motor neurone disease association

Reading and West Berkshire

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News Letter



Great-gran Dottie is a MND race day VIP

Great-grandmother Dottie Channing-Williams became horse racing royalty to present the trophies at a big fundraising race day supporting the MND Association.

Dottie was both surprised and delighted when she was asked to be a VIP at Ripon Racecourse in memory of her beloved husband, ex-jockey Steve Jobar, who lost his hard-fought battle with MND, aged 75.

She said: "It was just out of the blue; I couldn't believe it. I said there must be someone famous they could ask."

Dottie, her daughter Nicole Vokins and grandson Joe, were invited by the Association to support its fundraising partnership with Evoke plc via its William Hill brand. They travelled from West Berkshire up to North Yorkshire for the latest fundraiser at Ripon on August 16th which raised nearly £33,000 on the day.

Several of the races were renamed to drive awareness of MND and all profits from the feature race – the Great St Wilfrid – were donated to the Association.

Dottie, from Wickham, near Newbury, presented the trophies for the third race - William Hill Supporting MND Silver Cup Handicap - to Havana Rum's jockey Ethan Tindall and representatives of owner John Doyle and trainer Richard Fahey.

"I had to go into the parade ring next to the horse, I nearly died," joked Dottie. She also gave interviews about her and Steve's tough journey living with MND



Dottie, her daughter Nicole Vokins and grandson Joe with winning jockey Ethan Tindall and representatives of Havana Rum's owner and trainer

and the fabulous race day they organised at Newbury Racecourse last year raising an incredible £192,000 to help fight the disease.

She said: "We were able to talk about the dreadful effects of MND on families as well as the person who has the disease. And I spoke about how much money is needed for research. We were looked after extremely well."

Evoke has committed to raise £400,000 for the Association after the charity was nominated by colleagues as its charity of the year in honour of Tamara, a young, former William Hill employee, who was diagnosed with MND in 2016, aged just 26.

Both animal loving Tamara and her mum say they find it very difficult that Tamara can no longer ride her dressage pony. The tragic story has impacted many people including Tamara's aunt, Leisa Byers who is William Hill's Retail Operations Manager, and all their colleagues.

Tamara, who had one of the Ripon races named after her, recently said: "As a past employee of William Hill, knowing that over 1,300 stores are getting behind this fight means the world — not just to me, but to many others facing this devastating disease.

Continued on page 2

Dottie is a MND race day VIP (cont from page 1)

"We are very excited about this charity partnership and look forward to seeing the amazing fundraising efforts of the entire team at William Hill and Evoke over the next year."

Ben Wright, Director of ESG and Sustainability at Evoke said the Ripon course looked fantastic decked out in William Hill and MND Association branding and the press and TV coverage was sensational.

Jo Coker, Director of Income Generation at the MND Association, said: "We are thrilled to have been part of the St Wilfrid's Race Day with William Hill. It was a fantastic occasion and an invaluable opportunity to raise awareness and vital funds to support people living with MND and their families.

"The generosity shown on the day will make a real difference to people living with and affected by MND now, while also helping us to invest in the research to find treatments that are so urgently needed. Once again, a huge thank you to all the teams involved who helped make this such a success."

Jane Gilbert

Little Heath School honours Juli

Full marks to the staff at a Tilehurst secondary school for their fantastic fundraising in honour of much-loved former colleague Juli Morgan-Russell.

Juli, who was Head of English at Little Heath School until she retired and is now living with MND, was delighted to hear she had inspired a generous £1,150 donation to branch funds.

She said: "The Little Heath family is amazing - I'm very happy to have been part of it for such a long time. "

The funds were raised at the end of term when Juli's ex colleagues held a coffee and cake morning as well as a summer raffle to boost the proceeds.

Office Manager Jules Vallard said: "We are all thrilled with this total and know that it is because Juli is so well thought of.

"Juli is an incredibly important and special person and is cherished by so many of us here at Little Heath School where she made a huge impact on so many lives. We are so pleased that she is being so well cared for and totally agree - she is a 'true warrior'!"

The school is a special place for Juli as both her sons were pupils there, and she was on the parent teacher association.

She explained: "Then I taught there for ten years and when I retired, I joined the board of governors. So, you can see why it is so special to me. I'm still in touch with a few of my ex-students - one of them does my garden for me!"

Juli says she has brilliant memories of fun times in the English Department and whole school events like the welcoming of new staff in a pub in Reading and end of year parties at Goring and Streatley Golf Club.



"And during term time and during the difficult days, there was always someone who would give you a hug," she added.

Juli's ex-colleagues are pictured (from left to right) with her message behind on the big screen: Toby Jessop, Katy Nicholson, Jules Vallard, David Ramsden (Headteacher), Ro Harper, Rachel Jessop, and Alice Witcomb.

Jane Gilbert

In the swim to help beat MND

Massive congratulations to our two amazing fundraisers who have made a big splash to help beat MND.

Swimmer Sarah Foster, from Tilehurst, completed 6km in May in honour of her beloved dad Mike who sadly lost his battle with the disease the following month.

Sarah, aged 48, raised £1,269 to help other local families affected by this "horrendous" disease which her dad had endured for three years.
She said at the time: "It has had a huge impact on his quality of life as well as his loved ones around him."

Despite a late start due to back issues, Sarah fitted in the swims after her work at a children's day nursery in Binfield.

And she was so blown away by all the donations that she kept on swimming past her target to raise funds for MND Association Reading & West Berkshire.

"I feel great for doing it and I'm so pleased with the amount raised," she added before the donation page closed.



Mum Vickie Ann Hughes set herself a challenge to swim 21 miles in August raising money in support of her best friend Kim despite having her own health issues. Actually her original target was a little less but she decided to increase the target so that she swam the equivalent of crossing the English Channel at its narrowest point!

She wrote on her online donation page: "I am doing this for my best friend Kim who I have known for nearly 20 years.



"Sadly, Kim was diagnosed with the cruel MND around two years ago and was told the type she has is fast progressing.

"She was told she would only have two to three years to live.

"In the two years I have watched her go from just needing a walking stick, her speech a little slurry to now being bedridden, needing to be hoisted and has lost her speech completely. She now can't do anything for herself and is completely reliant on her husband, children and friends.

"This cruel disease needs more awareness and more funding towards finding a cure or at least a way to slow it down.

"I cannot imagine what people with MND are going through but it is 100% harder than us watching from the outside, and that alone is the toughest thing I have ever had to do.

"I know this fundraising won't help Kim, her family and friends but I know Kim would be the first to help anyone in her situation.

"Obviously, she can't do it so I'm going to do it instead.

"I am specifically raising money for the Reading and West Berkshire Branch as they are the ones who have been involved with Kim's care."

Vickie, who lives in Thatcham, says she is not a strong swimmer and has fibromyalgia.

"So, this is a huge challenge for me and I am determined to do it," she said.

Vickie, proudly wearing a costume with the MNDA logo, was hoping for a big turn out to cheer her on for her last swim at the Kennet Leisure Centre but was sadly unwell on the day.

Luckily she had already completed her 21 miles, raising a wonderful £585 so far to boost branch funds, Well done Vickie and thank you.

Hope you feel better soon.

Jane Gilbert

Help Vickie make the biggest splash here: - **www.justgiving.com/page/vickie-hughes-1**

Footy and 3 Peaks climb raise funds for Kev

Footy players and friends have given another amazing boost to dad of five Kevin Jefferies who is living with MND.

This year they took on the Surrey 3 Peaks Challenge as well as arranging their second annual reunion match in support of Kevin, a former footballer, from Spencers Wood, near Reading.

Organiser Lee Didcock and his team are determined to raise as much money as possible to help well-loved Kevin as well as other local families affected by MND.

They have set up a crowd funding page for Kevin and are giving a share of funds raised to the MND Association Reading and West Berkshire Branch which is supporting Kevin and his family.

Already, the donations are helping Kevin and his wife Natalie to convert a downstairs room into a bathroom and are being put towards an adapted vehicle to enable them to have day trips out with the family.

This year's football match was back by popular demand on May 25th at the Scours Lane ground, Reading, and was supported by the hard-working Dream Team of volunteers from MND Association Reading and West Berkshire Branch which will benefit by £2,500.

Congratulations and thank you to Lee and his team who later nailed the Surrey 3 Peaks Challenge for the fund on June 14th by walking 23 miles taking in three classic hills.

Afterwards, an elated Lee said: "What a day! Fourteen of us did it and completed it."

The team was welcomed back at The Farriers Arms, by Kevin and more than 70 people who turned out to congratulate them on the epic achievement. We hope they all enjoyed a nice cold, well deserved refreshment!

Cheers also to The Farriers Arms for arranging a day of music, food and family fun activities on August 3rd raising funds in support of the MND Association.

You can support Kevin by donating here:

https://gofund.me/91b2a7a9

Watch this space for Lee's big MND fundraising plans for 2026!

Jane Gilbert



Footy fundraising organisers Lee Didcock, Branch Events lead Mary Dodds, Gary Baynham and Matt Bicknell



Lee Didcock is pictured fifth from left

Two heroes push themselves to the limit to fight MND

Two heroes have smashed extreme challenges in memory of a beloved brother and friend who lost his battle to MND.

Chef Andrew Lenaghan, from Calcot, inspired both his brother Marc to show his true Northern grit in the ultra Leeds Ironman triathlon and his neighbour and pal Dave Smith to walk 50k in a blistering heatwave. Between them they have raised about £5,000 in donations for the MND Association Reading and West Berkshire Branch.

It was an emotional day in Leeds for newly crowned Ironman Marc Lenaghan as he was also honouring his dad who had sadly died of MND when he and Andrew were young.

Marc, aged 53, said afterwards: "MND Association got a massive shout out when I crossed the finish line.



"I'm absolutely shattered, I won't lie," he said after completing the three stages on July 27th in a gruelling 14 hours and 30 minutes, well under the 17 hours allowed.

The course consisted of a 3.8km swim, a 180km challenging cycle and a full marathon run to finish.

Marc, from Leeds, said: "I was very fortunate to have my wife Donna, son and daughter, their partners and my three grandchildren all on the course cheering me on. Lots of friends and extended family also turned up on the day, very overwhelming and I'm thankful to them all for making the effort to come and support. "

Marc's online donation page is still open and stands at a whopping £2,820 in aid of the branch which supported Andrew, who died, aged 60, in April.

Now Marc is pleased the generous donations will help other local families get the same "phenomenal" support.

Check out his story here:

https://localgiving.org/imleeds2025

What a hero 💙🧡

Plucky David Smith, 72, conquered 50kms of Britain's oldest trail in sweltering temperatures on July 12th to raise funds in memory of Andrew, who was his dear pal.

David, from Calcot, braved the blistering 30 degrees heatwave for the gruelling Race to the Stones Thames Valley route across The Ridgeway.

He finished declaring: "It was so hot it made the ground so hard but, in the end, it was so worth it to raise much needed funds in memory of Andrew."

Massive congratulations and thanks to David who raised £1,981, including Gift Aid, to help support local families affected by MND.



David said: "In extreme temperatures I managed to complete the 50k in memory of my dear friend Andrew. It was a tough challenge with the ground being as hard as rocks but the support given by the organisers was amazing and if it had been cooler it would have been easier.

"The sights and views were stunning and so many people were doing it for various charities.

"I hope my little bit may help along the way and I would like to take the opportunity to thank everyone for their kind donations and support."

Check out his donation page here:

www.justgiving.com/page/dave-smith-4

What a hero 💙🧡

Jane Gilbert



One day, one island for MND

Massive congratulations to Chris Warbey who nailed his 40 miles walking challenge around Guernsey in memory of his beloved dad Richard who lost his MND battle in 2017.

And well done also to his proud mum Jacqui Warbey who was his brilliant back up support to make it all possible.

Chris' tough one day challenge has raised a whopping £2,265, including Gift Aid, to help support local families affected by this cruel disease.

And he admits it was a personal challenge both physically and emotionally as well as a way of raising awareness of a cause that means so much to him.

His epic walk on July 7th took 12 hours, 5 minutes to complete and left him with an injured foot.

Chris declared afterwards: "I'm absolutely drained now, but buzzing to have finished it!

"Thanks to everyone who donated or gave encouragement along the way. Also, a massive thanks to my mum Jacqui Warbey for supporting me with refreshments all day along the way. Wouldn't have been possible without her."

In fact, Jacqui, from Woodley, clocked up 12 miles herself while supporting Chris. She has also raised thousands of pounds in recent years by selling plants and cakes as well as achieving match funding from her employer, Vodafone.

And Jacqui's little helper – Richard's teddy bear Goldie – also did his bit to raise awareness of MND on Guernsey.

What a team! 💙🧡

You can still donate here:

www.justgiving.com/page/chriswarbey1

Jane Gilbert



How's this for a showstopper!

Star baker Carol Coker's amazing Biscoff cake was among the tempting treats on offer at May's successful Art Café at The Old Rectory Stables, Whitchurch-on-Thames.

Our friends and supporters, aged from three to ninety-three, loved catching up with each other while raising £421 for branch funds.

Thank you to Katie Cooper and her Dream Team of bakers and helpers.



The Morgan-Russell family is pictured having a lovely time with Association Visitor Jan Gryglaszewska



The Warriors take on the Kennet and Avon



A big high five to jubilant Andrew Johnston and his friends who have raised £6,263 by walking 15 miles along the Kennet and Avon Canal from Great Bedwyn to the Plough on the Green, Newbury, on May 24th.

Groundsman Andrew, aged 50, from Greenham, lost his beloved mum Joan to MND four years ago during Covid and his friend Sasha-Marie Banning is facing the same heartbreak as her mum Kim (pictured) is now battling with the disease.

The fantastic team is planning a big cheque presentation to the branch on September 13th with another cheque presentation planned for a later date at The Crucible Sports and Social Club in Newbury which has kindly donated funds to help fight MND.

Check out the Warriors fundraising page here:

https://localgiving.org/fundraising/MNDWarriors

Jane Gilbert

Life was sweet at August's Art Café

What a wonderful morning at the Art Café on 16th August!

We loved catching up with so many of our amazing supporters and local regulars. A special highlight was meeting Vickie Ann Hughes, who took on the incredible challenge of swimming 21 miles (the equivalent of the shortest route across the English Channel) in August to raise funds for the MND Association in support of her dear friend Kim, pictured above.

We also had the joy of celebrating loyal supporter Gary Baynham's 70th birthday – the whole room joined in for a rousing "Happy Birthday," and we think he enjoyed every moment.

Of course, no Art Café Day is complete without cake… and our talented bakers delivered once again – every slice went down a treat!

Thanks to everyone's generosity, we raised £432.50.

Katie Cooper



Supporters Joaquim Torrao and Vickie Ann Hughes with some of the Dream Team – Association Visitor Jan Gryglasewska and Art Café Organiser Katie Cooper.

Newbury rocks to help fight MND

A fantastic night of live music in Newbury's Victoria Park Bandstand has raised about £1,300 to support the vital work of the MND Association's Reading and West Berkshire Branch.

Organiser David Rubery, who lives in the town, was so pleased with the gig on August 16th that he hopes it will be rocking again next year.

For David, aged 44, it was held for a cause close to his heart and he was joined by all his family including stepmum Sylvie, who is living with MND.

He said: "I do lots of gigs. We enjoyed it and the bands enjoyed playing."

David raised the magnificent funds from a bucket collection on the night and donations including one from his employer Nationwide Building Society based in Swindon.

Among the crowd enjoying the music were four branch volunteers – Mary and Barry Dodds, Jacqui McGachie and Andy Mancey.

Mary said: "The evening featured a fabulous variety of music with incredible performances from **Roadhouse, Casino Birds**, and **Jessie Black**, keeping everyone singing and dancing.

"Roadhouse, with David as lead singer, had the audience completely captivated, getting people up and dancing to their energetic music. The **Casino Birds,** a talented duo, delighted the crowd with hits from the '70s, '80s, and country classics - many guests, including myself, couldn't resist singing along! Meanwhile, **Jessie Black** had all the youngsters on their feet, bringing a lively energy to the event.

"It was wonderful to see so many families attending, with children of all ages joining in the fun. The atmosphere was full of joy, music, and community spirit - so engaging that I didn't even think to take a photo!"

A massive thank you to David, his family, and friends for making this unforgettable night happen, and to everyone who came along to support.

You can donate here:

https://www.justgiving.com/page/roadhouse-mnd

Jane Gilbert



The family group: L-R Charlie Marchment-Nelson with Honey the dog, Amy Marchment, Kirsty Marchment, Sylvie and Steve Rubery, Harry Marchment-Nelson, Zaylia and Reed



David Rubery (wearing his MND T shirt) is pictured with Doug, Ian, Lucy, Oli, Mark, Barry and Elliot from the bands

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



Thanks to Alec Jenkins for another amazing quiz - answers on page 17

Super-sized Dream Team hosts summer tea party

Our Dream Team of volunteers just keeps on growing to help support families living with MND.

And their magnificent efforts led to the success of a sumptuous summer afternoon tea party on August 28th.

About 85 guests enjoyed delicious sandwiches and cakes at this year's new venue, Beansheaf Community Centre in Charrington Road, Calcot, near Reading.

They were served by committee members and supporters including a team of four hard-working volunteers from the Reading Audi dealership. They were given a day's leave after the Association was nominated by an employee whose father was recently diagnosed with MND.



The afternoon also featured a raffle, which raised £253, and a very entertaining quiz devised cleverly as usual by Alec Jenkins, who is living with MND. Competition was as fierce as ever with the Ray of Hope's Up the Ding team beating Steve Baugh and Paul Morgan-Russell's Man Shed by just one point.

It was also the perfect opportunity to honour one of our unsung heroes – committee member Paddy Lunn who is always in the kitchen at parties!

Chair Margaret Moss said: "We have an unsung hero who is so quiet and reliable and always does such a wonderful job that we wanted to recognise her."

Paddy, who lost her husband Rodney to MND, works tirelessly behind the scenes at all the branch Drop-In support group meetings and tea parties. She was given a well-deserved bouquet of flowers and a hamper.

Jane Gilbert



A shocked Paddy (second from left) with Kerrie Newton, Linda Green and Mary Dodds



Photo shows Ray Dalfsen, holding the quiz prize, and some of the winning team



Shannon Jarnak, Liam Brinkley, Leah Thomas and Christophe Rousseau, the lovely helpers from the Reading Audi dealership



He's got the T-shirt as well as an international rugby cap – remarkable Denis Murphy, aged 93 in September, a former Welsh U18 rugby player and track athlete, who was still spinning in the gym when he was 85 before his MND diagnosis 18 months ago, with his wife Lorna



Our next generation of volunteers? They already have the T-shirts!

Love is . . .

Love is . . . . asking for donations to help fight MND in lieu of gifts for a silver wedding anniversary party.

Lesley and Lou Feinberg, from Wokingham, did just that when they recently celebrated 25 years of marriage with their friends and family.

Lesley, who set up a Localgiving page in aid of the branch, wrote: "We celebrated our Silver Wedding Anniversary on 26th July surrounded by the love and laughter of our wonderful family and friends. It was a day full of joy, memories, and meaning — made even more special by the incredible generosity of those who joined us."

In honour of Lesley's brother, Peter Cass, from Bracknell, who passed away in 2018 from Motor Neurone Disease (MND), they chose to forgo gifts and instead raise funds for their local MND support group.

Lesley wrote: "MND is a dreadful progressive illness that affects the nerves in the brain and spinal cord, slowly taking away the ability to move, speak, eat, and breathe.

"The MND Association Reading and West Berkshire Branch was a lifeline for my brother and our family during his illness, and we wanted to give back to help other local families facing the same challenges.

"Thanks to your kindness, we are thrilled to share that we raised over £1,000. Every penny will go directly to supporting local families living with MND, providing them with the care, resources, and comfort they need.

"From the bottom of our hearts, thank you for celebrating with us and for helping turn our milestone into something that will make a lasting difference. Your support means more than words can say."



Lesley and Lou on their wedding day



Lou and Lesley with brother Peter

Check out Lesley and Lou's page here:

https://localgiving.org/fundraising/silverann25

Voice banking gets the AI treatment

The recent amazing news story of how AI restored the voice of mum Sarah Ezekiel that MND robbed, might have got you thinking if it's possible for everyone.

Branch Voice Banking expert Michael Morrison has his finger on the latest technology and is here to help.

Michael writes:
Imagine recording 1600 sentences for your artificial voice to be created. That's what was needed only a few years ago.

The technology improved and the number of sentences dropped to around 300. Much better but still quite an onerous task, especially for anyone living with MND.

Now Acapela (one of the online services we use) needs only 50 sentences to make a fully functional digital voice that sounds like you.

Your voice can be downloaded into apps on several devices, and you can then type to speak if your voice gets tired, for example at the end of the day.

Now, with the help of Artificial Intelligence, and a simple 25 second voice memo from a phone, there are online companies who will make a very realistic digital voice - 25 seconds! That's all that is needed.

Longer recordings can improve the quality of your voice but, frankly, I've used the 25 second route with excellent results. Your AI voice will sound exactly like you. The only slight wrinkle is that your iPad needs an internet connection to send away your typed text to convert it back to speech.

Someone has obviously thought about this. There are apps (Predictable is one) where you can download a full 50 sentence voice along with the details of your AI voice. The app will use that voice but can automatically default to your downloaded voice when you are offline.

I realise that this can sound complicated, but it's an easy process to set things up and the MND Association will pay for things.

If this is something you would like to consider then please talk to your Speech and Language Therapist as the first port of call. For more details contact your Association Visitor, send me an email contact@mndrwb.org or come to one of our Drop-In support group meetings. And, as they say on the television: "Simples".

Michael Morrison

Sally and Derek's tea party was a scorching success



Garden Party guests from Purley W.I.



Branch Events lead Mary Dodds presenting Sally with 'thank you' flowers at the July Drop-In meeting

Huge thanks to Sally and Derek Hince and their amazing family for all the hard work in organising a garden tea party in July's scorching heatwave.

We were thrilled to hear the delightful summer gathering at their home in Purley-on-Thames raised £850 for branch funds.

"I was overwhelmed," said Sally, who cares for her 80-year-old husband Derek, who is living with MND. "It was so hot. I felt really humbled by all the support and the love."

It was too hot for Derek who enjoyed seeing a steady stream of visitors in the house and was equally thrilled with the support from family, friends and neighbours.

He said: "I had two fans around me and was sitting in my chair with people coming to say 'hello' which was nice."

Derek and Sally are grateful to all the support on the day from the MND Dream Team, their family, neighbours, members of St Mary's Church, Purley, and the Women's Institute, as well as friends from two singing groups, Singing for Fun and Thames Vale Singers.

Now Sally and Derek are planning "a bit of a knees up" on September 27th when their son-in-law's band The Mighty Triple 'O' is doing a gig at St Mary's Church, Purley-on-Thames, in aid of branch funds. (details on next page).

Come and join them for two hours of music, dancing and fun.

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

THE MIGHTY TRIPLE 'O' BAND

Join us in aid of the Motor Neurone Disease Association (West Berks)

ENJOY SOME MUSIC AND FUN!

SATURDAY SEPTEMBER 27

St Mary's Church, Purley on Thames
RG8 8TE

7:30 - 9:30pm

£8 - Adults
£5 - Children
£25 - Family (2 adults+3children)

THE MIGHTY TRIPLE 'O' BAND
@berkshireband

mnda motor neurone disease association
Charity Number: 294354

To book your tickets:
madeinpurley@gmail.com

localgiving

Our Magnificent 7 wear their badges of honour

The ever-popular Branch Drop-In support group meetings have spawned an exclusive club for the Over 80s with its first magnificent seven members.

Co-founder and Chair Margaret Moss, a sprightly 83-year-old, had jokingly suggested the idea after several octogenarian celebrations among our MND community.

Newsletter quiz supremo Alec Jenkins, who has been living with the disease for more than 20 years and is well-known for his quick wit, jumped on it. Alec, aged 81, arrived at the busy July meeting clutching a bag of badges he had designed and made. No-one could resist joining the club!

As you can see Drop-in meetings can be great fun as well as providing an opportunity to share experiences and thoughts with friends who understand what it is like living with MND. Delicious sandwiches, cake and hot and cold drinks are always served at these friendly sessions where our Association Visitors and our Dream Team of volunteers are on hand to offer support and advice to anyone affected by MND.

The meetings regularly attract up to 50 people and for some people it takes precedence over anything else.

See back page for the dates of upcoming meetings where relatives or friends are also welcome. Dates for next year will be in the next newsletter.

Jane Gilbert



"We've got the badge!", say Derek Hince, who is living with MND, and Mike Taylor who is a carer for his wife

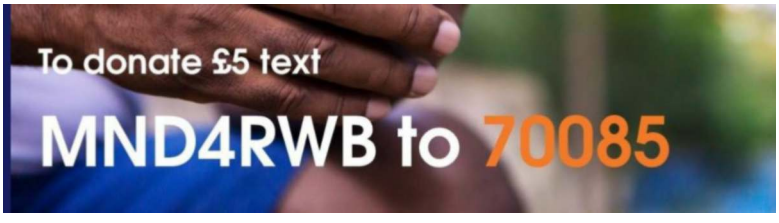


They haven't got a badge but they have fabulous hair styles! – it was all smiles at the June Drop-in as Becky Carey and committee member Linda Green had a colour compare



Founder members Alec Jenkins and Margaret Moss





Kitty's challenge in memory of her granny

A young West Berkshire woman will be running London's stunning Royal Parks Half Marathon next month in memory of her beloved granny.

Kitty Gilbert, the daughter of Branch Publicity Officer Jane Gilbert, is in training for her first big running event on October 12th to raise funds in support of other local families affected by MND.

Kitty, aged 33, who works in London as Head of Marketing for hospitality agency Toast, says she is taking on the 13.1-mile challenge aiming to raise £1,000 for The MND Association's Reading and West Berkshire Branch.

She said: "This year marks 25 years since I lost my beloved Granny, Pamela Wyatt to Motor Neurone Disease. She died aged 77 after having lost the ability to speak or swallow food - cruelly denied of two things she loved most: connecting with others through conversation and sharing her joy of cooking.

"At that devastating time she was thrown a lifeline of support by the Reading & West Berkshire branch to which we're eternally grateful. This support inspired my mother Jane to volunteer as its publicity officer ever since."

Kitty and her brother Jack were aged 8 and 11 when their widowed granny died at the Duchess of Kent House hospice in Reading.

Jane explained: "My mother came to live with us in Bucklebury when Bulbar Palsy took hold and she could no longer look after herself in Sussex. I know that she would be incredibly proud of Kitty taking on this huge challenge.

"We have never forgotten the wonderful support we received from two legends – Association Visitors Lady Hallifax and Dr Monica Stewart - who shaped the branch into the brilliant team it is today and inspired me to volunteer as a committee member ever since."

Kitty will be joining #TeamMND's 75 fundraisers taking in many of London's famous landmarks on closed roads and four of the eight royal parks.



Help us get closer to an effective treatment and eventual cure for this horrible disease that devastates families. Thank you for any kind donation you're able to give.

www.justgiving.com/page/kitty-gilbert-1

Micky's friends need a little help



The 4th Micky Denny Memorial Golf Day will soon be teeing off raising funds to help beat MND. Could you donate a raffle prize or auction lot to help his friends smash their target?

Co-organiser John Mann has had a fantastic response from players and says the event at De Vere Wokefield Park, near Reading, on October 17th is full and has a reserve list.

He would now like a few more auction prizes to boost the proceeds and says: "Every penny raised goes to the MND Association on behalf of our friend Micky."

Dad Micky, pictured on the left, a popular golfer, footballer and card player from Earley, near Reading, has inspired three previous fabulous days of golf, a dinner and fundraising with John Mann expertly wielding the auctioneer's gavel.

Micky, who died aged 63, in 2022, was also hugely popular among his work colleagues from energy firm SSE.

If you can lay your hands on any sporting equipment/memorabilia or a hot ticket, please contact John Mann directly or via the branch contact@mndrwb.org.

Jane Gilbert

Lin's incredible fundraising year

Branch fundraiser Lin Jenkins is about to wrap up another incredible year's work having raised more than £7,000 to help fight MND.

Lin, from Tilehurst, who works tirelessly selling donated items at fetes and car boot sales, says: "These days my 'financial year' ends at end of September, as this takes me to the end of the summer events.

"Some years are more challenging than others, each bringing their own trials and tribulations, but overall, it is a thoroughly enjoyable experience.

"When I first joined the MND Association as a volunteer, there was no hope for a cure. These days, with all the money being raised by celebrities, I can feel the excitement of the scientists and researchers. We ARE making progress; we ARE beginning to work towards winning this fight.

"I may come home cold, too hot, worn out, hurting, but I can recover - our people cannot. Therefore, I will keep fighting to raise cash for as long as I can.

"I have met some wonderful people through my work with the MND Association and have heard some amazing stories. Keep fighting everyone!"

One of the most enjoyable events that Lin attended with her stall was the Thames Traditional Boat Festival at Henley where the river spectacle made up for the extremes of hot and wet weather.

While she did not sell as much as she expected she says there were many MND awareness raising opportunities.

"We had a thoroughly enjoyable day and I have already booked for next year.

"Thanks to Daniel Fung and Julie Dix, for helping out, and withstanding the weather".

On June 5th and 6th Lin set up her popular retro stall at Stoke Row Steam Rally thanks to her team of helpers who arrived with their cars loaded with goods to sell. Lin was especially grateful this year to have help from volunteer Vlad of Virgin Media. As the team arrived, stallholders and steam enthusiasts crowded around them to buy items from the boxes even before the fair was due to open the following day!

Hard-working Lin is no stranger to early starts, numerous car journeys back and forth with her stock as well as the vagaries of the English weather. Was it all worth it?



Lin meets all sorts of people in her charity work – here she is at Pangbourne Fete in June with two minders!

"Oh, Yes," she replied. "Nearly £600 raised and six carloads of stock sold.

"But the main thing is .... the goodwill, the happy people, the 'feel good' factor. I wish I could bottle it. Everyone goes away with a smile and good memories of the MND Association stall."

Jane Gilbert

Bravo to branch fundraiser Lin Jenkins who still managed to salvage items from the Reading Festival site despite the Branch losing its storage facilities. You'd think the hassle of finding somewhere to store all her existing stock would have put her off but not our Lin!

Lin arrived at the Richfield Avenue venue with helpers Julie and Bea after August Bank Holiday and bagged six abandoned tents and 120 folding chairs.

She'll be storing these in her own garage and back garden while the remainder of her stock will be kept in a nearby garage she has been offered free of charge.

Lin will be selling these items to help fight MND at the many car boot sales and fetes over the coming year.

Reading Joggers put fundraising in their stride



Neil Holloway (back row, third from left) gave these Reading Joggers £500 for volunteering at the three-day international youth football tournament.



Claire Rayner (centre) was the lucky winner of this barrow load of booze. She is pictured with Reading Joggers Charity Co-ordinators Tracy and Dave Hawkins proudly wearing their MND T shirts at the family BBQ and fun day.

On your marks, get set, Go! Reading Joggers have chosen the MND Association as their charity of the year – a cause close to their hearts.

And the runners have got off to a flying start by raising £1,000 from their first two events this summer.

They say: "Two of our fellow joggers Nicky and Andrew lived with MND and have both sadly passed away. For that reason, and as a fitting tribute to them, the MND Association Reading and West Berkshire Branch was chosen by the Committee as the Joggers' charity for the year."

Tracy Hawkins, who is joint charity co-ordinator with her husband Dave, was "incredibly pleased" with the success of the first fundraising weekend.

The Joggers held their annual family BBQ and fun day on August 16th at Linear Park in Calcot where the bumper barrow of booze raffle raised a brilliant £500.

And the same weekend Reading Joggers had volunteered with traffic and crowd control at a three-day international youth football tournament being held at Bradfield College. They were delighted to receive £500 for their efforts from organiser Neil Holloway.

Tracy said: "It was a busy and successful fundraising weekend, and we are now thinking of autumn fundraising activities. "

A car wash has been planned as a joint fundraiser at the Wokingham Road fire Station, Reading, on September 6th, from 12noon – 4.30pm raising funds for The Fire Fighters Charity and the MND Association Reading and West Berkshire Branch. Fire fighters from the station were ready to wash cars for a suggested £5 minimum donation. As we went to print before September 6th we are unable to tell you how much money was raised.

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**

ANSWERS

1: Errol (Harry Potter) 2: Zazu (The Lion King) 3 & 4: Heckle & Jeckle 5: Roadrunner (Looney Tunes) 6: Scrooge McDuck (Walt Disney) 7: Ludwig von Duck (Walt Disney) 8: Pingu (stop motion series) 9, 10 & 11: Louie, Dewey, & Hughey 12: Tweety (Looney Tunes) 13: Mr Ping (Kung Fu Panda) 14: Foghorn Leghorn (Looney Tunes) 15: Daffy Duck (Bugs Bunny cartoons) 16: Sam Eagle (The Muppets) 17: Daisy Duck (Donald Duck's girlfriend) 18: Big Bird (Sesame St) 19: Hennie (Hey Duggee) 20: Count Duckula (Danger Mouse)

NOTICE TO QUIT!

Ten years ago, we were fortunate to be invited to use an empty unit at Beacontree Plaza in Reading's Gillette Way through a charity called Centric Community Project. This meant that committee members' lofts and garages could be emptied and branch material and records stored in this neutral place and - importantly at no cost to the branch. Other charities worked alongside us and next door, and some disappeared or moved out during covid.

This very large space then allowed more storage for Lin Jenkins' vintage and seasonal fundraising materials.

At the end of July, a month's NOTICE TO QUIT arrived. (The lease said ONE WEEK!)

The message went out asking for alternative space and many were considered. We must applaud the team who took on this task - immediately getting quotes, visiting storage facilities and organizing and decluttering. Lin has now been offered free garage space for a large amount of her donated items.

As the end of August loomed, many trips to the recycling centre in Island Road were made, where possible using the reuse area.

And finally, Removal Day on August 26th - branch records, history, display materials, leaflets, banners and, of course, raffle prizes were all rehoused in the new facility. A wonderful team effort – but what else would you expect?

The difference, however, is that there is a cost! We now realise the benefit of free storage - and for ten years – being 'no cost' it has saved a large amount but also enabled the branch to operate comfortably and safely, running its events and supporting volunteers as well as



raising considerable funds over the years including those from Lin's efforts.

Now we will continue our work supporting those in our area affected by MND from our new space. Big Yellow in Rose Kiln Lane was chosen because there is a charity discount, and it is very convenient.

Our grateful thanks to all concerned at Centric Community Project and to staff at Beacontree Plaza for all the support over the past ten years.

Huge praise to Michael Morrison, Jan Gryglaszewska and Mary Dodds for completing this mammoth project and to Lin and her team for their stalwart efforts too!

Here's to the next ten years!

Branch Chair Margaret Moss

Christmas is coming …

I know it's only September but we have already started selling our MND Christmas cards and remember that **every card sold** by us **benefits the branch**.

We had our first sales at the Summer Tea Party and there will be more opportunities to buy cards at the Drop-Ins in October and November and at the Christmas Tea Party on December 2nd.

In a week or so there will be a video displaying all the cards on the Branch Facebook page so please take a look and make your choice.

We will also be at Thatcham Leisure and Craft Market on Saturday October 18th and Tadley Christmas Market on Friday November 28th, when they will also be switching on the Christmas lights, Do come along and see us at either or both of these events.

There may be a few more events sorted out over the next few weeks so keep an eye on Facebook for any announcements or send me an email.

If you can't get to any of the venues then you can collect cards from my home in Burghfield Common or I can post them to you but I'm afraid I will have to add postage to the cost of the cards.

Mary Davidson

Email: marydavidson1123@gmail.com



Don't miss out on a champion Ray of Hope MND bloom

There is still time to register for a blooming lovely Begonia grown in honour of Reading's Ray Dalfsen, who is living with MND.

The aptly named grower Phil Champion will start harvesting tubers during October and will then know exactly how many he has available to sell in aid of branch funds.

Former Reading man Phil, who played football with Ray and now lives in Scotland, took five years to raise the specimen bloom for exhibition.

After a difficult growing year, he has managed to win back the British cut bloom championship and kept hold of the Scottish pot title.

Now Phil's brother-in-law David Ling, a friend of Ray who came up with the fundraising idea, is delighted that the first few tubers will soon be



available for us to sell at £25 each. Phil will also provide some tubers to commercial suppliers who can expect to retail them at double the price.

David says: "Phil is a great guy and is doing this for the love of Ray."

It is hoped the tubers will be sent to their new homes in February or March ready for the new growing season.

Phil explained: "Sending them out before Christmas means they must be stored properly and we don't want people losing them before the correct time of starting them back up.

"Any questions just ask, I will put together an instructional on how to start them back up and how to look after them as well."

To register an interest or join our waiting list please email Branch Committee member Kim Facer: contact@mndrwb.org.

You can also follow the growing from greenhouse to show bench on Phil's Facebook page – Phils Begonias.

Jane Gilbert

Young dancers work their magic to help fight MND

We were over the moon to get this lovely message out of the blue from Linda Butler, the Principal of Linda Butler School of Dance:

"We have great pleasure in telling you that we have raised £3,669.68 for your amazing cause. We had a great weekend producing the show and to make a good profit is the icing on the cake. I admire so much the work you all do and I would love to visit you at some point if this is allowed."

Huge thanks to Linda , her teaching colleagues and all the pupils for this very generous donation to help us support local families affected by MND. We look forward to welcoming Linda at one of our support group meetings or tea parties so she can hear what a difference this surprise cash boost will make.

Linda writes:
"Recently we presented a show, called 'We just love to dance' at the Wilde Theatre in Bracknell. I believe that we had a total of nearly 800 tickets sold over the weekend, which was fantastic.

"Our youngest dancer was aged six and the oldest was 18 and we did a ballet, called the Two Pigeons and a Modern and Tap section too. There was such a lot of laughter and happiness that it was lovely to be part of the action.



"Each performance lasted for nearly two hours and there were four performances; at the end there were tears, but they were not of tiredness, they were of sadness because it was all over. (Until the next time).

"We hope that you enjoy spending the money that we raised in the process. "

Drop-in Meetings - An open invitation

You are warmly invited to our Drop-in Meetings

The Calcot Centre, 3 Highview, Calcot, Reading RG31 4XD

12.30 - 2.30pm

These meetings are an opportunity for you to share experiences and thoughts, meet with friends who understand. We would be very pleased to see you. Please feel free to bring a relative or friend - all are welcome.

RSVP to secretary@mndrwb.org or call 07760 854957.



A selection of sandwiches will be available.

The venue has wheelchair access, toilets and car parking on site.

From junction 12 of the M4 head on the Bath Road (A4) towards Reading. You will pass Sainsbury's/IKEA on your left and in a few hundred yards at the next roundabout take the first exit onto Royal Avenue. Take the 4th road on your left, Highview, and the centre is on the left (signposted). Click here to view venue in Google maps,

SAVE THE DATE

OUR BRANCH

CHRISTMAS TEA PARTY

WILL BE HELD ON

TUESDAY, 2ND DECEMBER

THE BARN, GOOSECROFT LANE,

BEECH ROAD, PURLEY ON THAMES, RG8 8DR

We look forward to celebrating with you!

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