Issue 106
August 2022

mnda motor neurone disease association

Reading and West Berkshire

News Letter



www.mndrwb.org

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Fashion show debut is given a resounding Encore!

The first fashion show held to put MND and hospice care in the spotlight has been hailed a huge success.

Delighted Co-organiser and Branch Fundraiser Lin Jenkins described it as a wonderful event on so many levels.

"We took nearly £900 and everyone had such a good time. Much networking went on between the two charities and many old friendships were re-kindled," she said.

Now Lin and Jeannie Briant, from Sue Ryder Duchess of Kent Hospice, plan to put on the style once more on October 18th at Theale Village Hall.

Lin and Jeannie acquired hundreds of items of clothing and accessories for the first sale in July which also included jewellery, skin care, scent and make up stalls.

It all began with a Caversham man's generous gift of his late wife's extensive wardrobe collection for a fundraising event.

Lin said: "The lady liked shopping and many of the items still had their price tags. Other people then added to this initial donation so that we had a huge collection.

"It was such a success, attended by 80 people, and we still had a lot of clothes left over, that we have decided to have one more sale. It's surprising how many of us have unwanted items in the wardrobe, still with labels.

"In these austere times a party dress for £5 must seem enticing!"

A large team of volunteers rallied to help Lin and Jeannie transport the array of clothes, set up the event and sell raffle and entry tickets on July 5th.

They are also grateful to all the models who were introduced by Dr Alison Talbot, a former Associate Specialist at Sue Ryder Duchess of Kent Hospice.

"Didn't they do well," added Lin. "We look forward to seeing you all in the autumn."



Organisers Lin Jenkins (right) and Jeannie Briant

Footnote: Lin has now donated all her remaining tents salvaged from last year's Reading Festival to a charity taking items to Ukraine for the winter.

This summer she has been out and about with her vintage stall at Stoke Row Steam Rally, had a "magnificent" day's takings at Thatcham Fun Day and met the Newbury MP Laura Farris while raising awareness at Yattendon and Frilsham Fete, to name but a few.

The branch committee continues to be thankful to Lin's amazing dedication in helping it to support local people living with MND.

Jane Gilbert

More photos on page 2

More from the fashion show



Supporters Jo Lawson, Izzy Rastall, Jane Westwell, Paddy Lunn, Kerrie Newton and Jan Gryglaszewska



Branch Secretary Kerrie Newton (left) and fundraiser Lin Jenkins with helpers looking on make the draw for the Tudor Lodge Holiday - see page 3



Lin and Jeannie with compere Dr Alison Talbot



Helper Helen Varley models a little black jacket



Branch Secretary Kerrie Newton had her eye on this cardigan

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.



And the winner is ……

We are delighted to announce that Deborah Hayhurst and her husband Ray, from Earley, have won the prize draw for a one-week holiday in Cornwall.

The free stay at Tudor Lodges in Looe (www.tudorlodges.co.uk) was kindly gifted to the branch by the owners Michael and Julia.

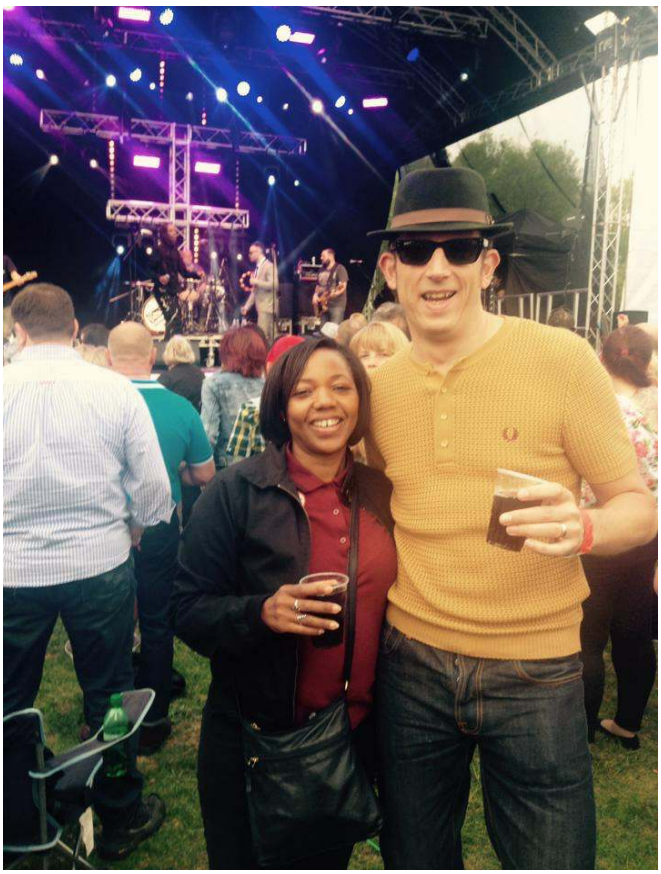
A delighted Deborah, who is living with MND, said: "We were shocked to hear we had won.

"Thank you so much for allowing me to enter. I'm very glad I did now."

The branch was given this wonderful holiday offer following a review of Tudor Lodges in the Newsletter by Alec Jenkins, who is living with MND and writes regularly for the Newsletter.

Deborah and Ray will be able to enjoy a break at one of the fully accessible lodges sleeping up to six people with the availability of mobility equipment such as hoists, profiling beds, riser recliner chairs and many other aids.

Readers may remember that keen cyclist Ray took on the epic challenge of the 100-mile Ride London-Essex on May 29th. He was "absolutely blown away" by the response raising £5,228 for the MND Association and nailed the ride with a time of 04:58:33.



It is not too late to donate:

justgiving.com/fundraising/ray-hayhurst-1

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**

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**

Time for tea with Chris and friends

Chris Gray, who has been living with MND for eleven years, decided it was time for tea with a little help from her friends.

Her idea was so popular at the complex where she lives in Woodley that Chris has been able to donate £390 to branch funds.

She said afterwards: "It was hectic and hot on July 8th but everyone enjoyed it so much they asked what was coming next.

"I want to raise awareness of MND and help with research where I can."

Chris and her carer Jane Turner made up 30 boxes containing cake, a cream tea and sandwiches which they sold for £5 each. Jane's husband Trevor organised a quiz and there was a successful raffle with prizes donated by Chris's daughter Jools Pomfret-Gray and friends. A competition to guess the name of the doll – MaNDy – was also a winner.

Wendy Gouldthorpe, who is Chris' Association Visitor, said the quiz on recent decades was great fun. She was on the winning team with Chris, who happens to be a massive Elvis fan and now has ideas for a quiz night.

Watch this space!

Jane Gilbert



Chris with her helpers (L to R) Jane and Trevor Turner, Chris's daughter Jools Pomfret-Gray, Kirstie Emberson-Wines and Lia Mountstevens

A message from Maz!



Photo shows Maz (front right) with her bestie Kim Facer thanking some of the team at the July drop in – (LtoR) Margaret Moss, Michael Morrison, Corinne Bertrand, Wendy Gouldthorpe and Val Pearson

We love this message from the inspirational Maz Swann who has been robbed of her voice and the ability to swallow food by MND.

Here she is pictured with bestie Kim Facer and some of our dream team at the recent very warm, but welcoming drop-in meeting at Theale.

Maz, from Lower Earley, also gave us a peak of some of the brilliant artwork she has done since being diagnosed with MND in February 2021. Maz, who had to give up her job as a hair stylist in Pangbourne, has now discovered she has a talent for painting and paints for friends and family.

Getting out and about

Lin and Barrie Wells have tried to maintain a normal life as much as possible "since the spectre of MND raised its head in our lives."

One thing the Reading couple enjoy is being out in the fresh air, especially if it's by the sea. These trips became more difficult after grandmother Lin was diagnosed with MND, which has affected her mobility and robbed her of her speech.

Committee member Michael Morrison, our Voice Banking expert, helped Lin set up an iPad to make it easier for her to communicate. The iPad and the app to use her digital voice, is on loan from the MND Association's national office. Michael also arranged the loan of the mobility scooter.

Barrie writes: "What a very useful piece of kit this is. Going out now is far easier and we have managed quite a few lungfuls of sea air on this and other trips out. So, thank you Michael and the branch, we do really appreciate it."





Lin is pictured on her travels including a visit to the "royals" at the Queen's Platinum Jubilee decorations in Mayfield Road, Reading





Linda and Barrie's grandchildren in Australia sporting their 'Fight MND' hats
Theo, aged 3 on the left and older brother Eli

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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!

Steve's selfless farewell gift



A Berkshire man, who recently retired from work due to MND, had selflessly asked for donations to the Association in lieu of a leaving gift.

Very sadly, Steve Woods, who worked at Visa in Basingstoke, died just a few weeks later.

Steve, from Tilehurst, had earlier shared the story of his colleagues' fantastic fundraising on his behalf with the branch. And he was keen for the money to be spent helping others locally living with MND.

Visa's group of volunteers had put aside their normal job on one of the hottest days in June to wash cars in aid of the MND Association.

The team – John Boden, Trudie Seeney, Paul Ford, Paul Fawcett, Rachel Walmsley, Mike Phillips, Matt Lyons, Paul Woodward, John Woodruff and Romi Trimmer, washed a total of 18 vehicles ranging from small coupés to VW transporters raising £283.

Another £553 was gifted to the Association in a collection for Steve's retirement. Both were match funded by Visa to raise a whopping £1,672 grand total.

Steve's wife Fiona added: "I'm pleased the money raised is hopefully being used locally."

Jane Gilbert



Have you heard about West Berkshire's specialist therapy gym?

Trustee John Holt says only about sixty per cent of the clients at West Berkshire Therapy Centre have returned to exercise since it reopened after the pandemic.

John said: "It has been great that we have been helping these individuals to regain some of the mobility they lost during the lock downs. However, forty per cent of our clients remain cautiously at home, which we know is generally having a negative effect on their mobility, socialising, psychological outlook, independence, and long-term health.

"We do not charge clients for using our service, rather we invite them to make voluntary contributions. These contributions do not cover all our costs, but we have been fund-raising effectively and are looking forward to helping many more individuals with their mobility needs for many years to come.

Everyone is welcome to visit the Centre at Thatcham to see its safe approach to exercise. There is no waiting list, just give the front desk team a call on 01635 864561.

See **www.westberkshiretherapycentre.org.uk** for more information.

Marjorie helps mark Global MND Awareness Day 2022





Two photographs of Marjorie Moore, from Reading, have featured in a virtual photography exhibition, marking Global MND Awareness Day 2022.

This special photography exhibition is the brainchild of award-winning photographer Richard Cannon. Over the last two years Richard has voluntarily travelled the length of the UK to photograph 16 people living with MND.

His exhibition highlights that MND can affect anyone from any background and that the disease progresses differently for each person. There are two creative concepts behind his work – in the first you will see the person living with MND looking at their loved one who is out of shot, and in the second image you will see the person's primary carer(s) alongside them.

He says: "I am very aware of the pain caused by MND. It has been an emotional project but one I knew I needed to do to help raise awareness of this terrible disease. What struck me at each photoshoot is the strength of the relationship between each person and their carer – in nearly all the shoots these have been family members who probably wouldn't ever even use the term 'carer' to describe themselves but are simply doing what they do for their relative out of love as someone's partner, child or parent. I have found it a real privilege to meet them all and to have been welcomed into their home."

To view the full gallery visit:

mndassociation.org/about-us/who-we-are/mnd-awareness-day/virtual-exhibition/

Jane Gilbert

Marjorie is pictured with her daughter Lisa Charles and her carer

CALLING ALL CAKE BAKERS!!!

Do you like to bake cakes??? We are seeking bakers to donate yummy homemade cakes for our upcoming events:

- **Bucklebury Beerfest 2022, RG7 6PS- 27th August**
- **35th Anniversary Branch Family Fun Day, RG8 8DR - 10th September**



If you can help by baking one or more cakes, please do contact Mary on promotions@mndrwb.org

THANK YOU!!

Clever Goldie Bear's holiday appeal

Clever Goldie Bear packed a fundraising QR code as well as sunglasses for his summer holidays with pal Jacqui Warbey.

Jacqui's husband Richard lost his two-year battle against MND in April 2017, aged 56, and she's determined to raise awareness at every opportunity.

This year Goldie, Richard's old teddy, and Jacqui have been doing a series of walks during the summer to raise funds for the Reading and West Berkshire Branch which gave them great support during Richard's illness.

Jacqui said: "We are raising awareness of this dreadful disease and Goldie is very good at engaging people in conversation."

The loveable bear dressed in his MND T-shirt and carrying his fundraising placard and QR code has caught the eye of passers-by on walks in Guernsey and Berkshire as well as coffee shops and garden centres near Jacqui's Woodley home.

"It's shocking to hear that so many people have some connection to MND," said Jacqui who has already raised nearly £700 on her travels with Goldie. And she is hoping that her bosses at Vodafone in Newbury will match fund some of the money as it has done previously.

"Please help us raise funds for the Branch in memory of Richard to help those such as my friend, Debs, who is currently living with MND", she adds.

You can find Goldie and Jacqui's online donation page here:

justgiving.com/jacqueline-warbey4

Jane Gilbert



Thank you, Kim and friends



We were delighted to receive a £170 donation and a fabulous hamper from supporter Kim Facer and her friends at June's successful Art Café event.

Kim, who works at Purley Park Trust which supports adults with learning difficulties, raised the money by selling a menagerie of hand knitted hats which winged their way to friends in Wales.

We'll be back at the Art Café, The Old Rectory Stables, High Street, Whitchurch-on-Thames, RG8 7DF, on December 17th, 10.30am - 12.30pm.

Do come and join us!

Farewell to Association Visitor Carol Allen

Carol has been the Branch Contact and Association Visitor (AV) for some years after retiring as a clinical nurse specialist for rare and complex neuro illnesses.

We met her originally when the pioneering post of specialist nurse was first secured. Carol had been Team Leader at the local Duchess of Kent Hospice and had met people there with Motor Neurone Disease so she knew what the condition was. The newly created post by the Royal Berkshire Hospital came about because of work done by John Holt of the West Berkshire Neurological Alliance with the support of the Reading and West Berkshire branch of the MND Association. Together we raised £90,000 to fund and research the impact of the post for two years.

In 2006, Carol Allen became the first specialist nurse for Rare Neurological Conditions and what a wonderful job she did - always in contact with the



branch and supporting people living with MND in an extraordinary way. She remembers that 'the post' won the South-Central Health and Social Care Award in 2008 and was one of the four national finalists that year at Wembley but perhaps it was the person Carol who won?

On winning the Association's Extra Mile Award she said: "The majority of people I come into contact with are so incredible. So many services are run on people's goodwill and going that extra mile, so to get an award to say that I have done that, makes it extra special."

On retirement from this post several years ago in 2016, Carol, who lives in Thatcham, trained as an AV and joined the branch. She has covered the West Berkshire area since then and has been an important support for those people living with MND in that area.

We thank Carol for her years of support and know that she will always be remembered for her commitment and care.

Margaret Moss

Flying the flag for MND



Linda and Barrie Wells (1st and 3rd from left) with their daughter Panda Phelan, Linda's brother David Robins and Bobby, aged 7

Barrie and Linda Wells were in top gear for their day out in July at the Berkshire Motor Show.

And while Barrie and brother-in-law David Robins were showing their vintage vehicles, Linda was flying high with her grandson enjoying the fun of the fair at Prospect Park, Reading.

Linda, who has been robbed of her voice by MND, is keen to raise awareness and firmly believes "knowledge helps".

Barrie and David attracted a lot of interest in their 1968 Morris Minor car and BSA Bantam motorbike and used the opportunity to hand out leaflets about the MND Association.

We're very grateful to them, their daughter Panda Phelan, and all the family both here and in Australia for spreading the word.

Our Amazing volunteer Lin Jenkins also did a terrific job there with her fundraising stall.

Jane Gilbert

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

Rugby heroes' cycle #4Ed

Former Gloucester lock forward Ed Slater and his team-mates were given a heroes welcome as they completed a 350-mile cycle ride in scorching temperatures.

The 34-year-old retired from rugby in July after being diagnosed with MND. Father-of-three Ed was overwhelmed when he finished the three-day ride amid huge crowds back at Gloucester's Kingsholm Stadium on August 10th.

Here are the squad pictured earlier in the day with Branch Publicity Officer Jane Gilbert at their final pit stop in Stanford Dingley, near Reading, where they were treated to essential fuel by The Bull Inn.

The aim of the ride was to raise £444,000 for the #4Ed campaign, set up to cover his treatment costs and to support his family as well as others. Soon after the ride the fund had reached £173,740.

Ed Slater said his friends and former team-mates had done every mile with him.



Day one of the ride saw him cycle from Kingsholm to Welford Road - home of his former club Leicester, alongside Cherry and Whites captain Lewis Ludlow, Fraser Balmain and Billy Twelvetrees, as well as friends and former team-mates, including Charlie Sharples, Alex Brown and Jim Hamilton.

The group then travelled south to Milton Keynes – Ed Slater's home town - and visited his first club Milton Keynes RFC on day two, before making the 106-mile return trip to Gloucester through Berkshire on the final day.

To pledge support #4Ed visit:

justgiving.com/crowdfunding/gloucesterrugby-4ed

Jane Gilbert

Drop-in and meet us!

Since our last Newsletter we have hosted two Drop-in Meetings. These informal sessions are an opportunity to share experiences and meet with friends who understand how families are affected by MND.



Our July drop-in meeting saw the lovely return of former Branch Secretary Val Pearson, who has supported our work for many years. Amongst our guests was inspirational Maz Swann, who is living with MND and showed us photographs of her paintings, including the raven that she recently completed for her nephew Matt.

It was good to see so many people attend our August event, even on such a hot day! We welcomed a few new people, some who are living with MND and others who are spouses and family members. Our wonderful Association Visitors (AVs) were on hand to offer support and advice.

We were also very fortunate to have two members from the MND Association attend; Chris Bennett, who is Head of Regional Care Partnership and Helen Mackie, who is a Regional Fundraiser. They both thanked the branch for hosting these events and for all our continued efforts in helping support those living within MND.

Kerrie Newton

If you do not currently receive drop-in meeting invitations and would like to, please contact our branch secretary via email – secretary@mndrwb.org.

Your branch needs you!

Would you like to join a team of dedicated volunteers who do so much to make our branch the success it is? If you answer 'Yes' then please read on as we need two people to join our wonderful Team MND.

We need a Chair and an Events Co-ordinator - job descriptions are below. Please feel free to talk to anyone on the committee or email **contact@mndrwb.org** for more information about how you can make a difference to people living with MND and their families.

Branch Chair

We are looking for a Branch Chair to be responsible for the different activities being undertaken by branch volunteers, and to give a sense of continuity to our local work.

As Branch Chair, you will:

- plan, prepare for and facilitate committee meetings
- ensure appropriate decisions are made in a timely way when required
- support branch volunteers in planning and coordinating branch activities
- ensure branch volunteers are aware of and follow the Association's policies and procedures
- induct and mentor new volunteers
- work in partnership with staff to recruit new volunteers
- act as an ambassador for the Association and as a host at branch events.

This is an excellent opportunity to develop your leadership skills and get involved with your local community. We are looking for someone reliable, warm and empathetic with the ability to motivate others. Leadership skills and experience of chairing meetings would be an advantage along with good organisational and listening skills.

The Branch Chair will usually work for approximately 2-3 hours a week and facilitate monthly committee meetings.

You'll be inducted into the role and informed about the Association. As part of this, you will receive e-learning, face-to-face training and mentoring.

Events Co-ordinator

We are looking for an Events Co-ordinator to organise events to raise awareness of MND and the Association, and to help raise funds for the branch.

As an Events Co-ordinator, you will:

- plan with the branch an annual programme of awareness raising and fundraising events
- ensure appropriate resources are available for all events
- encourage other local organisations to run events in support of the Association and provide them with appropriate information and support
- support individual fundraisers in achieving sponsorship
- keep track of all the events and those involved and offer any help and support required.

This is an excellent opportunity to develop skills and get involved with your local community. You don't need personal experience of MND but will have good communication skills, good organisational skills, and the desire to help.

Ideally we are looking for someone that can give approximately 1 - 2 hours a week including willingness to attend the regular Committee meetings. Full training and induction will be provided and travel expenses will be reimbursed.

Save the dates

Bucklebury Beerfest on August 27th - see separate flyer

35th Anniversary Family Fun Day on September 10th- see separate flyer

Caversham Rock 'n' Ale Festival on September 10th from 6.30pm

at St Anne's School playing fields
Washington Road, Caversham, RG4 5AA

Three great local bands - The Skavanger's, Big Audio Twynamite and Dino's

Hog roast, veggie chilli, a bar by Caversham's very own The Last Crumb and fun for all the family.

All in aid of the MND Association Reading & West Berkshire Branch.

To buy tickets call 0118 958 4628 (office hours only) or visit wegottickets.com/event/541534

It is a family and community event and people of all ages are welcome.

Dust off your Royal Ascot attire for a Race Night at Wokingham Cricket Club, Sindlesham, Wokingham, RG41 5AW, on October 1st in aid of the Branch

Deck the Halls
Berks, Bucks & Oxon Flowers
Christmas Flower Festival

at Falkland Islands Memorial Chapel, Pangbourne
November 26th, 10am - 5pm, November 27th, 10am - 4pm

In aid of MND Reading & West Berkshire Branch
and Falkland Islands Memorial Chapel Trust



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