mnda
motor neurone disease association

Reading and West Berkshire

www.mndrwb.org

Tweet to @MND_RWB

Join us on Facebook -
MND Association Reading & West Berkshire

Issue 113
April 2024



News Letter

Steve's race raises staggering £180,000 for MND

"Let's do it!", said the inspirational Dottie Channing-Williams and ex-jockey Steve Jobar at their huge fundraising event.

And Wow! – they certainly did. The incredible day at Newbury Racecourse is now expected to have raised a staggering £180,000 to help fight MND.

More than 450 supporters enjoyed Champagne, a sit-down lunch, live auction and an online silent auction as well as a great day's racing with one of them in Steve's name. It was the biggest event Newbury Racecourse had ever catered for.

One overjoyed guest, farmer's wife Mary Snook from Wiltshire, went home with a brand-new car worth £13k which she won in the raffle.

Steve, a former champion jump jockey and glider pilot from Wickham, near Newbury, was diagnosed with MND exactly two years ago. It has cruelly robbed him of his voice and his ability to swallow food.

Despite this, Steve, aged 75, has worked tirelessly with his wife Dottie in their determined race to find a cure.

The support of so many of his family, friends and wider racing community meant the world to Steve who posted on Twitter to say what an extraordinary day it was, both positive, generous and fun.

He wrote: "If you could bottle the feelings coming from all in the room, I think we would have a cure tomorrow. I may not be functioning right, but it was still one of the best days of my life. Thank you.

"Of course, without my committee it would never have happened – what a team they turned out to be."

Racing author Jonathan Powell, who led the organising committee, was equally delighted with the event which exceeded all expectations.

"The main thing was that Steve embraced it from start to finish.

"He definitely won the best turned out award."



Steve's friend and colleague John Francome admires Steve's amazing tie



Dottie Channing-Williams and Steve Jobar

Continued on page 2

Steve's race raises staggering £180,000 for MND - cont

Steve's big day on March 22nd was filled with heartwarming moments and fun led by Sky Sports presenter Mike Cattermole, Steve's weighing room colleague and friend John Francome and trainer Richard Phillips.

The live auction of amazing items and experiences entertained the guests who included many top names from the world of horse racing and two world champion glider pilots.

Top auction lot of the day was an oil painting by acclaimed artist Peter Curling of Steve riding Heighlin to victory in the 1980 Triumph Hurdle. The painting was bought for £7,000 by Heighlin's trainer David Elsworth.

Steve and Dottie later presented the trophies for the race named in his honour, the Steve Jobar MND Handicap Hurdle – the most exciting race of the day with a cracking photo finish.

Dottie captured the spirit of the event saying: "The community is full of hope, raising funds to spare future generations from this awful disease.

"A huge thank you to the MND Association, especially our Reading and West Berkshire Branch, for being our safety net."

Funds are still coming in to boost the proceeds which will be split equally between MND research and the MND Association's Reading and West Berkshire Branch.

The branch is over the moon with the amount of funds and MND awareness raised by Steve and Dottie as well as being enormously grateful to all who so generously contributed to the success of the event.

At least five other people living with MND and their partners attended the day in support of Steve and Dottie and enjoyed a thrilling afternoon.

Steve's fundraising page is still open for donations:

https://www.justgiving.com/page/stevejobarmnd

A huge thank you to all who donated the fabulous auction prizes, the six branch volunteers who were out among the crowds with their collecting buckets and the event's committee members who worked tirelessly for more than a year to attract donations and sponsorship.

Thank you everyone.

Jane Gilbert

More pictures on page 3



Artist Peter Curling, John Francome, David Elsworth and Steve Jobar with Peter Curling's painting of Steve riding Triumph Hurdle winner Heighlin



Steve writes "Well Done" to Mary Snook from Devizes, who won a new car in the raffle



Angela Hay and her husband Graham Attridge enjoying the Champagne Reception

An invitation to talk at Pangbourne Rotary Club

Debbie Webb and Margaret Moss were delighted to join fundraiser Andy Findlay to talk to Pangbourne Rotary Club about the MND Association, and particularly the work of our local branch.

Andy is involved in the Ray of Hope Committee which runs a successful annual event in aid of the branch. As his father had MND, Andy has first-hand knowledge of how hard it can be on all family and friends. The spectacular Reindeer Rays of Light show in his front garden in Tilehurst last Christmas was a big draw and fund raiser. He is already working on bigger and better ideas for this year.

This prompted Andy's neighbour who belongs to the Pangbourne Rotary Club to invite us to speak at a regular Monday club meeting. We were warmly welcomed by President Brian Davies and after the business and dinner, we spoke about the MND Association, its purpose and what support we are able to offer.

I talked first about my role as a trained volunteer Association Visitor (AV), why I had got involved and the support I and the other AVs offer those living with MND and their families.

Andy then spoke about the struggle his family had as the disease progressed, and the help and the support offered by the branch. He told how it helps everyone to feel that they are not alone and that there is support available. The branch understands the challenges of MND and can offer appropriate advice.

Finally, Margaret talked about the roles and activities of the branch. She also explained how funds are needed to both offer support locally and to contribute to wider research to understand the cause of MND, find ways to diagnose it earlier, find effective treatments and ultimately a cure.

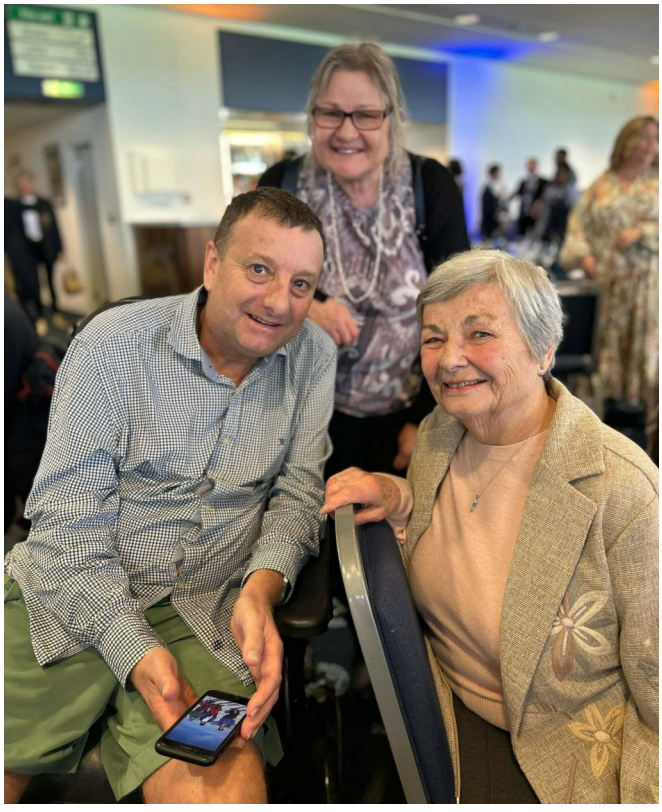
All this seemed to be very well received and we took many questions from the floor. Finally, on a personal note it was heart-warming to realise that one of Pangbourne Rotary Club members knew my close friend who had died of MND.

Pangbourne Rotary Club has around 35 members that work hard all year round aiming to raise about £25,000 to donate to charities. More details can be found here:

www.rotary-ribi.org/clubs/homepage.php?ClubID=1669

Debbie Webb and Margaret Moss

More pictures from Steve Jobar's Race Day



Steve and Paula Palmer with Dottie at the lunch.



Shaune Munday, therapist Amanda Munday, Ray and Ruth Dalfsen.

Artist's delight to be painting again

Talented artist Derek Hince was forced to give up painting when his hands became too weak because of MND.

Now he can enjoy his passion once again thanks to a gadget which enables him to hold a paintbrush or crayon.

Derek, a former art teacher, and wife Sally shared their delight when they brought his latest work in watercolour and a scrapbook of some of his earlier work to the March Drop-in meeting for all to see.

He said: "The little gadget makes it easier for me to hold the brush and it's still painting which is good."

Up until a few years ago Derek, aged 79, from Purley-on-Thames, was doing commissioned portraits and highly detailed studies of birds of prey. Now he is happy to be painting for his own pleasure again even with a looser, very different style.

He has been able to achieve this using Remap Berkshire's MakeAbility service which provides free, custom-made equipment for people living with a disability or special need.

For Derek painting is a skill shared by all his family. His wife Sally is a ceramicist, potter and stained-glass artist; their daughter Kate Lockhart teaches art and designs cards while grand-daughter Evie, aged 16, recently achieved an A-star and looks like she's heading for an art career.

The family has now kindly offered to support the MND Association by donating prints of this beautiful painting of a robin with Chinese lanterns from Derek and Sally's garden.

Please contact the branch if you would like to buy one or might be able to sell some of them raising funds to help fight MND.

For more information about Remap's work visit: **www.MakeAbility.org.uk**, call 07790 127123 or email: berks.caseofficer@remapgroups.org.uk.

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

Steve's brave bid to help vital MND research

Father-of-three Steve Palmer has been taking part in a clinical drugs trial which could lead to a treatment for other people living with MND.

Steve, from Earley, bravely shared his story with the News Letter to help give a better understanding of the process.

He says: "I hope it encourages other people to become involved with this vital research to help find a cure."

Steve, aged 57, a former electrical engineer in the aviation industry, is now taking a repurposed drug typically used to treat enlarged prostates and high blood pressure.

The drug, terazosin, has shown promise as a potential new therapy for motor neurone disease, according to a study using zebrafish, mice and stem cell models. Experts have demonstrated that the drug protects against the death of motor neurons by increasing their energy production. Now scientists at the University of Oxford are running a feasibility study into the drug's effect in MND patients.

Steve, who was the 25th participant out of 50 in the trial began talks with Professor Kevin Talbot and his team at the John Radcliffe Hospital in January 2023. He says communication with all the neurology team was outstanding.

Steve has outlined the process here:

Visit 1: Initial assessment was in February 2023. This checked medical history and medication being taken. The doctor also listened to chest, measured my blood pressure and took urine and blood samples which were all tested within an hour. Eligibility to join the clinical trials was confirmed to allow the next stage of the assessment process.

- Edinburgh Cognitive and Behavioural ALS Screening (ECAS) questionnaire.
- ALS Functional Rating Scale (ALSFRS-R) questionnaire.
- Forced Vital Capacity (FVC) spirometry test. This test measured the strength of the intercostal muscles & diaphragm.
- Blood samples: these samples were taken specifically for the study to be analysed for biomarkers of ALS.
- Lumber Puncture: collection of spinal fluid CSF which is carried out under local anaesthetic.
- Urine sample: this sample was taken specifically for the study.

Steve says: "After a long day and on successful completion of the above process I was issued with a three-month supply of the clinical trial drug which commenced with 1mg increasing to 2mg, 5mg then 10mg.

"Care calls with the study doctors were carried out at the end of weeks 1, 2, 3 and 4 to ensure that the trial drugs were safe and not causing any side effects. The neurology doctors at John Radcliffe were very kind, informative and supportive during the weekly care calls.

Visit 2: This visit was three months after the first and involved the same tests and samples being taken as on the first visit, excluding the ECAS questionnaire. A further three-months supply of the clinical trial drug was issued. After a long day I was happy in the knowledge that I was contributing to the MND clinical trial research programme.

Visit 3: This visit was six months after the first visit and involved exactly the same tests and samples being taken as on Visit 2. As this was the final clinical trial visit I felt sad that I had finished the trial as I had enjoyed meeting with the neurology doctors who had always given me great encouragement and advice over the past six months."

Steve still has 'great' three-monthly monitoring visits with the neurology team at Oxford and he continues to take the clinical trial drug daily which is now prescribed by his GP. He has not received any feedback on its success so far.

Information about the clinical trials and the repurposed drug involved can be found at:
https://www.ndcn.ox.ac.uk/news/repurposed-drug-could-help-patients-with-motor-neuron-disease

Jane Gilbert



Steve and his wife Paula pictured with all the family proudly wearing their medals at the finish of the London to Brighton Cycle Ride for the MND Association last Summer.
From left to right; Steve's sons Charlie and Ben, nephew Scott, Matt (daughter's boyfriend), nephew Thomas, daughter Emily, brother Mark, and sister-in-law Diane

Surprise! - a Day for Ray

When "all-round legend" Ray Dalfsen joined his friends for a day at Newbury Racecourse he was totally unaware that a race on the afternoon's card was named after him.

Now Ray, who is living with MND, says the big surprise will live with him forever. And he can't thank his friends enough for treating him to such a memorable day in his honour.

Ray, from Tilehurst, who was still buzzing afterwards said: "What a wonderful day at the races with great people and true friends.

"I can't thank them enough; it will live with me forever. The staff at the races were amazing, so thank you all for a memorable day."

Ray was especially grateful to his friend Shaun Aldridge, who he has known since childhood, and had arranged the 15.10 race in his name – the Ray Dalfsen Mares' Handicap Hurdle.

Shaun was among the group of Ray's friends from school and footballing days who made sure he had the time of his life.

One of them, Chris Millard, said: "It was an incredible day spent with wonderful people and seeing Ray have so much fun was just amazing."

Chris, who recently qualified as an Association Visitor, described his longtime friend and neighbour as an "all-round legend" who completed his celebrity tasks well during the VIP Day on January 23rd.

On arrival at Newbury Racecourse Ray and his friends were shown to the sponsors' lounge - time for a few pints and to place some bets.

Later they headed off to the parade ring and on to the Royal Box with a glass of Champagne in hand to watch the big race.

"Ray had picked a horse out and despite our ferocious cheering, it came in second," said Chris.

"We then made our way to the presentation area where Mr D was tasked with presenting the trophy to the winning owner, all of this on Sky Sports racing!"

Chris also thanked Shaun and all the organisers for a great day and says he can't wait for the next one.



Ray, seated in the middle is pictured in the Royal Box enjoying a glass of fizz with (L-R) Sid Grover, Harvey Richardson, Liam Diggens, Phil Diggens, Gary Baynham, Shaun Aldridge, Kevin Sheppard, Chris Millard (seated) and Dave O'Riordan.

Other members of the party who are not in the picture include Jimmy Aberdein, John Brady, Ian Slade, Ian Bedwell, Paul Slatter, Albie Stevenson, and Craig Pottinger.

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





A while ago, someone, I think it was the late - and much missed - Colin Moss, began compiling quizzes for the Christmas/New Year Teas/Lunches. When he moved from the area I took over from him. Some people said my quizzes were too difficult, so I tried to make them a *bit* less taxing, without making them *too* easy. As there's always a prize for the winning team it would be self-defeating if every team scored the maximum. In addition, if you know the answer to a question it's easy, if you don't it's difficult. Therefore, one person's difficult question is another person's easy one!! Just as a test I gave my son a a copy of the last Christmas quiz for him and his friends to attempt. They scored 40 out of a possible 50!!

More recently I began to include quizzes in the Newsletters. As with the annual quizzes there were some people who complained that they were too difficult, so I decided to change the format: I dropped the general knowledge questions - which you either know or you don't - in favour of more 'lateral-thinking' type questions. As it wasn't necessary to produce an instant answer I thought people would enjoy taking time to ponder the answers. It's the reason ***I*** enjoy doing cryptic crosswords. I thought people would enjoy the challenge. Apparently I was wrong!! At the September drop-in it became apparent that some people *still* want to be able to answer the question instantly. I went home very upset, decided not to do any more quizzes and e-mailed Jane Gilbert and Mary Davidson, the two lovely ladies responsible for the Newsletter telling them of my decision. They persuaded me to continue.....for the moment



So why the picture of me in the guise of Lord Kitchener? Well, I have still decided that at my age - I was 80 in January - I don't need the hassle. I therefore hope that one of you can take over compiling future quizzes - and you don't mind the criticism. So many people kept telling what I was doing wrong and what I *should* be doing that there should be no problem finding a replacement!! Will I miss it? Of course I will. I've enjoyed compiling them. I'm just sorry that people didn't seem to enjoy doing them as much as I enjoyed setting them.....so, your branch needs you.

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

Lily's London Marathon challenge for her beloved dad

Well done to Lily Pearce who took on the tough challenge of running the London Marathon raising nearly £5,000 even before the big day on April 21st.

For Lily, aged 24, from Bradfield, near Reading, it's a cause very close to her heart as her dad Paul was diagnosed with MND last year.

She says: "Considering I have never run more than 5k before, this will be my toughest challenge yet."

Lily, who works as an events co-ordinator, for a national charity, is kindly donating all her funds to the MND Association's Reading and West Berkshire branch.

We can't thank her enough for this wonderful support.

Check out her story and donation page here:





https://www.justgiving.com/page/lily-pearce

Jane Gilbert

Kim's Easter fundraiser was Egg-cellent



So many eggs! The Easter bunny made a bumper delivery of tasty treats to the residents of Purley Park Trust near Reading, in March.

And we are very grateful to branch committee member Kim Facer and her fantastic team who helped to raise £406 for local families affected by MND.

Cakes, coffee and a raffle were also part of the fun morning organised by Kim, who is employed at the charity which supports adults with learning disabilities.

Committee member Kim Facer is pictured second from right with her lovely helpers from Purley Park Trust all wearing their MND T shirts.

Double trouble at the Art Café!



The Dream Team – (From left) Katie Cooper, Barrie Wells, Mei Tan, Linda Green and Barry Dodds

The Art Café was blessed with a brace of Barries lending a hand at the lively Art Café morning in March.

And events co-ordinator Mary Dodds will be making sure volunteers Barrie Wells and Barry Dodds will be wearing their pinnies next time!

Not surprisingly, the Dream Team had a fun time at the popular community cafe in Whitchurch-on-Thames and almost ran out of cake.

Organiser Katie Cooper said: "We raised a fantastic £339 for branch funds – it was lovely to see so many locals, friends and family coming together."

A massive thank you to our dedicated cake bakers and hard-working volunteers for their support in making the Art Café such a great success.

We'll be back with delicious cakes, coffee and a raffle at **The Old Rectory Stables, High Street, RG8 7DF, on May 25th from 10.30-12.30**.

Jane Gilbert



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

Dates for 2024:

21st May
2nd July
13th August
24th September
29th October

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,

Jacqui's Easter cake and plant sale keeps on growing

Loyal supporter Jacqui Warbey's popular Easter event was another huge success raising nearly £1k for branch funds.

She put her green fingers and culinary skills to good use once again in memory of her beloved husband Richard, who died of MND, aged 56, in 2017.

Here Jacqui, from Woodley, shares how she worked her magic:

My Cake and Plant Fundraising sale was held on Easter Saturday again this year. I was really worried about the weather as the date approached given all the rain and strong winds we have had. Clearly, someone is looking out for me as it turned out to be the best day of the weekend with some blue sky and sunshine but, even more important, no rain or gusting wind.

I always give my friends and neighbours plenty of options to help me out. Some lend me tables, some bake a cake, others donate plants, some come and help on the day, some allow me to park my car on the drive and others just come and spend money!

With Easter being quite early this year, it was also a bit of a panic to get the plants ready on time. My tomato seeds were sown back in January with the hope the plants would be big enough to sell. Luckily my friends and colleagues once again donated plants that they had nurtured from seedlings or from cuttings.

We had about twenty different cakes include gluten free, dairy free, a vegan option and several slimming world recipes. Friends had also kindly donated prizes for a raffle – a sure way to make extra money.

It took about two hours to get set up on the day with help from Lin Jenkins, and my sons James and Christopher Warbey. We had barely finished when the first eager customers arrived to get the pick of the plants.

The morning rush saw lots of people, many staying to enjoy a cuppa and a slice of cake. Several people decided to buy a second slice to take away.

Most of the publicity was via Facebook with people sharing the post to other groups and we had a fabulous turn out. It was great to catch up with someone I had not seen for about ten years and one of the raffle prizes was won by a lady who had worked for me as a temp over twenty years ago.

It was a successful community event which has raised £953 and, hopefully, another £350 from my employer Vodafone's matched funding scheme.





Jacqui's son James proudly wearing his MND T-shirt

Many thanks to my sons, James and Christopher, and to all those who helped out on the day or contributed in some other way. I already have a promise of plants and cakes for next year!

Jacqui Warbey

Cheers to The Walkaholics and Wine!

Congratulations to Panda Phelan and friends Debbie Hobbs and Gill Mead aka The Walkaholics and Wine!

They nailed the London Winter Walk Half Marathon in January raising more than £1k for the branch in memory of Panda's mum Linda Wells, who died of MND last year.

The trio took four-and-a-half hours to complete the 13-mile challenge including a necessary half-hour stop for tea and foot plasters.

Footsore and weary they let the train take the strain back to Reading while celebrating with a welcome glass of fizz.

Panda said: "Mum always found fun and positives in the hardest of days. We shall forever be grateful to the MND Association and the support they gave Mum and our family."

Jane Gilbert



Panda in the centre, with friends Debbie Hobbs (left) and Gill Mead proudly show their medals.



A celebratory glass of fizz on the way home

Howabout one of Terry's Reading Walkabouts?

If you fancy a guided walk of Reading's history, culture and its people, then Terry Dixon's your man. And this year you will also be taking a Walk to d'feet MND.

Terry started to show off his hometown in 2016 and raise money for local charities offering an amazing twenty different themed routes.

From now and until April next year big-hearted Terry will be donating all his proceeds to the MND Association's Reading and West Berkshire Branch and children's literacy charity ABC to read.

Most walks are easy two/three miles and take up to two-and-a-half hours depending on the route. Terry charges £5-£10 per adult, £1 per child over 5 and £12 for a family of four.

You can find Terry's Reading Walkabouts on Facebook or check out his webpage here:

www.readingwalkingtours.co.uk

Ray of Hope Begonia is blooming lovely

MND legend Rob Burrow has a rose named after him. And now Reading's Ray Dalfsen has a begonia growing in his honour.

The specimen bloom called the Ray of Hope Begonia has been officially registered after being chosen by Ray and his wife Ruth.

Ray, from Tilehurst, is also the inspiration behind the successful Ray of Hope MND fundraising event which returns this August thanks to an amazing team of his friends.

Committee member, David Ling, said: "Everyone loves Ray. The idea came into my head when I was watching a TV programme about Rob Burrow who has his own rose and I thought we could do that."

David, who was Ray's manager at Peppard FC in the 1980s, reached out to his brother-in-law Phillip Champion, who is the British champion begonia grower. Now the Ray of Hope begonia is in production and can be seen on the Facebook page Phils Begonias.

Phil has posted the special bloom saying: "In honour of an old footballing friend Ray Dalfsen who has been diagnosed with MND, a seedling named Ray of Hope."

Delighted Ray was amazed when he heard about the tribute bloom.

"It's such a privilege," he said, "especially from an old friend I haven't seen for years. I feel very overwhelmed – I can't thank him enough."

Phil is now bringing on more and more of the special begonias which will be available to buy on the Ray of Hope MND Family Fun Day and Walk on August 17th.

Follow Phil's growing from greenhouse to show bench on Facebook here:

https://www.facebook.com/Phil.Champ44

Jane Gilbert



The wonders of nature - from knobbly tuber to a lovely healthy plant and finally this beautiful flower. Well done Phil and David!





Ray (centre) with Rona and David Ling



Birthday celebrations (and an AGM) at March Drop-In

This was a particularly significant drop-in as I had recently resumed my role as chair of the branch (Interim Chair they call me).

At the committee meeting in January it was decided that there should be an AGM. Although no longer obligatory for branches, a greater number of interested people attend a drop in so that's the obvious place to have an AGM. So we did! There were about 50 people in the room (committee, plwMND, families, friends, companions, supporters and volunteers). What a great turnout!

This was a brief AGM! Thanks were given to the team who kept the branch going and who work hard to provide support, care, events and funds for all those, in our patch, who have Motor Neurone Disease. All this is made possible by the wonderful work of our supporters and volunteers who raise funds to provide whatever is needed by those living with MND.

The branch treasurer gave a summary of the financial position describing the branches restricted funds as well as the current funds. Restricted funds are those reserved for a particular purpose and described as such at the time.

At the end of the financial year 50% of unrestricted branch assets/funds are transferred to the National Association for research or care. See more detail from our Branch Treasurer on the right.

There was a significant 80th birthday to mark – a small birthday cake, a plant and a card were presented to Dottie Channing-Williams as the assembled crowd sang Happy Birthday.

Margaret Moss

Branch Treasurer's summary

2023 was a very good year for donations and fund-raising activities which amounted to £67.5K in total.

The branch spent £29K of which £22K was "care-related" outgoings and £7K was for operating costs.

This left the branch with a surplus for the year of £38,500.

Taking account of branch transfers to head office of £46K, this surplus turns into a cash deficit of £7,500 for the year.

The branch's bank balance at end-2023 was a comfortable £182K with £106K of this being held as restricted funds (basically the Sheila Hamblin legacy).

The 2023 annual transfer is calculated as £38K. So, the general funds available to the branch at the start of 2024 is £38,000.

Ed Gryglaszewski



Would you like to help?

If so there is an ideal opportunity for you to get more involved with branch activities.

We need a Minute Secretary - someone who can attend bi-monthly committee meetings which take place on a Thursday evening at 7.30pm in Calcot and then write up and distribute the minutes. That's it! Nothing too onerous but it is an excellent opportunity to become part of a friendly, successful and dedicated team who give their time to benefit people living with MND and their familes and friends.

If you would like to volunteer or just have an initial chat with somebody about this position please email contact @mndrwb.org or phone 07760 854975

A full season ahead for Fundraiser Lin

Although the season is only just starting up, the grass hasn't been growing under my feet. I have been doing as many events as possible with some indoor and a few outdoor car boot sales.

We had a really successful jumble sale at Grange United Reformed Church in Southcote on 2nd March. It was just a short, sharp two hour event, with my usual little band of helpers. When the doors opened we had quite a queue – always a good sign. Three of my friends, from other charities also brought a stall. By the end of the day we had over 60 paying adults through the doors and we took almost £300 on the day, which I am thriiled with. Thank you everyone who helped or attended.

I also had a lovely afternoon at the Community Hub in Coronation Square, Southcote on 16th March when the Easter Bunny made a rare appearance. My washing line game was very much Easter themed.

The main fund-raising season is off to a squelchy start. As I write all fields and parks are totally waterlogged, with the first few events already in jeopardy. Despite this, I have planned a full programme again this year - if the weather DOES pick up.

While I attend car boot sales when no other events are on, I try to book as many fetes and fairs as possible. For those I generally have a washing line game, which is like a tombola, but with a prize every time (some large and some smaller). As you can imagine, I need loads of prizes. I also run a variety of "Green or Eco Days" where I recycle old tools, gardening equipment, bird boxes etc. My favourite events are probably retro stalls which I take to country and steam fairs. Anything "old fashioned" features on these stalls, and people come looking for my pitch each time.

A key event in this year's calendar is the Ray of Hope MND Family Fun Day and Walk, on Saturday 17th August, at Westwood Club and Recreation Ground in Tilehurst. This is the BIG ONE. We need prizes for lots of stalls like a tombola, my washing line game, and a lucky dip as well as those for the variety of events which people compete for throughout the day. Bottles of alcohol are required for the Booze Cruise Tombola (we sold out last year!).

There are also plans for a large handicraft stall, and we have a small army of people making items. We'll be selling raw materials, too, for all the crafters out there and any unused items would be appreciated.

So, as you can see, our begging bowls are large!



On top of all that, we will need as many helpers as possible to set up, run stalls, and pack away at the end.

Please contact me or the branch if you can help and check on Facebook for up to date details and requests.

Thank you!

Lin Jenkins

Editor's note: For those who don't know Lin has been invited to a Garden Party at Buckingham Palace next month so look out for her in her finery in the next newsletter.

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

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



PLEASE NOTE THE REVISED DATE

The day kicks off with the walk at 1.30pm and the fete opens at 2.00pm

For more information or to make a donation scan the QR code or go to www.localgiving.org/appeal/rayofhope/

The 3rd Micky Denny Memorial Golf Day

also has a new date - now 5th October

Wokefield Park Golf Club, Goodboys Lane, Mortimer, RG7 3AE

WI funds will help fight MND

Our tireless Fundraiser Lin Jenkins and Association Visitor Wendy Gouldthorpe were given a very warm welcome by Tilehurst Triangle Women's Institute (TTWI) when they spoke about MND and the Branch's work at the group's recent AGM.

WI member Carole Seymour, who lost her father to MND, had nominated the Branch as its Charity of the Year for 2023. Thanks to this support and generosity, Lin and Wendy were delighted to receive a cheque for £900.00. The pair were able to explain how the funds would be used to support people locally living with MND and what a difference this could make to their quality of life. The importance of supporting carers was also stressed, something which resonated particularly with Carole who had cared for her father in his final months.

Fund-raising efforts included the sale of raffle tickets, teas and coffees at the monthly WI meetings together with personal donations. WI member Sue Jones also organised a very successful skittles evening at Tilehurst Bowling Club and, thanks to her powers of persuasion, both the venue and the barman for the night generously agreed to waive their fees!

Wendy Gouldthorpe



Lin Jenkins and Wendy Gouldthorpe receive the cheque from W.I. members Ginny England and Carole Seymour (right)

Some dates for your diaries

17th - 19th May	Fawley Hill Steam and Vintage Festival, Fawley, Near Henley-on-Thames RG9 6JA
25th - 26th May	Island Farm Donkey Sanctuary Country Fayre, Old Didcot Rd, Brightwell-cum-Sotwell, Wallingford OX10 0SW
30th June	Thatcham Family Fun Day, Henwick Worthy Sports Ground, Thatcham RG18 3BU
7th July	Theale Summer Fete - to be confirmed
19th October	Thatcham Leisure and Craft Day, The Broadway, Thatcham

Branch Contacts

Chair
Margaret Moss
contact@mndrwb.org

Secretary
Kerrie Newton
secretary@mndrwb.org

Branch Contact
07760 854975
contact@mndrwb.org

Publicity
Jane Gilbert
contact@mndrwb.org

Events Coordinator
Mary Dodds
events@mndrwb.org

Treasurer
Ed Gryglaszewski
treasurer@mndrwb.org
07973 875506

Newsletter
Mary Davidson
mary@rfdg.org.uk