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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Miles of smiles for Colin

Professional carers Dee Gunning and Trudy Churcher are on a mission. They're organising a Walk to d'feet MND to help their client Colin Wilkes keep smiling.

Colin, from Thatcham, who has been living with motor neurone disease for seven years, was given a big boost when he heard about their plans to cheer him up.

He said: "When Dee and Trudy said they would like to organise a walk for MND I was quite emotional. What a lovely thing to do.

"My carers are amazing, and we have a lot of laughter together.

"MND has taken most things from me but, fortunately, not my wicked sense of humour which puts a lighter note on things when I'm struggling physically."



Colin with the Blister Sisters (L to R) Dee and Trudy

Dee and Trudy, who work for Newbury-based Care Partners, are organising the 20km sponsored walk along the Kennet and Avon Canal on May 22nd, starting in Hungerford and finishing with a glass of fizz at the Swan pub in Thatcham. All the proceeds will be given to the MND Association's Reading and West Berkshire Branch which is supporting Colin.

Dee said: "We wanted to do something to cheer Colin up. MND is a horrible condition and it's sad that he is having to go through this."

Dee and Trudy, the self-styled Blister Sisters, will be joined by some of their work colleagues on the walk and are hoping for about 30 entrants. They still need to find a venue for a pit stop in Newbury where walkers can fill up their water bottles, use toilet facilities and re-fuel with some pastries.

The caring pair, from Mount Road in Thatcham, have started going out walking three times a week to get in shape and have set a £5k fundraising target for the event.

Colin is delighted the walk will also help to raise awareness of MND as well as raise funds for the local branch.

He said: "The branch is run by trained volunteers who can visit you at home. I found this very comforting particularly after diagnosis when you think your life has fallen apart.

"Another example of the help the branch has given me, was it sourced a used mobility scooter for me. That gave me so much freedom and allowed me to continue taking Bella my dog out, meeting people in the process."



Colin and Bella on the towpath "to prove that with MND you can still get out and about if you are fortunate enough"

For details on how to join the walk check out:

Kennet & Avon 20 km Walk | Facebook

or to donate:

https://www.justgiving.com/fundraising/2-blistersisters

Dee can also be contacted for an entry form via the branch contact@mndrwb.org.

Jane Gilbert



What will you give up?

Are you too tempted by chocolates? Could you quit alcohol? How about stopping using plastic for the month? Sign up today for Give It Up! and choose what you could abstain from in March. Give up whatever challenges you the most, share your struggles with friends and family to help raise money and support people living with MND.

Secretary Kerrie needs your dough!

Our Branch Secretary, Kerrie Newton, will be giving up the one thing she loves most: BREAD! Anyone who knows Kerrie will appreciate how hard this challenge will be for her.

Mum-of-two Kerrie is quitting the carbs in memory of her dad George Pearce, from Newbury, who died of MND in 2005.

Kerrie says: "His hope was one day there would be a treatment or cure and we could live in a world free of MND.

"I am truly honoured to be part of the MND Association Reading & West Berkshire Branch and I will not give up until my dad's wish comes true."

By taking part in the Give It Up! Challenge for the month of March Kerrie's donations will be supporting local families and helping to fund research, care and campaigning.

To sponsor her visit: **Kerrie gives up BREAD**

Check out our Reading & West Berkshire Facebook page to follow how she's getting on.

We'd really like to hear from you to help support and promote your challenge. Please contact us via email at contact@mndrwb.org.



To ensure your donations support local people, please make sure your story mentions that you are fundraising for the Reading & West Berkshire Branch. We hate to ask this so directly but if you want your 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 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 are not able to express our appreciation for the donation because we don't know about it.

https://giveitup.mndassociation.org

Birthday girl Val's generous gift



Val Williams, who cares for her husband Joff, met our friendly team of volunteers at a branch drop-in session and decided she wanted to give something back.

She hit upon the idea of a birthday fundraiser in lieu of presents and sold tickets for the MND Association's Christmas raffle.

Val, from Burghfield, near Reading, was delighted with the overall total of £717.

She said: "I am well pleased as it's the first time I have ever done something like this on my own."

Val's friends and family donated to her birthday fundraising page on Facebook to support her and Joff, who was diagnosed with primary lateral sclerosis (PLS), a form of MND.

"I know it will probably not help people who have been diagnosed but it should help people in the future, she said.

"Also having met the volunteers from West Berkshire I just thought it would be a nice thing to pay back for all the kind words and help they gave me.

"I sold the Christmas raffle tickets with the same sentiment and made £307. These were sold to family friends and work colleagues. Also, the local public house, the Six Bells in Burghfield Village, helped by raising £85 and a close friend of ours also sold £50 worth of tickets."

Val would like to thank everyone for their generous donations to a cause close to her heart.

Happy Birthday to Val from all the team at the MND Association's Reading and West Berkshire Branch.

Jane Gilbert

Thrilling way to raise cash

Off-road driving enthusiasts jumped into their vehicles on Boxing Day for a wheely fun event at Aldermaston in aid of the MND Association.

They enjoyed thrills and spills at the annual charity play day organised by Stephanie Awbery and the team at 4x4 Without a Club.

We are grateful to the landowner of the Harbour Hill Copse site who chose the Association to benefit this year as he had an aunt who had MND.

Club secretary Stephanie Awbery said £250 was raised on the day which was affected by the spread of the Omicron variant of Covid-19 over Christmas.

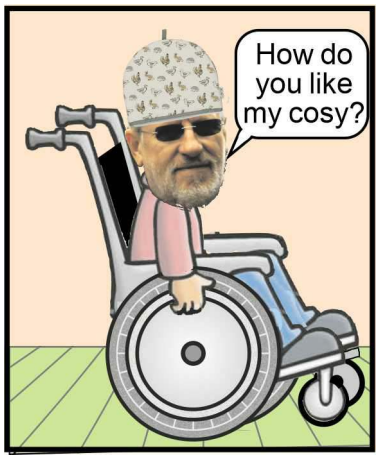
"Under covid conditions it was not a bad event," she said. "There were not as many drivers as we would have liked but it's better than nothing."

Jane Gilbert



A wheely cosy idea

I'm always amazed when I go out on a cold day by the number of people I see in wheelchairs with just a blanket, or similar, over their legs, not using a cosy. Not like that. That's a tea cosy. That would be silly! I'm talking about a wheelchair cosy but be careful where you buy it: caveat emptor - 'let the buyer beware'! Soon after I started using the first one I bought, the zip failed. I contacted the company I bought it from online and they refused to do anything about it. For legal reasons I'm unable to mention the name of the company but I think I'm ok to say that they have an alliterative trading title, and they are based near Blackpool. Avoid them!



I then contacted a company called Ability Superstore and spoke to a lovely lady named Sandra. When she heard about my experience with the previous cosy, she offered me one made by a company called Simplantex. It was made to a much higher standard than the first. On top of that she offered me a special discount on it. At the price she charged I don't think they could have made any profit on that deal!



The bad news is that when it wore out and I tried to re-order in late 2019 Simplantex had gone out of business and Ability Superstore had sold all their stock in my size. The good news is that another company has started making cosies for Ability based on the same design and I received my new cosy (Ability Superstore Deluxe Wheely Cosy) late last year. Once again Sandra did me a very special deal.



One of the principal differences between this cosy and others I have seen is the zip extends down one side and then up the other so you can remove the front panel if it suddenly gets too hot when you're out.

Some time ago I, very cheekily, asked Sandra if she would be willing to extend a discount to others in a similar position to me.....and she agreed! If you ring 0800 2550498 (freephone) and ask for Sandra or e-mail to heretohelp@abilitysuperstore.com for her attention and mention my name you will get 10% discount on many items. Obviously on some bigger items their mark-up is insufficient to be able to offer a discount.



Just in case you're wondering no, I'm not on commission with them!

I'm normally very reluctant to make recommendations: if everything goes well you hear nothing back. However, if something doesn't go right .....

Alec Jenkins

It's good news on our bank balance

The man who holds the purse strings has shared the good news – the Reading and West Berkshire branch began the new financial year with £28,000 to spend.

Treasurer Ed Gryglaszewski has given his end of year summary saying: "All things considered, it was a surprisingly good year fiscally."

The coffers were swelled by £18k from £36k and, while donations had fallen by £14.8k, this drop was more than compensated for by £33k's worth of fundraising revenue, largely due to the fantastic Summer Garden Party run by the Forresters hair salon group and The Old Boot Inn, Stanford Dingley, near Reading.

"Our costs have been held at a modest level," says Ed. An increase in costs from last year is mainly due to more money being spent on care for people living with MND.

After transferring the required £33.5k to the MND Association nationally, branch income exceeded its outgoings by £38K. Last year this was £31k.

In total, the branch had a healthy bank balance of £182k at year-end. This is largely due to its restricted funds; the main two being the Sheila Hamblin Legacy, which is still being distributed, and the Jenkins Family Fund. Both have restrictions on how the money can be spent to help local people living with MND.

Amazing Lin is all set for the coming fundraising season



Lin pictured at her first pop up sale of the season.

Spring is almost upon us, the sap is rising, and I am excitedly getting ready for the coming season. Over the winter months I have had a rest. OK, I have been to the scrap metal yard a couple of times, sent off several boxes of books to sell, not to mention preparing for the season, but, of course, money has only trickled in.

Due to Covid-19, and other circumstances, several of our big events have been lost, so we are having to look at new ideas, and be as inventive as we can. I would like to thank my husband Paul, who is a football referee, for donating his recent £45 match fee in thanks for the help I have given him since being diagnosed as diabetic.

Now I have moved house into a smaller bungalow, not only have we lost the walk by trade, but we can no longer just accept drop off deliveries. From the end of March people will be asked to 'phone, text or email me, to prearrange deliveries. During my winter break we have been able to get sorted, and settled into our new home, and we love it.

My former neighbour, Cheryl, who lives two doors away from my previous house, is keen to have the odd garden sale at 257 Overdown Road, Tilehurst, in aid of the MND Association, so we will see how well this goes. At our first venture on Saturday, February 12th, we took £95.00, and it was lovely to see old friends again. The next day takings were only £15 as it was unfortunately rained off.

Lin Jenkins

Editor's note: Don't forget to save your unwanted electrical cables for Lin who takes them to the scrap yard to sell.

All discarded cables and wires or those cut from electrical items that no longer work are ideal. If you don't have Lin's details, contact the branch on 07760 854975 or contact@mndrwb.org and we will gladly put you in touch.

Come and meet Lin at one of her upcoming events:

Thatcham Car Boot sales are due to start on **Sunday 27th March** and will be held every Sunday for the rest of the season.

Saturday, 9th April, Easter Sale at The Grange in Southcote, Reading.

Saturday, 23rd April, Beanpole Day at Caversham Court, Reading - an eco friendly day, where she sells used tools and gardening equipment.

Sunday, 1st May, Lambourn Vintage Machinery Spring Country Sale.

Monday, 2nd May; Yateley Fete.

Sunday, 8th May; Burghfield Village Fete selling all tents and camping equipment salvaged from Reading Festival.

Saturday, 28th May, Thatcham Fun in the Field, Memorial Recreation Ground.

Saturday, 4th June, Yattendon Village Fete (moved from usual Bank Holiday Monday).

Sunday, 5th June, Tadley Treacle Fayre.

Saturday, 11th and Sunday 12th June – Stoke Row Steam Fayre. Lin always has a large Retro Stall at this 2 day event.

Fond farewell to our hero Colin

Tributes have poured in for former semi-professional footballer Colin Moss, who sadly died in January, aged 71, after bravely fighting MND for a remarkable 20 years.

On a rainy afternoon in Royal Wootton Bassett a crowd of more than 100 mourners gathered to say farewell to Colin, fondly remembered as a Reading and West Berkshire Branch member, Association Visitor and PowerPoint photo expert.

Former branch chair Margaret Moss described him as a man determined to make the most of his life with MND. Some readers will remember his photos at the branch Thank You lunches and his competitive 2009 'Shortest Walk' event in Forbury Gardens with Newbury's Alec Jenkins (see separate tribute).

Margaret, who represented the branch at Colin's funeral on February 16th said his football life, his humour, his work life, and his outliving an MND diagnosis of 18 months by more than 20 years were highlights of the afternoon.

She said: "Thank you, Colin for all you gave us and the branch - you're a hero."

Colin, who joined the branch when he lived at Hermitage, near Newbury, eventually moved back to his native Wiltshire with his partner and carer Shan Mills. They tied the knot at Swindon Register Office in May 2018 with Colin recording his vows and speech on a tablet to avoid his emotions getting the better of him.

In 2020, Colin was unable to have a 70th birthday party due to Covid-19 but thanks to Shan and his brother he was shell-shocked to receive 126 birthday cards as well as Facebook messages.

Colin said at the time: "It was beyond my wildest dreams that I would reach the age of 70, when I was diagnosed with MND, aged 51.



"My neurologist can't really explain my very long survival, other than to suggest it must have tended to affect mainly my upper motor neurones."

Branch Publicity Officer Jane Gilbert fondly remembers Colin for his sense of humour, passion for his Mercedes cars and willingness to help many other people affected by MND.

She said: "He was a true warrior both on and off the football pitch ably supported by his loving wife Shan."

On January 25th football fans observed a minute's silence before kick-off at Chippenham Town FC to remember Colin.

As a tribute to Colin donations are being given to the MND Association North Wiltshire branch and Prospect Hospice in Swindon via:

hillierfuneralservice.co.uk/obituaries/colin-charles-moss

Jane Gilbert

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**

Alec Jenkins, from Newbury, who is living with MND, pays tribute to his friend Colin Moss



In the 20 years that I have been involved with the local branch of the MND Association, the passing of three people I've met has saddened me more than most.

Firstly, my first Association Visitor, Dr. Monica Stewart; secondly, Brian Rayner; and now Colin Moss. I must confess to shedding a few tears when I heard he had died. I know it's silly but I thought he would be around as long as me.

We have tended to keep up to date by e-mail. He used to say that I made him laugh with my silly illustrations.

I was trying to find a programme to turn photographs into videos. I wanted to use the photos from our participation in the 2009 Shortest Walk Challenge in Reading's Forbury Gardens with added speech bubbles. These are two that I was going to include. I hope he's looking down and that he's amused. I will miss you Colin.



Au revoir from our Chair

I have been part of the branch committee for four years, first as Secretary then as Chair since autumn 2020. My personal circumstances have changed since agreeing to step into Margaret's shoes and I am finding that I just can't do justice to the role or indeed to my colleagues' enormous efforts. So I have reluctantly and with much regret decided to step down as Chair and from the branch committee.

I will be ending my term at the end of March and the committee are very keen to welcome a new person to join them as Branch Chair. What can I say? - they are a truly lovely bunch of people and a joy to work with.

If you have 2-3 hours a week to spare and are happy to spend the third Thursday evening of the month in the company of this inspirational team, then being the next Chair of Reading & West Berkshire MND Association branch committee could be right up your street. If you'd like to find out more about the role, please get in touch with me via the branch email address, contact@mndrwb.org.

I'll end with a simple message - thank you and good bye for now. Hope you'll have me back when my life is a bit less frantic!

Jane Westwell

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

It's about quality of life

Sometimes, when you're caring for a loved one who is struggling with MND, it feels as if there is no respite. Did you know there are many ways the MND Association can help make a difference?

Here, a grateful partner, who asks to remain anonymous, shares her story in the hope that others might also benefit from the same support.

She writes: "My husband has had MND since 2018 and a fellow carer mentioned the Association's Quality of Life Grant (QOL) to us. We had never heard of it - there's just so much to learn with MND! We decided to find out more and were grateful to be kindly supported by Adele Petcher, who was the Area Support Co-ordinator at the time.

"My husband was getting regular myofascial release massages when first diagnosed, to try to help him cope with the constant cramps he experienced. Myofascial release is a type of physical therapy often used to treat discomfort caused by sensitivity and tightness in your myofascial tissues. These tissues surround and support the muscles throughout your body. As his condition progressed, he started to have wasted muscles and swollen feet and continuing use of the therapy was beneficial.

"However, whereas he had previously visited the therapist's practice, this was no longer viable. The therapist agreed to make fortnightly home visits but the cost was much higher. This massage therapy is a serious boost to my husband's quality of life and, when we heard about the QOL grant, we decided to apply for it. We were delighted to get the support we needed.

"One issue with MND, that is not widely acknowledged, is that the cost of the illness is substantial. Often at a time where the sufferer or carer has, or both have, had to stop work, such expenditure may be difficult. The QOL grants can be for a whole variety of things and for him, the opportunity to continue with the massages was very welcome indeed.

"Another area of expense is the challenge of getting around, be that the purchase of a Wheelchair Accessible Vehicle or the use of taxis or other transportation service and the QOL grant could be used to support that. This might mean that the person living with MND is not housebound or the carer's worries about getting to necessary medical appointments are relieved.

"It just remains to be said that we are deeply grateful for the generosity and support given by the Reading and West Berkshire branch, its volunteers and fundraisers, and to the MND Association. We hope that this article will help disseminate information about this grant so others may benefit from the same."

Festive fun at the Art Café

A lovely festive morning was held at the Art Café in the Old Rectory Stables, High Street, Whitchurch-on-Thames on the 18th December. Organiser Mary Dodds and her merry band of volunteers had appealed to our star cake bakers and, as usual, there was an impressive array of donated goodies including an amazing five-tier cake made by supporter Carol Coker.

Despite it being near to Christmas, there was a steady stream of customers enjoying tea, coffee and cake as well as a chance to catch up with friends.

A raffle completed the successful and enjoyable morning which raised a total of £253 for branch funds – that's not bad for two hours opening to the public!

We'll be back again at this popular venue on the 26th March, 10.30am–12.30pm so do drop in for a chat, a cuppa and a slice of yummy cake.

Sandra Wilkinson



Volunteers Carol Coker, Paddy Lunn, Linda Green, Barry Dodds, Lin Jenkins, Margaret Moss, Sandra Wilkinson and Gill Selby

Friends rally to support brave Deb

After Deb Hayhurst, a fitness fanatic, was given the shock diagnosis of MND her many friends rallied to support her with generous donations of more than £8,000.

Deb, aged 54, and her husband Ray, pictured on the right before Deb's illness took hold, were regular gig goers and were delighted with the huge turn out at Reading's Purple Turtle bar for a music afternoon in aid of the MND Association. See picture below.

Organiser Rob Callaghan said the event was held because his good friend "is suffering from this awful disease".

The Motofest afternoon of bands and DJ sets which took place at the Gun Street bar in January raised a massive £3,281 in Deb's honour.

Now her husband Ray, a keen cyclist, is training for the 100-mile Ride London – Essex on May 29th. Their generous friends have so far donated £4,773 to his online donations page.

Ray said: "The progression for Deb has been rapid and the help we've had from the MND Association is brilliant.

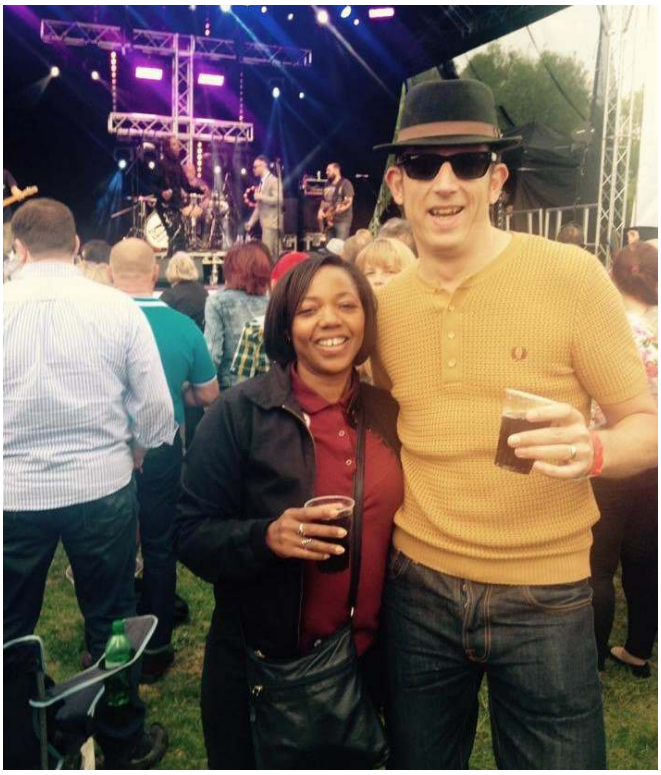
"I want to raise funds so that it can carry on giving support to people who really need help. Words can't describe how hard it is for people with this disease and their loved ones.

"This is going to be a huge challenge for me mentally and physically as it's taken its toll on me."

Ray, an IT consultant, from Earley, is now also caring for Deb, who has been forced to take sick leave from her software job at Fujitsu.

Early last year she started getting odd pains in her hips and shoulder, explained Ray. "She's a fitness fanatic and





we thought 'just one of those things at our age, you'll shake it off'.

"As each month went by the mobility got worse and worse, to the point of walking with a stick in July, a wheelchair in August, to complete immobility in September.

"Still undiagnosed, it came to a head when we went to A&E because she was so weak. One week later, the news no one wants to hear, it is MND."

Ray's cycle challenge will be tough, but he's determined to complete it as fast as he can to support the work of the Association.

"The Association does two really important things; it provides support and raises awareness of this truly disgusting disease.

"Any donation you can make will be massively appreciated.

justgiving.com/fundraising/ray-hayhurst-1

Jane Gilbert

Stamp collecting – Jill's got it licked!

When it comes to stamp collecting, Jill Gaisford from Thatcham, has got it licked.

The loyal supporter has a regular buyer of used postage stamps and was able to sell two bags of them after Christmas for £25 – thanks to many of you!

Jill's special delivery is just one of many she has made over the last 24 years since her son Peter died.

At first the money was given to King's College Hospital in London but when Jill's husband John died of MND in December 2009 she decided to raise funds for the Association.

She explained: "He first had symptoms (which probably were MND) in November 2008 which we thought were due to his arthritis. John was referred to a consultant in January/February 2009 and it took until late August to have a diagnosis."

Jill said Carol Allen, who was then a clinical nurse specialist and is now an Association Visitor, was an amazing support.

"I don't know how we would have coped without her knowledge and just knowing that she was 'there'."

Sadly, John's journey with MND progressed rapidly and he died within three-and-a-half months of his diagnosis. This tragedy has fuelled Jill's determination to do what she can to help fight MND.



"I collect stamps all the time and watch them mount up," she says. "But, as you know, it takes a long time to collect enough to raise £20-£25.
"Thank you for asking people to carry on collecting their used postage stamps."

If you would like to help Jill raise funds for MND 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.

Jane Gilbert

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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!

15,000 steps - they've smashed it!

It's time to congratulate three of our wonderful local supporters who smashed the MND Association's 15,000 steps a day in January challenge.

Well done to Kim Facer, Beth Andrews and Andy Findlay on their massive personal achievements and fantastic fundraising.

Kim and Beth stepped out for their beloved Marian 'Maz' Swann, from Earley, near Reading, who is living with MND. Maz inspired both her 'bestie' Kim and her niece Beth.

Beth, pictured below with auntie Maz said: "It's an honour and a privilege to raise money for such an incredible charity which is so close to my and my family's heart."





Best pals Kim and Maz, pictured bottom left, had a fun day out together in Windsor to help Kim notch up some of her steps while taking turns in Maz's wheelchair. "We had a lovely giggle," said Maz.

Businessman Andy Findlay, aged 55, from Reading, was walking in memory of his dad and raised nearly £5,000 for the MND Association.

He says the response was 'unreal' and shares his family's story with readers here:

"Just after Christmas I was looking to start walking in January on a treadmill to try and lose a few kilos of weight.

"I had been wanting for some time to do something for MND to repay the support provided to my dad who, unfortunately, was diagnosed with MND in February 2018 and lost his battle in August that year.

"We had been taking my dad for eighteen months backwards and forwards to hospitals for a diagnosis, after he lost mobility in his right leg. Dad was a very active landscape gardener and was still looking after gardens in the Ascot area as he had been since in his twenties. He had been a keen sportsman in his early years.

"I was amazed at the lack of knowledge in the medical profession regarding the diagnosis of his condition, many thinking it was something to do with the nerves in his back.

"After a couple of falls dad was eventually diagnosed at Frimley Park Hospital in February 2018. We were absolutely devastated to learn of his condition and that there was no cure. He had been given a life sentence and, probably, not a very long one. Dad then spent time in St Marks Hospital in Maidenhead and eventually returned home to be with our mum who was older and frail with arthritis.

"We were lost initially and did not know where to turn but, thankfully, my friend Linda Green helped us with some contact details, and we found the MND Association who helped guide us through the horrific possibilities that the disease consisted of.

"Dad wanted to stay at his home of 54 years. He had completely lost his mobility and we had to alter the house for a wheelchair, adapt the front room for a hospital bed, get a chair to help lift him and, eventually, a hoist to get him in and out of bed. Dad's grip then began to disappear, and we could see his muscles wasting away; he had always been a very strong man.

"Dad's sense of humour and his willpower remained but you could see how frustrated he was with just sitting in a chair unable to look after his garden and be active.

"I am certain that dad made sure he was there to celebrate mum's 80th birthday on August 8th - just 12 days later we lost our dad and mum lost her soul mate of over 55 years. Dad died peacefully with us by his side. This was his way of beating MND. We know that things could have got much worse for him, and, with no cure, we were pleased that he had escaped this horrendous disease.

"I have wanted to do something in dad's memory since then. I saw the 15,000 Steps a day in January challenge and thought, yes, this ticks all the boxes: something for MND in dad's memory and a fitness programme for me in January.

Continued on next page

15,000 steps - they've smashed it! (Continued)

"I am a very competitive person; when I take a challenge on, it gets all of me. I decided if I was doing this it was going to be a tribute for my dad. I wanted to attack it like he would. I wanted to raise as much as I could, I wanted to walk as far as I could, and I wanted to be very vocal in spreading the awareness of this horrendous disease.

"I started straight away, my main walking would be at 6.15am every morning and would be topped up with further walks during the day as well as dog walks. Every morning I recorded a video and put it up on my Facebook page and Instagram as I wanted people's attention. This I kept up for all 31 days.

"The response was unreal I had to keep changing the donations target as I kept beating it.

"Our steps target was 475,000 over the month; no, I wanted more and changed this three times to eventually exceed 700,000 steps over the month, the equivalent of walking 13 marathons in the month. My daily steps target was also changed several times and ended up with me exceeding 42,000 steps one day - over 21 miles.

"I am so pleased to have been able to take part in this challenge in memory of my dad and I know that dad and mum would be very proud of how I stayed focused all month and completed each walk without fuss. It was a mental and physical challenge that I enjoyed, but I could win my battle, whereas sufferers of MND currently cannot. I hope my efforts can help with a cure to give other sufferers and their families more hope than we had when dad was diagnosed."



Jane Gilbert

Big-hearted golfers tee up the cash



Club Captain Mike Miller, Richard Jones and Colin Cox

A big thank-you to Deanwood Park Golf Club near Newbury!

During November and December, its golfers raised an amazing £623 for our branch.

It was a cold and wet November morning, but this didn't dampen the spirits of several keen golfers from taking part in a fun round of golf and, together, they raised £180.

Sadly, due to Covid their Christmas raffle had to take place behind closed doors. Golf Captain, Mike Miller assisted with the draw and would like to thank Curry's, Waitrose, Waterstones, Toni & Guy and the clubs' members for their donations. The raffle raised £443.

Kerrie Newton

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

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

Jacqui has bags of fundraising ideas

Dedicated volunteer Jacqui Warbey has literally bags of ideas for raising money to help people living with MND.

She has been busy making these beautiful, decorated gift bags and planning another cake and plant sale at her home in Woodley, near Reading, with all proceeds in aid of the Reading and West Berkshire branch.

Not surprisingly, Jacqui's handiwork has been selling fast but, there might still be a chance to bag a bargain.

She says: "Can I suggest that anyone who is interested emails me (jacqui.warbey@mndrwb.org) with their contact details so they can find out which bags are still available or if I will be able to make to order. Prices will be £5 for the 20x20x10 cm bags and £7 for the 30x30x20 cm bags - the same as on my Facebook page. I should also be able to bring any remaining bags to the branch's Art Café at Whitchurch-on-Thames on 26th March."



Jacqui's plant and cake sale will be on Saturday, 16th April (Easter Saturday) from 10am - 4pm, on her driveway at Scott Close, Woodley RG5 4UP. The plants on sale will be mostly perennials but there should also be some house plants. As usual, she will be joined by Goldie, her late husband Richard's beloved bear, who will be wearing his MND T-shirt.

"If anyone has any plants or is able to divide and pot up perennials, donations would be much appreciated," added Jacqui, who will also be selling a range of delicious home-made cakes. Weather permitting, people can sit and enjoy the cake with a cuppa or take slices of cake away to enjoy later. If anyone has a few hours to spare on the day, their help would be very welcome.

Jane Gilbert

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**

Glenvale Nurseries' Spruce Boost

We are very grateful to Helen and Duncan Varley for their continued support to the MND Association during Christmas tree sales at Glenvale Nurseries.

Generous customers donated £75 to branch funds in a festive raffle at the plant centre in Hungerford Lane, Bradfield Southend, near Reading.

Three other charities – Parkinson's UK, the MS Society and Diabetes UK – also received a contribution.

Branch Drop-in Meeting

With Covid-19 restrictions easing, we are delighted to be hosting our first in-person drop-in session for 2022 on Tuesday, **March 22nd,** 12.30 - 2.30pm, at our regular venue in St. Luke's Church Hall, Theale, near Reading.

Drop-ins are a good opportunity for people living with MND and their families / carers to share experiences and thoughts, meet with friends who understand and get to know some of our branch volunteers, including Association Visitors.

Refreshments, sandwiches, and home baked cakes will be available. To receive more information, please contact our Branch Secretary on secretary@mndrwb.org.

Art Café

CALLING ALL OUR STAR BAKERS – we need your help!

Could you donate a home baked cake for our fundraising coffee morning at the Art Café on **Saturday 26th March**?



We will be serving tea and coffee from 10:30am – 12:30pm and there will also be a raffle.

Drop in for a chat, a cuppa and a yummy slice of cake - you will be helping us to support local families affected by MND.

We will be at **The Old Rectory Stables, High Street, Whitchurch-on-Thames near Reading, RG8 7DF**

If you can help, please contact Mary at promotions@mndrwb.org

We're looking for MND Association Visitors in the Reading & West Berkshire area, to provide support to people living with #MND, their families and carers. To find out more, visit: www.mndassociation.org/volunteer

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