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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Wow! Party raises amazing £22k for MND



Maz Swann, John Forrester, Rebecca James, Andre and Anton Claassen pouring the cocktails

A summer garden party with the freedom feel-good factor has raised an incredible £22,000 to help fight motor neurone disease.

Hair salon group Forresters and The Old Boot Inn at Stanford Dingley joined forces on July 25th for the sparkling event, which was inspired by two women affected by MND.

One of the organisers, John Forrester, who founded the company with his wife Jill 50 years ago, said: "It was a fabulous evening with drinks, delicious eats, music, dancing, an auction and raffle.

"It was the first time in 18 months that a group of people could come together to have a wonderful evening and raise money for charity."

He explained the MND Association is close to their hearts because a treasured member of the Forresters Pangbourne salon team, Marian 'Maz' Swann, was diagnosed with the disease earlier this year.

John said: "It's a shock for everyone but we're able to do something positive by raising funds for the charity that's helping Maz to live her life to the full."

Andre Claassen and Rebecca James who run The Old Boot Inn at Stanford Dingley have personal experience of MND too as Andre's sister Sharon Budde lost her life to MND in April.

The organisers were bowled over by the many local businesses and clients who donated fabulous prizes, and by the auctioneer Simon Fryer and top DJ Stephanie Jay for their impressive work on the night.

Branch publicity officer Jane Gilbert, who was one of the organising team, was overjoyed with the success of the sell-out event.

She told the 200 partygoers: "This amazing generosity will help us improve care and support for local people living with MND, their families and carers.

"No-one can describe the devastating impact of this cruel condition better than Maz whom we helped to bank her voice digitally and which she is using to give a speech tonight."

Hair stylist Maz, who was diagnosed with MND in February just before her 60th birthday, said the news completely shattered her world.

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Maz with some of the organising team as well as friends and family

Summer Garden Party (continued from front page)

She said: "What an incredible turnout. I apologise that I am using my digital voice for this short speech, but the type of motor neurone disease that I have is called bulbar onset, which affects all the muscles in the top half of my body first; and has therefore affected my speech."

Since Maz was forced to give up her job she has enjoyed painting and kindly donated one of her works which sold for £600 at the auction.

Afterwards she said it had been wonderful to see all her lovely friends and clients supporting her.

"What an amazing bash we had – I felt like a Queen."

On the night the audience heard that the understanding of the causes of MND has improved dramatically over the last two decades but the biggest challenge remains: to turn this knowledge into effective treatments. The Association believes that MND is not incurable, but it is underfunded.

Jane added: "Researchers are already making good progress, and urgently need more Government funding to take the science out of the labs and into clinical trials."

To donate to the event page visit:

https://localgiving.org/appeal/forresters/

Jane Gilbert



Maz with Forresters' style director Stuart Forrester and his painting of David Bowie that was sold on the night



DJ Stephanie Jay certainly got the party going with a swing!



Oh, For Ducks' Sake!



It all began on June 18th when my partner asked for a lift to collect his car from the BMW garage at Junction 11 in Reading. Of course, no problem, and plenty of time before taking my son to his swimming lesson.

Well, that was the original, straightforward plan . . . until getting stuck in Friday rush-hour traffic and a man in a hi-vis jacket running alongside my car, pointing frantically underneath it!

My initial thought was, who is this crazy guy and should I open my window? (a safety-first reaction). I slowly peeled down my window and asked what the problem was. "You have ducklings under your car!" he exclaimed.

The man began to coax the 10 or so ducklings out from under my car, off the A33 and onto the pavement.

The ducklings could only have been a couple of days old and were scattering around like 'headless chickens' (so to speak!) without a mother-duck in sight.

Two other people also stopped to help out and it was decided that the best plan of action was to take the little ones away, or they would never survive on their own.

I bundled two into the boot of my car and the others were rescued in the other vehicles.

Not such a straightforward plan after all . . . what was I going to do with two ducklings in my car?

Fortunately, I had a storage box at home to put them in and was able to pop to a pet shop, purchase some chick crumble and seek advice from Dr Google.

Wow! There's no such thing as a 'House Duck'. Like a couple of kids, they have no regard for the person who cleans their poop up and they talk with their mouths full of food splattering it everywhere! Then they decide it is a good idea to do the same in their bathtub. They have the audacity to endearingly tilt their heads and innocently gaze up at you. OK, I forgive you, because you are cute.

One of the ducklings was suffering with a 'bumblefoot' injury, which can be caused by a niacin deficiency. Over the short time, the foot has greatly improved and I am hoping it will now completely heal.

So three weeks on, the not so little ducklings were moved to an outside area and once fully feathered and mature, will be taken to the Waterfowl Sanctuary in Banbury (run by an inspirational 92-year- old lady, who has just had her leg amputated!)

It has been a fun, interesting, and messy experience but hopefully by rescuing these ducklings it has given them a fair go at life and therefore it will have been worth it.

A friend said that it was fate that they chose to run under my car that day, or maybe they just had an instinct that I was a little bit quackers?

Samantha Morgan

Newsletters

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

Kerrie Newton:
secretary@mndrwb.org

Yippee! Holidays are here again



As I start writing this article in mid June we have just returned from our first holiday for nearly two years. The picture shows me sitting in my wheelchair outside the lodge we stayed in. OK, that wasn't really it! In actual fact we stayed at a site called Tudor Lodges in Morval, a small village just outside Looe in Cornwall. It's a group of seven holiday lodges purpose-built to accommodate people with a range of different disabilities. The lodge was very spacious and has been built to a very high standard. I have no hesitation in recommending it, but check their web site for yourself at tudorlodges.co.uk. It is run by a lovely couple, Michael Tudor (hence the name of the site) and Julie Lang.

We had a great time and brilliant weather. OK, it wasn't quite like the picture but we had wall-to-wall sunshine every day and it's a beautiful part of the country. There was one slight draw-back possibly caused by all the hills in the area - the satnav wasn't reliable. One morning on the way to visit Mount Edgecumbe House the satnav indicated a right turn ahead. As we turned we saw a sign saying that the road ahead was very narrow and if we were following a satnav then ignore it! On another occasion we set out to visit Cotehele, a National Trust property. On that occasion the satnav said to turn off the A390 onto the A388. So far so good as both are quite major roads. We weren't unduly worried when directed onto a minor road but after travelling for many miles on roads not even marked on the road atlas which had grass growing up the middle and were so narrow that the hedges on both sides were scraping the car we realised something was wrong! Fortunately we eventually saw a local who confirmed that we were miles from our destination and put us right.



We had two holidays booked through Disabled Holidays which we deferred from 2020 to 2021: When we contacted them to defer the first holiday they said the owners (Tudor Lodges) were very understanding and helpful and had allowed us to change it to the same week this year at the same price. The second holiday booked through them for August 2020 was for the three generations of our family. When we asked them to defer that one they said we had to pay a £35 admin fee plus an additional £220 for the same period this year! When I recovered from the shock I asked why and was told that it was booked through a second agency and it was they, not Disabled Holidays, who levied the additional charge. We have since discovered that the other agency is Hoseasons. Well, I guess we won't be using them for future holidays! In addition we had a four-night short break booked for later in the year at Marchamley near Shrewsbury just for my wife Chris and myself. It's the only holiday accommodation which we've returned to more than once. It's run by another lovely couple, Karen and John Powell. They too allowed us to change it to this year at the same price. They put out bread, butter, local cheese and home-made biscuits for when you arrive. It's worth going just for the biscuits! Give them a call on 01630 685325 or 07811 457723. Both they and Tudor Lodges have shown that they take great care cleaning between each new batch of occupants.



~~The~~ *second* COVID-19 jab and me!

In the last Newsletter I wrote about my first vaccination and how I felt at increased risk owing to the lack of organisation at the vaccination centre. I had different problems with the second 'jab'. The day after I felt very weak. At bedtime I walked, using my rollator to the bedroom via the bathroom. With my wife's help, I got to within two steps of the bed when my legs just gave way and I collapsed in a heap with my legs bent under me. I was in great pain. My wife and our son couldn't get me up and so called the paramedics who came out about an hour later, got me up and onto the bed. For the next few days I needed to use the wheelchair to move round the house. I gradually regained my strength, but it took about eight weeks to get back to full strength. Well, maybe not that strong but to my pre-vaccination strength!! The fact that I can walk at all after nearly 25 years living with MND I take as a bonus!! I'm writing this to see if any other plw (person living with) MND has had anything similar following the second 'jab'.



Alec Jenkins

Voice Banking - in just 50 sentences

Branch volunteer Michael Morrison explains:

1. This is almost how long it takes to bank your voice.
2. This article is 25 sentences long.
3. You need to record just 50 short sentences online.
4. Read this article twice, and you could have done it!
5. You must use a headset microphone.
6. The MND Association's local volunteer can help you.
7. The Association will pay for your voice.
8. You just need an internet connection.
9. We can lend you everything you need, including the headset microphone.
10. It's a very clever process that produces a digital voice that sounds like you.
11. There are many reasons why people living with MND bank their voice.
12. Maybe their voice gets tired.
13. Maybe they get tired.
14. Perhaps it's a "just in case" precaution.
15. Their speech and language specialist might have suggested it.
16. Friends could have suggested it.
17. Their Association Visitor (AV) told them about it.
18. Research has shown that most people living with MND don't bank their voice.
19. That's because surveys show most people don't know they can bank their voice.
20. And that's a terrible omission.
21. If you would like to know more, please get in touch.
22. It's all done remotely and is, therefore, Covid safe.
23. And that's it, almost 25 sentences.
24. You can even stop and start as you choose when to record.
25. Read this again, and you've done it!

For more details email: contact@mndrwb.org

If you have already banked your voice, would you like to submit a short piece about how you found the process for our next newsletter? We'd love to hear from you.

Thank you to our loyal branch supporter and volunteer, Clare Tilley, for kindly donating a Microsoft software package to the branch. Clare's father, Derek Prior lost his battle with MND in 1990.

Kerrie Newton

Fundraiser Lin and Little Ted take a break in Iceland

It seemed so simple when I first thought of it – a trip to an erupting but fairly safe volcano almost on my doorstep. I waited for Boris Johnson to give permission to visit a "green" country, and off I went.

It has to be said that very little went according to plan, but never mind, Wednesday was "The Day".

Suitably masked and with correct clothing and food we got a coach to the foothills of the mountain. We then had a 9.2km round trip to get to the summit of the mountain from where we could safely view the volcano. Sadly the weather was against us and everything was shrouded with very low, very thick cloud. We could see nothing!



We could hear the volcano each time it spurted out a loud and rushing noise, we could smell it, but not a sighting. After a couple of hours on top of a cold, windy mountain, we started our sad journey back down.

Halfway down, the clouds started to lift a bit, and 50 feet to our right was a red hot molten lava flow. It was just beginning to cool/go black but we were able to get right up close to take a quick photo, then quickly move back a bit. Boy was it hot! The red molten lava kept breaking through the crust which was forming and meandered off down the valley. It was out of this world. It certainly saved the day and has made lots of memories.

I took Little Ted dressed in his MND vest with me for company, as I travelled alone. I think he enjoyed it!

On the way to the airport in the early hours of the morning on our last day I finally saw my erupting volcano, albeit from a distance. We had a good view for over 20 minutes, and could see it spewing high into the sky before running away.

For those of you following it, you will know that it altered from a constantly flowing stream in the early days to an



almost geyser effect, erupting into the sky as high as the Empire State Building every two to four minutes. Spectacular!

So, not exactly as I planned it, but I have finally seen my erupting volcano. Thank you Geldingadalir.

Lin Jenkins

Lin's awareness and fund raising events

Lin will be setting up her stall at:

Winnersh Fete on Saturday, 4th September

Tadley Treacle Fayre on Sunday, 5th September

Theale Christmas Fayre on Saturday, 4th December outside in the main High Street

All other Saturdays and Sundays, weather permitting, she will be doing car boot sales.

Contact Lin by email - rlp.jenkins@tiscali.co.uk for more details about any of these events.

Fundraiser Lin Jenkins has a skeleton staff

After all the gloom of Covid and the dismal weather we finally had a beautiful sunny spring bank holiday in May for Thatcham's Family Fun Day and Classic Car Meeting.

With Covid restrictions gradually lifting and the stalls all really spaced out people came in their droves, pleased to finally have somewhere to go. There were times when I abandoned my stall and just watched all the vehicles arriving - more than 300 cars, bikes and fire engines.

Hardly anyone felt the need to wear a mask, there was plenty of hand sanitising everywhere and toilets were operating on a one in, one out system. It felt safe. It felt normal. People were smiling, happy, and enjoying themselves. It was the most wonderful day.

I took a fair bit of money and my stall was very successful but this year I think it is less about the money and more about providing entertainment and fun for people. Boy did that work - we all had such fun!

I have two special memories: one was having my photo taken on the back of a Harley Davidson with a skeleton called Dave but the best must be seeing a young couple sitting on the grass near my stall with their two daughters aged about two and four just eating ice creams! The younger one would not have done this before, and the older wouldn't be able to remember. It was the most heart-warming and "normal" sight and brought a tear to my eye.



Lin Jenkins

Get in touch with MND Connect on 0808 802 6262

MND Connect is available Monday to Friday between 9am - 5pm and 7pm - 10:30pm.
Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. You can also email mndconnect@mndassociation.org

We can help in so many ways . . .

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

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

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

Email: contact@mndrwb.org **Tel: 07760 854975**

Lady Hallifax says "Hello!"

Many of our friends have been asking after Lady Hallifax, the Association's former president, who for many years worked tirelessly supporting local people living with MND.

Her late husband, Admiral Sir David Hallifax, a Falklands War veteran was diagnosed with MND when he was Governor of Windsor Castle and they moved to Englefield House where his sister's family live. Sir David and his wife bore the final challenge of MND with characteristic great courage and spirit as well as a strong sense of humour. He sadly died, aged 64, in 1992.

Lady Hallifax, aged 87, still lives in the village and is well looked after by her carers.

Her nephew Lord Benyon is our branch patron.

Here she writes to you all:

Dear Friends,



During the pandemic I have been watching a lot of David Attenborough documentaries. I have also managed to get outside in the garden and do the weeding, etc.

Anna and I managed to go to Windsor Horse Show which was a special event and we sat opposite the Queen.

Our new cat Marmalade is very cute but also very naughty! She likes to escape and last night stayed out all night hiding in the bushes! We have had to have a special fence put round the garden to stop her escaping.

My son Tom and my daughter Louisa are visiting most weekends which is lovely.

I very much enjoyed the coffee morning at Cobbs, particularly seeing Mary Dodds as she was one of the first to join the committee before me and has done a fantastic job. I am delighted to see the branch doing so well! I am SO grateful for all the hard work the team and supporters put in to raising money despite the COVID restrictions. Please say thank you for the friends and supporters asking after me, that's really thoughtful of them.

As for the cure; we have been trying to find one for a very long time, I do hope that we are getting a lot closer.

Despite everything, I would like to end my message with one of my amusing stories about when my husband David suffered with MND. Driving through Windsor one day, we passed a choir singing on a hill. David asked me to wind down the window. He then heaved his leg up through the window and waved to them with his foot. Despite the MND he still had his sense of humour!

My best wishes to you all,
Anne

Our hero Lin's shining example

Branch Fundraiser Lin Jenkins was featured by West Berkshire Council in its publicity for National Volunteer Week (June 1st-7th).

Her fellow committee members are so proud of Lin who is a shining example being voted a Community Champion by the local authority for selling donated goods in aid of the Association at her Tilehurst garden gate during the pandemic lockdown.



Caversham Rock'n'Ale is back!

Saturday, September 4th, 2021, from 6.30pm

Now in its ninth year this annual event features three great local bands (Rigsby, The Skangster's and Dino's), a bar by The Purple Turtle, a hog roast and vegetarian chilli plus children's entertainment.

Join us for what will be a great evening in support of the Motor Neurone Disease Association's Reading and West Berkshire branch.

To buy tickets call 0118 958 4628 (office hours only) or visit:

https://www.wegottickets.com/event/517469

Lisa runs in the footsteps of dad Roy

Mum-of-two Lisa Langton will be running the Great North Run on September 12th in memory of her beloved dad who died from MND ten years ago.

Roy d'Archambaud, from Henley, was a fit man in his early seventies when he was affected by the devastating condition. As a young man he had run long distances many times representing England and daughter Lisa thinks he would have approved of her efforts.

She said: "He attended the very first Great North Run in 1981 – not as a runner – but in his capacity as director of one of the first major sponsors of this iconic event. 2021 marks its 40th anniversary."

Lisa, who lives in County Durham, with her husband Rob and two teenaged sons, decided to use the opportunity to get fit when her work in the travel industry was hit by the pandemic. She has not run much since the age of 15 and says it is quite an adventure.

Lisa is running to raise funds for the Association to find a cure for MND and wants half of the money raised to be given to Reading and West Berkshire branch which supported Roy and his wife Diana.

She added: "My father died from MND ten years ago and I promised myself that I'd do something in his memory and to support the Association which is a very underfunded charity compared to the big ones. It provided a lot of support to him and us during the three years he suffered with the disease and also continually works with researchers to crack the code."



Lisa has almost hit her target of £500 and is hopeful of raising a little more by the time of the race in Newcastle-upon-Tyne.

https://www.justgiving.com/fundraising/lisa-langton6

Jane Gilbert

And on the same day Anton runs in memory of his big sis



Marathon runner Anton Claassen is taking on another challenge on September 12th for a cause very close to his heart.

He'll be running the Brighton Marathon for the MND Association in memory of his eldest sister Sharon Budde who died in March, aged 64.

Sharon, who lived in South Africa, lost a brief 15-month battle with a very aggressive form of MND.

Anton, whose twin brother Andre runs the Old Boot Inn at Stanford Dingley, near Reading, said: "It really is an awful and debilitating disease, for sufferers and families, and unfortunately there is no cure at the moment.

"I will be training and competing with my lovely sister Sharon very much in my thoughts and my heart."

Jane Gilbert

Chef cooks up a challenge



Chef Andrew Lenaghan cooked up a challenge for himself on every one of the 31 days in May.

He ran five miles a day come rain or shine to raise £1,251 for the MND Association in memory of his dad James who died of motor neurone disease 31 years ago on May 5th.

Yorkshireman Andrew, aged 56, who lives in Calcot, Reading, was also inspired by former Leeds Rhinos rugby league player Kevin Sinfield who ran seven marathons in seven days on behalf of his brave former teammate Rob Burrow who is fighting MND.

Andrew, who works at Horris Hill School near Newbury, still follows Leeds Rhinos and is grateful for the support his dad received from the MND Association.

He says: "I want publicity for MND so that more people know about the disease and can donate more money for research work."

Andrew was also chuffed to receive a letter of congratulations from Business Minister and Reading West MP Alok Sharma.

Andrew ran with Reading Joggers most nights and was joined by some of them on the final run home amid cheers from his proud family and Team MND.

Well done Andrew – you smashed it!

Jane Gilbert

To connect with us on Facebook please click on the following link:

https://www.facebook.com/mndrwb/

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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:

1. **Sign up for AmazonSmile via smile.amazon.co.uk.**
2. **Search for the 'Motor Neurone Disease Association' via the charity lookup.**
3. **Select us as your AmazonSmile charity of choice.**
4. **Look out for products which are marked as "AmazonSmile eligible".**

Enjoy your shopping.

Jacqui and Goldie are Formula Richard champions

Dedicated fundraiser Jacqui Warbey was racing against the weather during her latest determined bid to raise more funds for the MND Association.

The challenge, with a fitting Formula 1 theme, involved walking a total of 190 miles in July and August - the distance of the British Grand Prix so beloved by her husband Richard, who died four years ago aged 56.

She said: "I try to make my fundraising challenges personal to Richard in some way although I am sure I am running out of ideas.

"I was up against the weather getting caught in torrential downpours and I also had to get up early while on holiday in Guernsey to walk before the day got too hot."

Jacqui was joined on all the walks by Richard's teddy bear Goldie who was dressed in an array of hand-made outfits all decorated with the MND Association logo.

"Goldie is very good at raising awareness," says Jacqui. "He is the conversation starter and allows me to explain what we are raising funds for."

The little bear soon became famous on the beautiful beaches and countryside of Guernsey as well as at some of Berkshire's beauty spots.

Jacqui, from Woodley, started walking an average of three miles a day on July 18th, the day of the British Grand Prix, and was due to finish by August 18th. It all had to be done on evenings and at weekends, apart from a two-week holiday, as Jacqui works full time for Vodafone. She says only walks with the bear and her wearing an MND T-shirt were counted.

At the time the Newsletter went to press Jacqui's fundraising page had reached £814 in donations (with Gift Aid) and she hoped, as usual, to get another £350 in match funding from her generous employers.

"Some of the donations come from friends and colleagues in different countries – it is lovely to feel that support," she added.

To make a donation please visit:

www.justgiving.com/fundraising/Jacqueline-Warbey3

Jane Gilbert





Bob's nailed it – again!



Bob Wearn, the remarkable 71-year-old with a passion for pedalling, has completed all 950 miles of the Dover to Durness cycling challenge in memory of his friend Peter Colvin.

The big-hearted grandpa from Old Windsor coped with daunting hills, high mileage and some very early starts to raise a fantastic £2130 for the branch.

It was his third and toughest ride yet inspired by his dear friend and former BT colleague Peter who, since Bob's last ride in 2019, sadly died of MND.

Bob said: "When I did my last ride Pete was so encouraging and supportive and, despite how ill and incapacitated he was, followed my daily progress with great interest."

This time, although he was sad not to receive Peter's daily texts, he knew his friend would have approved of the amount raised for the branch as its support was so much appreciated by Peter's family.

Bob said afterwards: "It's been a great adventure and together we have raised a very significant amount of cash for MND - thank you so much for your donations.

"I met several people on the tour who had lost friends or relatives from this terrible disease".

Bob admitted that every day after leaving Dover on June 26th had been a tough one with always another hill around the corner. He bravely battled on averaging 71 miles a day, despite some pain in his right knee, to arrive on the west coast of Scotland on July 8th.

The branch is enormously grateful to Bob for his unstinting support and for the generous donations from his friends and family.

Check out Bob's donation page here:

https://www.justgiving.com/fundraising/Robert-Wearn

Jane Gilbert

Stamps for the MND Association

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 taking care not to damage the stamp.

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



Editor's note: As membership secretary for Reading u3a I normally receive around 500 letters at this time of year so I save all the stamps for Jill. People have heard that I collect stamps and arrive with their donations. I even received a childhood stamp collection from somebody - it all helps Jill to raise funds for a charity close to all our hearts.

Michael tees up cash to help fight MND

Thank you to Michael Miller, Captain at Deanwood Park Golf Club, at Stockcross, near Newbury who has chosen the Motor Neurone Disease Association as his charity to support this year.

Michael says he has had several friends that have been affected by MND and he knows how important it is to support people living with the disease and to fund research to help find a cure.

More than forty keen golfers enrolled to play on the morning of July 28th which was followed by a raffle and the auction of a golf bag kindly donated by the club's shop. Other fund-raising events are planned during Michael's captaincy.

Former branch chair Margaret Moss also attended and thanked the players for their generosity and support.

Carol Allen



Photo taken at Deanwood Park Golf Club shows Margaret Moss, Michael Miller (Golf Captain), Ady Theadore, John Bowness (Golf Club Manager) and Association Visitor Carol Allen.

Maz and Kim's sparkling Prosecco and bake sale



Star baker Kim Facer decked out her lovely garden on a warm sunny day in June ready for a summer tea party in support of her dear friend Maz Swann, who is living with MND.

Mary Dodds and I went along to join small groups gathered around tables beneath bunting, garden umbrellas and MND Association banners. A glass of Prosecco started the party while chatting to friends of Kim and Maz (pictured left to right). Mary did fall off her chair but I can assure you it was the chair sinking into the soft lawn and nothing to do with the glass in her hand!

An amazing tea was served including home-made sandwiches, scones and cream, cakes plus endless cups of tea in beautiful teacups.

Maz had recorded a digital message of her voice to thank her friends for all their continued support and for joining her on the day in Whitley Wood, near Reading.

At the end of the party there was an amazing amount of money raised for the branch in buckets and online donations – nearly £2,000.

If ever a bunch of friends could fill a garden with a feeling of warmth and friendship, Maz's friends did it in style.

Paddy Lunn

Editor's Footnote: Our thanks to Brian Mac, who is married to Maz's big sister Chris and is taking on the 100k Thames Path Challenge-Ultra 2021 on September 11th in aid of the MND Association. For more details and to pledge your support visit:

https://www.justgiving.com/fundraising/brian-mac

Meet Debbie Webb our new Association Visitor …



Hello, I'm Debbie Webb and I'm pleased to be able to try and make life a little more bearable for people who are going through a tough time.

I have spent my career in a corporate environment and I am currently working full-time as a financial advisor specialising in retirement planning. I have just started my own company, so a new experience for me. I love being able to do things that help people, in any way.

My inspiration to train as an AV came from one of my best friends' being diagnosed with MND. We were very close to each other, and I was overwhelmed by the diagnosis, the inability to do the things we all take for granted and the viciousness of MND.

It's a tough time, and it's very difficult for those close to the person with the disease. I would like some good to come from the terrible experience of being close to, and losing, someone so precious to me.

I live with my partner and have a 25-year-old son who has just bought his first home with his girlfriend.

When not working I enjoy playing golf – am still learning – cycling, walking, eating and drinking. During lockdown I really enjoyed cooking more.

… and Sandra Wilkinson our new committee member and events co-ordinator

Sandra spent most of her life in the Newbury area living on Crookham Common for many years until recently moving to Purley-on-Thames which involved significant down-sizing. She has two daughters, four grandchildren and, having recently remarried to Greg, also has two stepdaughters.

Some years ago, Sandra's mum died of MND and she saw at first-hand how devastating this condition can be. She has also been impressed by the amazing work undertaken by the Reading & West Berkshire branch of the MND Association and looks forward to joining our ever-growing team of fantastic volunteers.





Are you raising funds for the branch?

If you decide to fund-raise for the Reading & West Berkshire Branch, please get in touch with us at the start of your plan. We will help with publicity and materials to help you achieve your aim. To help fund-raisers pay money direct to the Branch we have a page on Localgiving https://localgiving.org/charity/rwbmnda/. If you prefer to have your own page for your event then we can help you set up your own localgiving page.

If you prefer to use a national site such as JustGiving, please make sure that your story mentions that you are fundraising for the Reading & West Berkshire Branch. We hate to ask this so directly but if you want funds to come to us, and don't say so on the fundraising site, we can't receive the money because it would breach the fundraising code of practice. This can be very frustrating for the fund-raiser, or worse, they never know that the money didn't get to us. It also means that we aren't able to express our appreciation for the donation because we don't know about it.

Branch Contacts

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