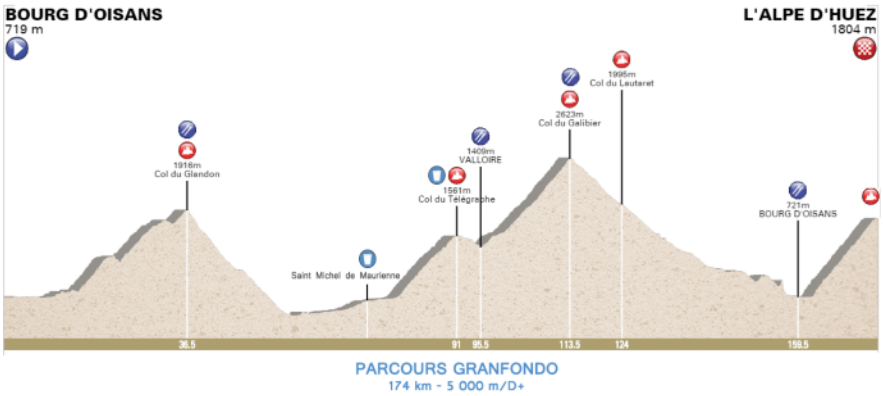
**1st April 2020**

If you have any queries please contact the Reading and West Berkshire branch on

07760 954975

or email readingmnd@hotmail.com

# Team Dean nails the mighty La Marmotte




Team Dean - Stuart Burnett (Chewy), Paul Clough (Cloughy), Kevin Fisher (Fisher), Mark Fisher, Mark Harris, George Goodchild (Gorgeous) and David Silver (Shrimpy) - embarked on La Marmotte Des Alpes, the legendary one-day cycle race and spiritual home of cycling on July 7th.

I had been asked to take part with close friends who wanted to mark their 40th birthdays and to raise money for the Motor Neurone Disease Association, in support of our school friend Dean Halkes who had been living with MND since 2015.

Initially started in the 1980s, 'La Marmotte' has grown to become an iconic event within road cycling. Elite professional riders compete for the yearly title but the field is also open to a small number of amateur riders.



Mark Harris (front left), Mark Fisher front right) with brother Kevin Fisher behind. Paul Clough is in the crowd

Covering 175 km of Rhone-Alpes mountains and valleys, the course is both spectacular and brutal. Winners commonly complete the course in around 5hrs 30mins whereas mere mortals struggle to avoid the broom wagon ending their race before the 18:30 cut-off at the base of L'Alpe d'Huez.

Our training had gone well. We knew we needed to take this event seriously, otherwise we would simply not complete it. We put 2,500 km into the legs in the months leading up to the event, and we were commonly seen over the Chiltern Hills. However, as it turned out, hills cannot replicate the French Alps!

The night before race day was a surreal event, with our wives flying out to meet us that day. Whilst they hit the hotel spa and started enjoying the French hospitality, the cyclists were drinking all sorts of non-alcoholic drinks and concentrating their efforts on consuming vast amounts of food to be converted into energy for race day!

That evening Dean sent a video message saying good luck for the big race. It was a truly inspiring video. Dean by now was unable to speak, but somehow managed to deliver a video message to us all with the help of his computer. If he could do that, then we could definitely complete this little cycling event.

Race day arrived. The alarm went off at 5 am, and we started to don our meticulously prepared race attire. I've run a couple of marathons in my time and ran the Brighton Marathon whilst pushing Dean in his wheelchair in 2018, but putting the shirt on and getting ready for 'La Marmotte' with Dean's name on my sleeve gave me an enormous sense of pride. Writing this now, I feel exactly the same.

As we crossed the 07:30 start line on the picturesque high street of Bourg d'Oisains, nestling at the base of the Alpes, cowbells rang in our ears.

The race did not disappoint. Breathtaking mountain peaks gave way to alpine lakes, interspersed with picture postcard villages. Cyclists from all over the world were competing, some for the first time, others had clocked up many previous attempts. If the finish line was the base of Alpe d'Huez perhaps 'La Marmotte' would not have achieved mythical status?

This is where the ride really begins to bite. On fresh legs the 21 legendary bends are a test for most with a keen amateur taking around an hour to the summit. With 160 km of punishing gradient already in the legs, it presents an almost incomparable battle.



Team Dean take a breather at Bend 7 (Dutch corner), L'Alpe d'Huez

With the evening sun beating down the only way is up. Each bend of the ascent becomes increasingly littered with slumped bodies, fleeting relief

Continued on next page →

# Team Dean nails the mighty La Marmotte - continued from page 8

from the heat only found through the hose of a generous spectator. As the altitude rises the temperature begins to ease, just as the air begins to thin. The last bend does not, however, signal mercy as a further 3 km through the town unwinds.

The overwhelming emotion on finishing was one of relief over elation. To simply draw a line under such a physically and mentally challenging day was reward in itself. We'd spent the best part of 12 hours in a saddle, cycling up some of the toughest gradients and mountains Europe has to offer, and now had a feeling of great pride and relief that it was over.

After the last of our team had finished, we grouped together to make a video for Dean. Emotions ran high as we all recognised the privilege of our health and how fortunate we are. With minor aches and pains truly put into context, fatigue started to creep in.

A photo from the finish line tells the full story of the day we had just had in the saddle, the hardest event I have ever had the pleasure of completing

We arrived back in the UK to the sad news that Dean had passed away on 14th July 2019 surrounded by his family. He was 39 years old, a poignant reminder of how fragile and precious life is.

We embarked on the challenge of 'La Marmotte' simply because we could do it and to raise money for people living with motor neurone disease. Others are not blessed with that choice. Our pain was insignificant compared to theirs.

**In memory of the bravery of Dean Richard Halkes 1980 – 2019. We miss you buddy. RIP now.**

**To donate to the Motor Neurone Disease Association via our La Marmotte website, now in memory of Dean, please use the link below.**

https://www.justgiving.com/fundraising/fordeano

**Paul Clough**




Mark Harris, Kevin Fisher, David Silver, Paul Clough and George Goodchild after the race

# Family's copper magic will shine in Dean's memory



Dad Richard Halkes has pledged to carry on the family copper work business in memory of his beloved son raising funds and awareness for the MND Association.

The pair started designing and creating copper homeware accessories as a way of spending family time together and having fun after Dean's diagnosis in 2015. His sister Shelley took care of the sales supported by mum Juliet.

Dean, who was a structural engineer, proved that MND doesn't stop you leading a fulfilled life, his loving family said.

"He continued to travel the world, start a business, ticked off bucket list wishes and found a new inner strength to live." "We have decided as a family to continue the business in memory of Dean and have roped in more family members."

"We donate 10% of all item prices to the Motor Neurone Disease Association for all products that are sold and hope that by doing this we can also raise awareness of what is a rare and somewhat cruel disease."

For more information visit

https://halkescopperwork.co.uk/

or check out their online Ebay/Etsy shops or Facebook page.

**Jane Gilbert**

# Bob's back with another big bike ride

Big-hearted Bob Wearn, a granddad with a passion for pedalling, has clocked up his second epic trip to raise cash for the MND Association.

This summer, Bob, from Old Windsor, took on a route from Dover to Penrith, near the Scottish border – a total of 430 miles in six days. So far his efforts have raised an equally impressive £1,864 for Reading and West Berkshire Branch's funds.



He admits it was hard work at times with some steep hills, changeable weather and a "bit of a stomach issue" in the last couple of days.

Bob, aged 69, said afterwards: "Overall a brilliant adventure and the guys I rode with were great companions of the road - and the bar stool!

"They certainly helped me keep going and it was great having a back-up van offering any technical support we needed plus the odd brew. And, oh yes, I was puncture free this time around. "

Bob was inspired to take on another challenge by his dear friend and former BT colleague Peter Colvin who is living with MND. Two years ago the plucky pensioner cycled from Land's End to John O'Groats in aid of the branch which is supporting Peter and his family.

For more of Bob's story and to donate visit:

**www.justgiving.com/fundraising/bobw-dovertopenrith**

**Jane Gilbert**

# Tandem WOW!

**'We are aiming to set a new world record for being the fastest women to circumnavigate the world on a tandem. 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.'**

These two intrepid women set off from Oxford at the end of June and now, four months later, they are cycling through Thailand having flown from Calcutta to Myanmar to continue their journey south through Thailand, Malaysia and beyond. (Of course they take the ferry or fly between watery places!)

You might know one of these as Rachael Marsden who is the Specialist Nurse and Care Co-ordinator at the Oxford MND Care and Research Centre. Rachael is pictured (left) with her equally awesome pedaling partner Catherine Dixon.

You can follow their route and their photos on:

followmychallenge.com/live/tandemwow/?TandemWoW

or find a link to sponsor them here:

www.tandemwow.com

**Margaret Moss**



# Jacqui's bear necessities for a walk around Guernsey

When keen knitter Jacqui Warbey stepped out around Guernsey this summer she took along Goldie the teddy bear dressed in MND Association colours to keep her company.

Jacqui, who was holidaying on the island, took on the challenge to walk around the coast in memory of her husband Richard, who lost his battle with MND in 2017, aged 56.

She said: "Richard loved Guernsey and we enjoyed many family holidays there.

"Taking his old teddy bear, Goldie, with me allowed me to take some lovely photos of the beautiful coastal views even if it did mean I was busy knitting him new outfits in the MND Association colours each evening!"

Jacqui, from Woodley, near Reading, posted regular photos and updates for the branch Facebook page to help raise awareness of MND. Her online page also raised £1115 plus Gift Aid in funds for the Association which supported Richard and his family during his illness.

She said: "I feel so satisfied to have walked around the entire island and to have raised so much money. I had great support from my friends in Guernsey and from my son James and his partner, Rachael who accompanied me on most of the cliff walks.

"I met a local lady who had lost her husband to MND five years ago and another couple walking on the cliffs gave me a donation as they had a friend who had died from MND.




"I was very lucky with the weather and finished the walking a couple of days before the hottest day of the year."

**Jane Gilbert**

# Bowled over by club's generosity

It is always lovely to receive a surprise donation and I was delighted to visit Palmer Park Bowls Club in September to accept a cheque for £360.

The cash was generously donated by members of the East Reading club during their President's Day fundraising event.

The MND Association was chosen as it is a cause close to the heart of President Rosemary Wincup - her husband lived with MND for 23 years and she is a long-term supporter of our branch.

Members enjoyed a day of bowls and a delicious lunch prepared by Rosemary and her daughter Anne Robinson who said: "It was a super event enjoyed by the club members and also fabulous to raise money for Rosemary's charity the MND Association".

Since then, Rosemary has sent us a further £40 raised during quizzes and games' nights when the bowling club was on tour, bringing the grand total to £400.

It was a pleasure to meet such a lovely bunch of people and we are very grateful for their kind donation which will help us to continue supporting local people who live with MND.

**Jane Westwell**



# Lin turns Reading Festival junk into gold

This article first appeared in the MND Association's September issue of Volunteer News which is sent to all branches

*Words by Keiron Henderson - Volunteer writer*

Some years Lin Jenkins is up to her welly tops in mud as she picks through the spoils left by revellers at the famous Reading Festival, but this year was drier and a little kinder, yielding loads of good quality gear for her many car boot sales and fete stalls.

Reading & West Berkshire Branch Fundraiser, Lin, brings in as much as £7,000 a year from her activities, with a lot of that coming from the tents, sleeping bags and other camping gear she rescues after the metal and hip-hop music lovers have melted away from the sprawling Richfield Avenue site.




Organisers at the festival invite registered charities to sign up and help clear the venue of useful items left behind so Lin, a veteran of five festivals so far, often finds herself lining up with volunteers from a range of other charities.

*"You register several months before hand. Homeless charities, asylum seekers' organisations, scout groups go along. It can be any charity as long as you've got a registered charity number. You become the salvage team. They're getting equipment to be used for their people, whereas I and others are getting stuff to sell on,"* says Lin.

And selling stuff is former school administrator Lin's superpower and a passion that sees her out of the house most weekends during the summer months.

*"From about April to the beginning of October every Saturday, Sunday and bank holiday Monday I'm out. If there's a fete or something of that nature, that takes precedence, but if not, then I'm carbooting,"* said Lin.

Years of experience fundraising means Lin is now a magnet for donations, the money for which all goes to the MND Association.

*"I started off doing it small time with friends and family and workmates and then their friends and family got into it, and because I have a garden sale once a year all the neighbours got into it. So I constantly get things on the doorstep, two or three times a week. Nearly every week of the year there are things donated on the doorstep. Prizes for my stalls tend to 'materialise',"* she said.

The most common item left behind at the Reading Festival is the humble folding chair, but tents, sleeping bags and pillows are next along with cooking gear and numerous cans of drinks and, perhaps unsurprisingly, lots of toilet paper.

*"There are not many items I cannot sell or use as prizes,"* says Lin. *"This year some of my 'yield' was 12 tents, 62 folding chairs, 53 sleeping bags, 24 blankets/throws – most of these will go to a local church group, who work with the homeless over winter. Of the 48 towels collected, many will go to my godson's dog grooming parlour. I collect unopened tins/cans/packets of food, packs of tissues, wet wipes, bum bags, ponchos, wellies and shoes, pots and pans, torches."*

Lin says she gets funny looks when picking up silly hats and wigs, but these can be used in a "photo booth" stall at fetes where people use her props and large picture frame, but take their own photos.

The super fundraiser is often amazed that festival goers will just wander away from hundreds of pounds worth of gear.

*"People literally go away from their whole camp and leave it as they've lived in it for the weekend. You cannot imagine it. If there's been a group you may find a central gazebo then a circle of tents around the outside, inside are the airbeds, sleeping bags, pillows, left over food etc. Outside, it's unused barbecues, pots and pans, shoes, wellies. It's as they walk away from it,"* Lin says.

The most unusual items abandoned include fancy dress outfits and toys, which Lin says make great tombola prizes.

Lin says festival salvage is clearly an opportunity for charities to raise money and suggested other MND Association branches near famous events might consider getting involved.

Continued on next page →

# Lin turns Reading Festival junk into gold - continued from page 12

*"Presumably all the other festivals around the country will do the same thing. I've got a feeling that the people that organise this (salvage) aren't just Reading people. Any branch that is near one of these (big festivals) might want to get in contact with them,"* says Lin.

The Reading & West Berkshire Branch Fundraiser prefers to work on her own and has access to lots of storage but acknowledges that getting a team together and storing and subsequently selling large volumes of gear can be a challenge.

*"It's not everybody's cup of tea. Not everybody wants to rummage about in a field but there are going to be other people like me out there interested in doing it."* And the conditions can be daunting, with mud and dust equally difficult to deal with.

*"This year the heat ranged between 30 – 32 degrees, and the dust had to be seen to be believed. Despite all that .... yes, I will do it again next year. I can't begin to tell you how rewarding it all is."*

Lin says she devotes so much time and energy to her fundraising efforts because it gives her a sense of purpose which helps her manage her depression.

*"I'm not embarassed about it but I suffer from depression and nervous problems and this has given a focus to my life. I must touch wood when I say this but I've kept much better mental health since I've been doing this.*

*"Of course it's more than that. I do it for the people living with motor neurone disease,"* says Lin. She pauses, briefly, before adding: *"And it's a way of getting out of the housework."*

# Life is full of surprises for Super Fundraiser Lin

It's the end of another "season", slightly delayed this year, to take me up to the date of the MND Association 40th anniversary on October 6th. I'm delighted to say that I have raised a total of £5,092.

Money has been very hard to come by as people are being cautious with how they spend their cash. I try to be inventive, to come up with different ideas, but something just "dropped on my lap" recently. At Spencers Wood Fete, Shinfield Parish Council was inviting people to vote for their best/favourite charity stall. I'm thrilled to say that I won, and got £50 for my efforts. What a bonus!

I've already done several reports of events throughout the year, with mixed results on the amount of money raised. However, the awareness is higher than ever. Many people look out for me at events, or send people to me. It's always a pleasure when someone wants to share "their" story with me, but I often have to go behind my stall for a little weep afterwards!

Car Boot Sales are my mainstay at the moment, but at this time of year it involves getting up in the dark, leaving the house just as it starts to get light, to arrive just as the day begins. Luckily it is not too cold so far this year and most of these will soon finish.

Donations still appear on my doorstep on a regular basis. The other day we could not get out of our front door, because a 5' x 3' pine mirror has been placed against it.



Lin pictured with ex England goalkeeper David Seaman at Padworth & Aldermaston Show in July

My favourite items have to be two bridesmaid dresses (age about 6 and 8) and two three-piece suits, suitable for page boys (aged about 3 – 4). I'm over run with rocking horses and children's bikes, but you know me - I never turn anything away!

I have several Christmas events coming up – one of them a craft fayre helping Mary Kaye and two nursery sales. Keep an eye on the branch Facebook page for details. With trips to the auction house and scrap metal yard, work will begin on next year's fund raising immediately.

**Lin Jenkins**

# A cuppa and a cruise for council chief

West Berkshire Council chairman Graham Pask and his wife Hilary enjoyed a cuppa and a cruise when they attended the branch's annual summer tea party at Burghfield Sailing Club.

They chatted with volunteers on a glorious sunny day in August and learned about the Association's vital work helping people living with MND.

"I will do my best to support the good work that you do whilst I am in office and afterwards," pledged Cllr Pask.

He also enjoyed a cruise on the lake in a power boat adapted for wheelchairs thanks to the club's Sailability Group which is dedicated to bringing boating to people with disabilities.

More than 40 guests enjoyed afternoon tea and cakes at the lovely venue thanks to the support from the sailing club. A raffle of prizes also raised £110 towards branch funds.



Time for tea - West Berks Council Chair Graham Pask and his wife Hilary with (from left) Mary Dodds, Sam Morgan, Brenda Rayner, Margaret Moss, Carol Allen and Linda Green

**Jane Gilbert**

# Sonning Summer Party



On a warm summer evening at the end of August there was a joyous party at The Sonning Club in the village near Reading. It was organised to raise funds for both the branch and the Sue Ryder Duchess of Kent Hospice and included a DJ, a bar and bring-your-own picnic.

Organiser Chris Goodchild, from Earley, decided he wanted to do something to help as he has a friend living with MND and another with bowel cancer.

"We had a fantastic time with more than 90 people," he said. "We got a good result - £1,453 shared between the two charities – and hopefully it will be useful."

During the morning the hall was decorated with balloons and bunting. In the evening, the crowds turned up, the raffle was drawn and prizes distributed.

Chris was helped by his wife Tracy, sister Yvette Tye and his friend Bernie Tiller from Northamptonshire who made a 120-mile round trip to run the disco free of charge.

Branch chair Margaret Moss, who gave a speech at the party, is pictured later receiving a cheque for £726.50 from Chris.

**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).**

# Total respect for our awesome volunteers



My mum Mary Kaye was running a stall for the MND Association at Hungerford Corn Exchange, and she asked me to go along and help out – of course, I was happy to!

It was a long day. We were on the go from 8am to 5pm and usually on our feet as people are much more likely to visit if you look active than if you are lazing around! We sold all kinds of things from hand crocheted hair scrunchies to a pair of decorative bottles encrusted with the logos for Arsenal and Tottenham Hotspur as well as providing leaflets with information about all aspects of the Association and the work it does in Reading and West Berkshire.

Whether they ended up buying anything or not, quite a few people who passed by our stall got talking to us about MND, and sometimes about friends and family who had been affected by it. They seemed pleased to see that the charity was there raising funds and awareness, and to be able to talk about their experiences.

My mum lost a close friend to MND last year, so she knows what a terrible disease it is and how much support is needed to care for patients and those close to them.

Working on the stall all day was a tough job with no real down-time – it is definitely like adding another day to your working week. Then of course there is all the work that I've seen that goes into producing or sourcing the items for sale and, of course, making arrangements with the venue.

Although we didn't make a fortune, every little helps. It was nice to do my small bit towards showing that MND Association support is out there connecting with the public wherever and whenever it can. I came away with a lot of respect for those people who regularly volunteer their time so selflessly.

**Steven Kaye**

# Team MND returns to the Art Café

Here we were again, back at the Whitchurch-on-Thames Art Café to serve customers on a sunny Saturday morning in August.

By the time the delicious home-made cakes had been laid out and the fresh coffee was ready to be brewed we waited anxiously to see how many would turn up this time!

Although the café is tucked away by the Toll Bridge it attracts a steady stream of Thames-side walkers as well as villagers coming to meet friends and to support a worthy cause each week. The branch is very grateful for the opportunity to swell its funds and raise awareness of MND. This time we made £80 on the raffle, and £146 from the sale of the coffee and cakes.

Throughout September 2018 visitors to nearby Pangbourne Meadow might have been surprised to see a display of over 500 clay cylinders threaded onto posts to form totem poles. This was organised by the Equinox Together 2018 Community Art Project and local schools, community groups, charities and individuals were invited to join in to create a Fibonacci spiral arranged to represent the changing seasons, month by month.

Proceeds from the display were shared out amongst charities that ran Art Cafe coffee mornings in 2017 and as a result fundraiser Gill Williamson, organiser of the project, presented Branch Secretary, Jane Westwell, with our share of the proceeds - a cheque for £41.40.

The Team always enjoys volunteering at this lovely venue, so do come along and join us next time we are there on **December 14th from 10.30 am -12.30 pm.**

**Paddy Lunn & Gill Williamson**



# 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 or, if you prefer, with our Regional Volunteering Co-ordinator Jo Campbell by email: jo.campbell@mndassociation.org
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**

# Awareness raising at Asda, Lower Earley and Bracknell Hilton Hotel
## - do come along and see us

**Saturday 30th November between 8am and 6pm**
**Lower Asda foyer, Chalfont Way, Earley RG6 5TT**

We will be in the foyer of the ASDA store in Lower Earley to raise awareness of MND.

We will have bucket collections, a stall selling MND Association items, including Christmas cards, some craft and gift items for the coming festive season, and a Tombola. We would love to see as many people as possible.

There are a couple of nice cafes in the foyer, so you can come along and see us and get yourself a coffee.

We are looking for some help too, so if you have a little time to spare please email and let us know. Nothing too difficult, just some big welcoming smiles and hands to hold some buckets. Contact Mary Kaye at ReadingMND@hotmail.com

**Sunday 3rd November between 10am and 4pm**
**Bracknell Hilton Hotel, Bagshot Road**

We will be raising awareness of MND at the Craft and Gift Fayre with some lovely craft items for sale as well as excellent Christmas presents.

**Mary Kaye**



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