Issue 108
February 2023

mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Remembering our 'amazing' Anne

A basket of spring flowers on her tricycle greeted mourners as they gathered to celebrate the remarkable life of Lady Hallifax – known to everyone as Anne.

Only two days before her death, aged 88, the former MND Association President and branch stalwart had been pedalling up the same drive with the magnificent backdrop of Englefield House, the home of her nephew Lord Benyon.

Hundreds of mourners packed into St Mark's Church, Englefield, near Reading, to pay tribute and hear of the many qualities which proved invaluable in her amazing work for the fight against MND.

Lady Hallifax became President of the Association after losing her husband, a Falklands War veteran, to MND in 1992. Admiral Sir David Hallifax was serving as Constable and Governor of Windsor Castle when he was diagnosed with the disease and the family moved to live at Englefield, then the home of his sister Elizabeth, Lady Benyon, and her husband Sir William.

Mourners heard how "kindness, charm and determination" meant that Lady Hallifax was able to raise huge amounts of funding for the MND Association including the opening of an MND Care Centre in memory of her husband. As well as her presidency until 2006 she also gave emotional and practical support as a visitor to families in the Reading and West Berkshire area affected by "this cruel disease".





Lady Hallifax pictured with her husband Admiral Sir David Hallifax and their surviving children Tom and Louisa

Her son Tom said in his eulogy: "I believe her own experience of the illness, as she almost single-handedly cared for my father, gave her an understanding and empathy that was a very great help to many people in the most difficult circumstances imaginable.

"She faced the great trials of her own life – the early death of her adored son Matt, and the illness and premature death of the husband to whom she was utterly devoted – with extraordinary stoicism, helped by her clear and simple faith, and by the support of the many, many friendships that her kind attention to others brought her."

Reading and West Berkshire volunteers are now hoping to organise an event later this year in fond memory of Lady Hallifax who they were thankful to see recently at two branch festive events.

Former Branch Chair Margaret Moss and Publicity Officer Jane Gilbert remember how they were both 'recruited' as volunteers by Anne in 2000.

They agreed: "She was the lynchpin of the branch at that time when it was flagging and she worked tirelessly to keep it going. Her ability to build a team came with charm and a genuine, compassionate interest in others.

"Anne has now handed on the baton for her wonderful legacy to be continued."

Continued on next page …

Remembering our 'amazing' Anne - cont

Former Association Visitor and speech therapist Joanna Knott, who also began her friendship with Anne at that time recalled how they discovered, when chatting about naval families, that they had both lived in the same house in Malta at different times.

Joanna said: "She was such a lovely person in every way and has done so much to help others, I think she is someone about whom one would say that the world is a poorer place without her."

Other tributes included one from Sally Light, former Chief Executive of the MND Association, who sent condolences to the branch and all those close to her.

"What an amazing woman she was," she wrote. "Incredible to think how the world had changed in her lifetime."

Anne, née Blakiston-Houston, was born in 1934 and raised on the County Down coast in Northern Ireland, one of five sisters and a brother. Though always elegant, she was a tomboy in her youth and went on to become a skilled potter, furniture and china restorer as well as an expert gardener creating, amongst others, a garden in the moat of the round tower at Windsor Castle.

The mother of Louisa, Tom and Matt, grandmother to Fergus, Lily, Una and Maya, she died unexpectedly at home in Englefield on December 16th.

After the funeral service a retiring collection was held in aid of Anne's four favourite charities including the MND Association. The branch specifically received a very generous cheque for £1,000 from Prue Douglas-Menzies who admired her older sister "who was so often busy at her desk writing to people who had lost someone dear to them. "

May Anne Rest in Peace.

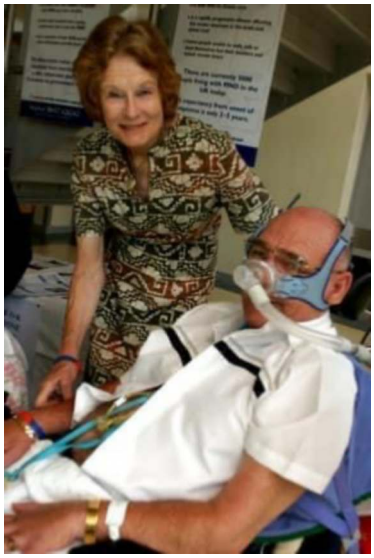
Jane Gilbert



Lady Hallifax got on her bike for a branch event







The above pictures show Lady Hallifax relaxing in her beautiful garden, in her role as an ambassador to the MND Association and as a carer. Another picture on page 3 shows her at the end of November 2022 when she attended the Christmas Flower Festival at The Falkland Islands Memorial Chapel.

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

Deck the Halls dazzled the crowds







Hundreds of people visited the dazzling two-day festive flower festival at Pangbourne College and generously supported families affected by MND.

They had the chance to see an amazing display of creative talent featuring 80 floral designs organised by Berks Bucks and Oxon Flowers, each based on a Christmas carol or song, with donations to two local charities.

The organisers are waiting on final expenses' claims and hope to have raised more than £3,500 for the MND Association Reading and West Berkshire Branch. A similar amount will be given to the Falkland Islands Memorial Chapel Trust which provided the magnificent venue for the event.

In addition, the branch had the great opportunity to raise huge awareness of MND and sold more than £1,000 worth of Christmas cards and other branded goods.

The sad news of rugby legend Doddie Weir's death also had a profound effect on many visitors who attended the floral spectacular on November 26th and 27th.

And it was also one of the last events attended by former MND President and branch stalwart Lady Hallifax – Anne – who died unexpectedly a few weeks later, aged 88. (See separate tribute).

We are very grateful for all the support from Berks Bucks and Oxon Flowers – formed of 36 flower clubs belonging to the National Association of Flower Arrangement Societies.

This was a big undertaking for the branch and we owe thanks to all our volunteers who acted as stewards and sold cards as well as to Andy and Zachary Mancey and their brilliant team from Reading Sea Cadets for their most welcome help and cheerful smiles on the opening day.

Jane Gilbert



Pictures show:

Top left: **Lady Hallifax pictured with Jane Gilbert and Mary Dodds**

Middle left: **Reading Sea Cadets Georgina and Olivia**

Bottom left: **Branch volunteer Mei Tan**

Above: **Gill Selby makes herself at home**

Linda's Celebration of Life!



Linda is pictured with daughter Panda Phelan



Linda with her grandson Bobby and nephew Mark Robins holding his baby Alfie

Fun loving Linda Wells decided to invite her friends and family to a fabulous party despite the difficulties of living with MND.

The "magnificent" mum and gran from Reading donned her tiara and boogied the night away on her mobility scooter having the time of her life.

Her guests at Thatcham Town Football Club on November 26th were encouraged to wear bright colours and asked to make a small voluntary donation.

And by the end of the evening Linda, who has been robbed of her speech and mobility, had inspired her generous guests to donate £2,310 to help support families affected by MND.

Linda's daughter, Panda Phelan, said: " My mum, a warrior, and my best friend invited friends and family to celebrate love and life.

"There was an amazing turnout from near and very far which showed the love and admiration for a phenomenal mum and friend.

"We had speeches, auctions, delicious food and dancing with plenty of laughter and bottles on the side, also the tremendous band Dinos which mum rocked to until the very end."

She said her "magnificent" mum wanted the night to be a fund raiser for the MND Association, Reading and West Berkshire Branch, which has supported Linda, her husband Barrie and family at this challenging time.

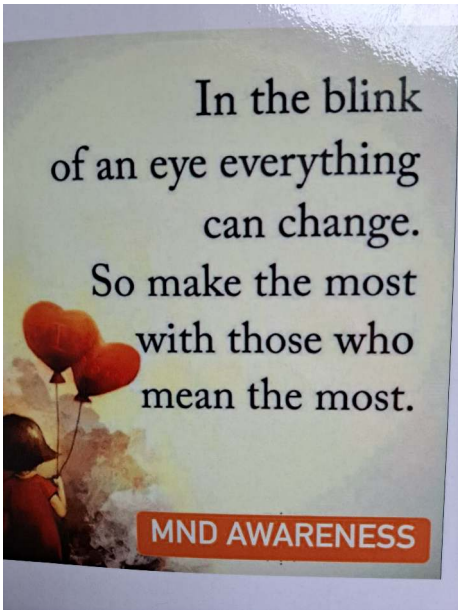
Panda added: "Thank you to everyone who played a part in this most memorable celebration – forever grateful."

Jane Gilbert









Goldie was so busy in Decembear

The advent antics of a little teddy bear kept us smiling with his daily posts on Facebook in the run up to Christmas.

Goldie's delightful calendar also raised £310 for the MND Association Reading and West Berkshire Branch in memory of his human Richard Warbey, who died of MND in 2017, aged 56.

Richard's wife Jacqui says Goldie, his childhood bear, helps her to spread awareness and to raise funds for other families affected by the disease."

She often takes him with her on her travels dressed in his own MND T-shirt and posts photos of him on social media in a variety of guises.

From 1st to 24th December Goldie and his friends appeared daily in a variety of wonderful costumes all made by Jacqui.

Jacqui got her inspiration a year earlier when one of her Facebook friends posted pictures of her naughty elves and she immediately set about collecting ideas and pictures for Goldie's Advent Calendar.

Before the start of December she had the 24 photos ready to go and had created the Facebook group.

Each day Jacqui checked that the post was visible and scheduled the next one.

She says "I am not that expert at using Facebook but I certainly learnt some new things."

It was mostly Facebook friends who followed Goldie's antics, including a work colleague from India.

She says: "Thank you to everyone who donated and followed his posts on the Goldie's Advent Calendar 2022 Facebook group.

"It was lovely to hear your feedback about how you looked forward to seeing each day's post and your favourite photos. It was the carol singing photo that received the most votes."





Which is your favourite?

You can see all the photos here:

www.justgiving.com/fundraising/jacqueline-warbey6

Jane Gilbert

More pictures from Deck the Halls



Carol Coker peeps out of We Three Kings



Volunteers Jane Iles and Mary Dodds



Ken Eggleton and Katie Cooper were stewards for Away in a Manger

It was Christmaaaaas . . . and we had so much festive fun now that the annual tea party was back.

Families affected by MND, supporters and volunteers enjoyed getting together for the December treat at historic Purley Barn, near Reading.

The branch is very grateful to Glenvale Nurseries of Bradfield Southend for the beautiful gifts, piper Michael Barnes of Reading Pipe Band and our very own brilliant Santa for his fiendishly difficult quiz.

Well done the Dream Team!



Newsletter editor Mary Davidson gets into the festive spirit with Lin Jenkins (left) and Jacqui Warbey (right) holding the cyclamen plant gifts



L to R: Tilly Lawson, Paddy Lunn with the fabulous wreath made in MND colours by branch membership and IT guru Andrew Wall, piper Michael Barnes and Lin Jenkins



Our very own Santa Alec Jenkins with his wife Chris

A big 'Shout Out' to our wonderful supporters and MND community

After an amazing year of events organised and run by both the branch and its army of supporters and fundraisers, the coffers saw a staggering income of £55k flow in between January and December 2022.

Because of these sterling efforts we have been able to fund the following for our MND community in the last year:

- 288 holistic therapies
- 24 counselling sessions
- 6 Carers Grants
- 5 Support Grants via National Office (Ramps, washer/dryer toilet/riser recliner chair/wheelchair)
- 8 wheelchair taxi journeys
- 4 Quality of Life grants (QOL)
- Regular social 'Drop Ins' that provide a safe space for our MND community to attend where they can make friends as well as receive support and advice
- Key events like the branch's 35th anniversary, the annual summer and Christmas tea parties.

These are just some of the ways we have helped families affected by MND using the funds raised by our fantastic supporters and fundraisers.

In addition, the branch will be transferring £32k to the MND Association's national office and has chosen to fund care (£16k) and research work (£16k).

A massive thank you and well done to all who have made this possible, you know who you are!

Association Visitor Jan Gryglaszewska

Keysight Technologies UK rocked the Purple Turtle raising money for MND research

Keysight Technologies UK based in Winnersh has held a fundraising evening of music in aid of MND research.

Music for MiNDs was organised by the company after their colleague David Mangan was diagnosed with motor neurone disease the day after his retirement. The company wanted to show their support for their much-loved colleague by raising awareness and to help other people affected by the disease.

Two members of the Keysight UK team perform in bands, so it made perfect sense for their company to come together with music to back the MND Community.

Taking over the Purple Turtle in Reading on the night of 10th November, the evening started with a set by Swallow treating the crowd to classic rock covers with people singing along and dancing. The Arboretum then took to the stage with a change of sound described by the band as "a sonic wall of sound, featuring loud guitars, deep grimy bass lines, industrial electronic rhythms, all layered over a hard-hitting rock-dance groove".



Helen Mackie, regional fundraiser for the MND Association, attended the event and was invited to give a talk about the difference the fundraising and awareness will make.

She said: "It was wonderful to see the Keysight Technologies community come together in support of a much-loved colleague on the evening. I was delighted to explain how the money raised will make a real difference and to say thank you for all the additional awareness raised".

The evening was made complete by the very special guest David Mangan who was able to enjoy all the camaraderie. David, who does not live in Reading and West Berkshire Branch's area, is being well supported by his local MND Association team. The fantastic event raised £876. A huge thank you to everyone at Keysight Technologies for all their hard work.

Helen Mackie, Regional Fundraiser



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

Wow! - £5k windfall in memory of Micky

Generous workers at wealth management company St James's Place have donated a massive £5k to help families affected by MND.

The boost came after service delivery manager Simon Miles nominated the Association's Reading and West Berkshire branch to receive the cash in memory of his friend Micky Denny from Earley.

Cirencester-based businessman Simon, whose daughter Anna is the partner of Micky's son Ollie, also lost an accountant to the ravages of MND.

He said: "I think it's the most horrible disease and anything that can be done to help to try and cure it has got to be good.

"Micky was a larger-than-life person in every respect - he was a big guy and it was sad to see him deteriorate."

Simon explained that every month his department co-workers donate part of their salary to the SJP Foundation Trust which allocates funds to a host of worthy causes.

This donation follows an earlier £6k boost from Micky's friends following a memorial golf and fundraising day at Wokefield Park Golf Club near Reading.

Popular Micky, a former golfer, footballer and card player, married his long-term partner Nicky after he was diagnosed with MND and sadly died, aged 63, in July last year.

Jane Gilbert



Local residents flock in for a sweet treat!



Volunteers Katie Cooper, Carol Coker, Paddy Lunn, Jan Gryglaszewska, Mary Davidson, Kim Facer and Gill Selby

Our recent Art Cafe was another huge success, extremely well supported by our MND family and friends.

The Dream Team served up tea, coffee, and delicious home-made cakes to a steady stream of customers. There was also the ever popular raffle with some fantastic prizes. We raised more than £425 including donations in just two hours, amazing, isn't it?

Our thanks to all our fabulous bakers, we couldn't do this without you.

Our next Art Café morning at The Old Rectory Stables, Whitchurch-on-Thames, RG8 7DF, is on 24th June - come and join us!

Mary Dodds

Another triumph for star baker Paddy

A Friday afternoon in November has now become an annual date in my diary to invite everyone I can to my house for a fundraising event in aid of the MND Association.

They know there will be a variety of homemade cakes, marmalade and chutneys, a raffle and my late husband Rod's unique notecards and Christmas cards.

Granddaughter Tilly Lawson was on hand to help beforehand and on the day she gave invaluable help selling raffle tickets while I dispensed tea and cakes from the kitchen, with Hugo my ever hopeful Labrador wandering around in his MND blue T-shirt.

One of the raffle prizes was kindly donated by The Village Hamper in Sonning – Tea for Two at the café which was won by our very own branch stalwart Mary Dodds (who, of course, took her husband Barry along as well!).

It was a happy afternoon and thanks to amazing and generous support we raised £813 for our Branch funds.

Paddy Lunn



Barry Dodds, Judith Howles, Sara Wright, Paddy Lunn, Sue Lunn, Mary Dodds, Jo Lawson and Tilly Lawson

CONGRATULATIONS to branch supporter Kay Murphy who won the first prize of £5,000 in the MND Association's festive fundraising raffle.



"I was told to sit down when I got the telephone call," said a delighted Kay who lives near Reading.

Thank you to everyone who bought and sold tickets – your efforts helped to raise a fantastic £130,000 for families affected by MND.

There will be another chance to win some great prizes and support people living with MND at the same time in the Association's Summer Raffle – details available in the Spring edition of Thumb Print.

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.



makeit! in March

Join our Amazing Lin Jenkins and get creative this March to support families affected by MND.

Branch fundraiser Lin has thrown down the challenge to makeit! –

Make your crafts
Create your fundraiser
Donate your money raised

Lin says: "This is an idea from national office and I think it's wonderful.

"It's a chance for us all to get out there and make something whether it be cooking, sewing, carpentry, gardening, or, more importantly, upcycling.

"What can you salvage? Does it need to be painted, oiled, varnished, or can you transform it totally? This is a good chance to be creative. Let's see what we can produce."

However, you decide to makeit! this March, the money you raise will help to make a real difference to the lives of people affected by MND.

Join the Association's Facebook challenge or set up your own donation page either online or with a printed sponsor form. And be sure to mention the branch in any wording if you would like the funds to be spent locally.

For more details: www.mndassociation.org/makeit

Do you know the branch has its own online page for any general donations?

Reading and West Berkshire Branch MND Association | Localgiving



Lin at her garden gate



Lin's Planned Events

- Monday 10th April: Spring Classic Car Event at Newbury Showground. Selling mostly retro items.
- Saturday 22nd April: Beanpole Day at Caversham Court Gardens. Selling gardening items, tools, upcycling and re-using as much as possible.
- Sunday 7th May: Lambourn Vintage Machinery Society. Selling mostly retro items
- Thursday 25th May: Fashion Show in Tilehurst. Due to be another fun packed evening with new items at £5 each as well as many more pre-loved bargains.
- Monday 29th May: Yattendon Fete – Lin's famous Washing Line Game.
- Saturday 10th and Sunday 11th June: Stoke Row Steam Rally. Huge, and now famous. Retro stall.
- Sunday 25th June: Either Theale Fete or Thatcham Family Fun Day. Would not like to miss either. **If you are available to help with manning the stall at Theale please do let us know.** Lin hopes to have her Washing Line Game at both events.

The look of love!

Congratulations to golden couple Alec and Chris Jenkins from Newbury who have celebrated 50 years of marriage.

The pair tied the knot at St Peter and St Paul Church in Yattendon a few years after Alec had gate-crashed Chris's 18th birthday party.

"I have had to put up with the same jokes for 50 years," said Chris who is often the affectionate butt of Alec's sense of humour which he is renowned for despite him having lived with the tough challenges of MND for 25 years.

Here they are pictured back in the day when Alec was a singer at Newbury Folk Club where Chris was a regular in the audience.

The pair recently celebrated their golden wedding anniversary with a weekend away together at Centre Parcs in Wiltshire. They were joined for the day by some of their family - they have a son and daughter and two grandchildren - to also celebrate Alec's 79th birthday.

Alec and Chris say the secret to their remarkable long and happy marriage is that they enjoy being together and rolling along.

"It helps," says Alec, "when I do what I'm told!"

Since his eventual diagnosis of MND in 1998, he has been a firm believer in thinking about what he is able to do rather than what he cannot achieve. Some of you will recognise him and Chris as the faces on the giant poster on display at branch events. They have also inspired branch fundraiser Lin Jenkins who is married to Alec's brother Paul.

For many years Alec carried on driving and went to work for a printer in Newbury. And Chris, who went seamlessly into the roles of wife and carer, has always been lovingly by his side.

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

Drop-in dates for 2023



Our regular drop-in meetings, run by our branch volunteers are an opportunity for people living with MND and their families to share experiences and thoughts, to meet with friends who understand. Our wonderful Association Visitors (AVs) are always on hand to offer support and advice.

Please mark your calendars for our 2023 meetings, which will be held at

St. Luke's Church Hall, Englefield Rd, Theale, RG7 5AS.

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

January Drop-in was a roaring success

Our January drop-in meeting was a roaring success, attended by 33 people including three of our AVs (Association Visitors) who went from table to table talking to everyone.

This was a great opportunity to share experiences and thoughts as well as a chance to meet with friends who understand. There was a huge buzz in the room, and I received wonderful complimentary comments from a lot of people such as … "been to other group meetings (not MND) and left as boring" – "This was the most wonderful friendly meeting I have attended, and I can't wait for February's meeting".

You are most welcome to join us at any of our drop-in meetings. Our next one is on Tuesday, 28th February, 12:30pm – 2:30pm at St. Luke's Church Hall, Englefield Road, Theale, Reading RG7 5AS. Sandwiches and hot drinks are served - the venue has wheelchair access, toilets, and car parking on site.

If attending please let us know by contacting Kerrie, our secretary - secretary@mndrwb.org or call 07760 854975.

Mary Dodds

Save the date!

Dedicated volunteer Jacqui Warbey is planning another of her successful plant and cake sales in aid of the branch on Easter Saturday (April 8th).

Jacqui will be setting up her stall outside her home in Woodley and would be grateful if any of her local friends could bake a cake, donate some plants or help for a few hours on the day.

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