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motor neurone disease association

Reading and West Berkshire

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News Letter

Golfers' £6k round in memory of 'big' friend

Generous golfers at a club near Reading have hit a fantastic winning putt of more than £6,000 to boost the MND Association's funds.

The surprise news came after Micky Denny's Memorial Golf Day on October 1st at Wokefield Park Golf Club.

Friends of the 'big character' rallied together for a day of golf and fundraising on what would have been his 64th birthday. Dad Micky, a popular golfer, footballer, and card player from Earley, died of MND in July.

Best pal and co-organiser, John Mann, said: "We decided to have some sort of Remembrance Day for Micky.

"I remember the day he told me that he had MND. It's a cruel disease. He never complained, he was so inspirational.

"Micky was a big character before he was diagnosed and a big character afterwards. There were more than 700 people at his funeral."

John said Micky had been a good sportsman, 6ft 2ins tall and weighing about 18 stone before his weight eventually dropped to nine stone.

"Seven of us played poker together every week and eventually he couldn't use his hands and needed help, he said.

"I will never have a friendship like it.

"The only way we can make it right is by donating money. Our target was about £3k and we have doubled that which is really good".

John and his friends Tony and Alison Stanley meticulously planned the golf day which raised a similar amount for Club Captain Dave Cooper's charity.

Eighty-eight golfers, including Micky's son Oliver, played a round of 18 holes and 160 people enjoyed a dinner, auction and raffle in the evening. They included Micky's wife Nicky and some of his work colleagues from energy firm SSE.

John said everyone pulled out all the stops and thanked golf course owner De Vere Wokefield Estate and its director of golf Jamie Anton for their generosity.

In 2019 Micky inspired his firm's biggest ever charity fundraising campaign at its Thatcham and Reading offices which resulted in a £5,373 boost to the Association.

Some of the cash was raised at a Wokefield Park golf day where Micky was made an honorary member when he was unable to play because of MND.

John and his fellow golfers were due to present a magnificent cheque to the Reading and West Berkshire Branch volunteers on November 5th.

Jane Gilbert



Micky Denny at a Wokefield Park golf day for MND in 2019



Co-organiser John Mann (far right) with (from left) Craig Smallbone, Stevo Smith and Adam Spires.

Rock'n'Ale – still rocking 10 years after!

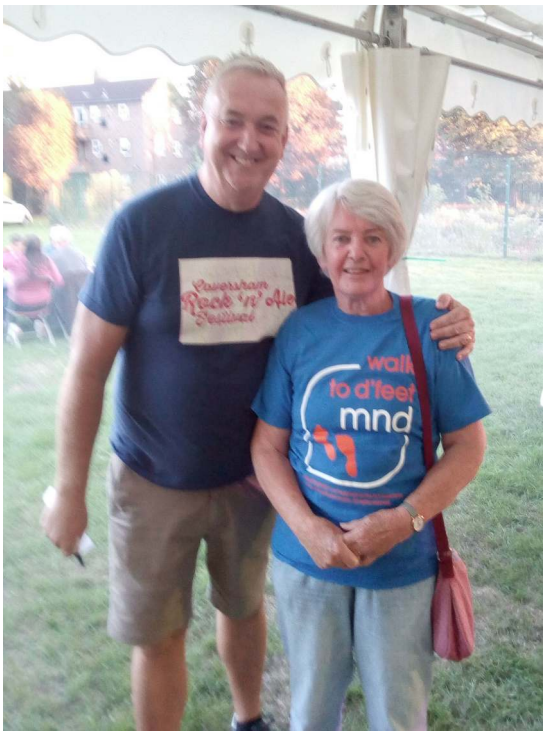
This year's tenth Caversham Rock'n'Ale Festival has raised a fantastic £2,500 to help local families affected by MND.

Former branch Chair Margaret Moss went along in September to listen to the bands and joined in the fun.

She writes:

On a late summer's evening on a school sports field, Rock'n'Ale worked its magic once again!

Crowds drifted in, more than five hundred tickets were sold, and others, probably another hundred, made their way later. The queue for drinks was much improved by The Last Crumb's efficient service but was outdone by the one for food; good natured and patient – hog roast or chilli – but just as popular as ever. An amazing atmosphere pervaded as everyone mellowed in the late evening's sunshine.



One of the organisers Damian Colehan with Margaret Moss

Then, the bands and the dancing began (sort of dancing in some cases); the evening was off to a great start. There was perfect weather, plenty of seating, entertainment for the children and what a goodly number of youngsters there were – a real family and community event.

It was all in aid of the MND Association Reading and West Berkshire Branch. The originators were friends of Angela Fung who died of MND. Angela had been supported by the branch which had never expected such a return.

Organiser Mike Ryan, his mates, and contacts, put on a fabulous evening's entertainment raising awareness of MND in a most understated way.

Our thanks to Mike and all his wonderful team for their commitment and continuing support!



'tis the season to make a difference

There are some great volunteering opportunities to join a wonderful group of people making such a difference across Reading and West Berkshire #MND

The branch urgently needs helpers across a variety of roles to continue its vital work at the same effective level.

Have you thought about joining our branch committee? "It's very rewarding," says Jane Gilbert, who has been part of the Dream Team for 22 years.

"We decide how all the fantastic funds are allocated and can make a difference to the quality of life for people living with MND.

"An essential part of the team's work is to make sure we can offer support to both affected families as well as fundraisers and events organisers who reach out to us.

"This is now proving more difficult without an events co-ordinator. We also need someone to take the minutes at monthly committee meetings and a person who has perhaps retired and would like to eventually become branch Chair. Food for thought . . .

"It's been fabulous to see how effective the branch has become with awareness of MND at an all time high. Now we need to build on this success."

Interested? You don't need personal experience of MND; just a can-do attitude and willingness to get involved with other volunteers.

For more details contact: secretary@mndrwb.org

Bucklebury rolls out the barrel for MND



Cake anyone? Jan Gryglaszewska, Chloe Hawkins, Mary Dodds, Jane Gilbert, Paddy Lunn and Ed Gryglaszewski ready to serve



John Brims, Chair of the Victory Room Trustees (centre) with L to R Chad Williams, Jane Gilbert, Publicity Officer, MND Association Reading & West Berkshire Branch, Dini Hunt from Berkshire Women's Aid and Clinton Clay.

Cheers to the organisers of this year's sell out Bucklebury Beerfest!

And thank you to all our wonderful helpers in the tea tent as well as those who drank the West Berkshire village's recreation ground dry.

Cheques for £1,000 each were recently presented to the MND Association Reading and West Berkshire Branch and domestic abuse charity Berkshire Women's Aid.

Branch publicity officer Jane Gilbert said the awareness raising had been fantastic too with volunteers out among the crowds as well as serving teas in the adjoining hall.

"We are very grateful to the organisers, The Victory Room Trustees, for this wonderful opportunity," she added.

More than 1,000 pints of beer and 200 pints of cider were sold at the event in August as well as all the burgers, raising a total of £3,500. Live music and trade stalls also kept the crowds entertained.

Jane Gilbert



Kim Facer, Jane Gilbert and Mary Dodds roll out the barrels

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**

Motor Neurone Disease: A Personal Story



I knew nothing about Motor Neurone Disease or the work of the Motor Neurone Disease Association until my apparently fit and healthy partner started having falls and was eventually diagnosed with MND. That was in March 2018 and, at the time, we were singing in a choir which was also attended by one of the visitors for the MND Association Reading and West Berkshire Branch. Her help and support, with that of the branch, as we set out on this unexpected and frightening journey was wonderful.

As John's mother had died from MND he had a clear idea of what was coming and remarkably set about preparing for future developments. He treated it as a project and one of the first things he did was to bank his voice since losing the ability to speak can happen early in the disease. Fortunately, John never needed to use this. He got his bathroom converted to a wet room, had a through the floor lift fitted, changed his car to an automatic which could be changed to hands only drive as he lost the use of his legs. Then there was the 'carbuncle' fitted to the roof of the car into which a wheelchair could be folded and lifted. Ramps had to be built to enable him to get in and out of the house once wheelchair bound. Eventually he had to get hoists fitted to help us get him up or move him from wheelchair to recliner.

He remained amazingly positive while he was working on all these developments, but the disease was gradually taking away his independence. For John it was his legs which weakened first and just over six months from diagnosis he was using a wheelchair most of the time. We were still managing to get out and about and go away; John was even still going to his choirs. It wasn't until the middle of 2019 that he felt that his voice was weakening, and he could no longer sing. We spent a lovely week in Devon in October 2019 but a month later he lost power in the muscles of his neck and needed to wear a support collar which was very uncomfortable and made it difficult for him to eat. Things seemed to deteriorate quickly from this point as his breathing became compromised and he needed various machines to help him. Everything was becoming a trial and in early 2020 MND finally took his life.

MND manifests itself in different ways, sometimes taking the voice first, sometimes the hands or as in John's case the legs, but it is always relentless and frightening. The support we got from NHS specialists was excellent and the Motor Neurone Disease Association supplemented this in a warm and friendly way which was invaluable.

So, I was delighted when I heard that the local branch of the Association is one of two charities which will share donations made at the 'Deck the Halls' Christmas Flower Festival at the Falkland Islands Memorial Chapel 26th and 27th November. It seemed particularly appropriate when I heard that the lead designer of this festival was one of John's close work colleagues. So, like me, why not visit this festival so that others who live locally and suffer from this devastating disease can receive the same support that we did.

***Sandie Harwood*, Upper Basildon**

Are you up for the 7 in 7 challenge?

Almost 700 people have been inspired by MND Association patrons, Rob Burrow and Kevin Sinfield, to take on their own 7 in 7 challenge.

Click here to join the team: mndassociation.org/7in7.

You'll be raising money to help families who are affected by MND to get the help and support they need when they need it most, Raise over £77 and you'll earn an exclusive 7 in 7 : Reloaded medal.

Complete seven runs, walks or bike rides over seven consecutive days. You could run a mile every day or 7k a day – it's your challenge, your choice. Join the team to raise money to support families affected by motor neurone disease and help fund vital research in the fight against MND.

Deck the Halls – Christmas Flower Festival

Deck the Halls – Christmas Flower Festival at the Falkland Islands Memorial Chapel 26th November, 10am-5pm and 27th November, 10am-4pm. The festival will be stunning, complementing the wonderful building in which it will take place. There will be over 70 exhibits each depicting a Christmas carol or song. Refreshments will be available in the Pangbourne College Café. There will be a Children's Quiz and some exhibits will be available for sale by silent auction. Entry will be by donation and all proceeds will be shared between the Reading and West Berkshire Branch of the Motor Neurone Disease Association and the Falkland Islands Memorial Chapel Trust, which this year held a special remembrance service commemorating the 40th anniversary of the 1982 Falklands War.

This festival is organised by Berks Bucks & Oxon Flowers, which is a group of 36 local flower clubs which are part of the National Association of Flower Arrangement Societies.

For more information about the area see bbandoflowers.org.uk or scan this QR code to take you directly to a page which has more information about the flower festival.

***Shirley Sexton*, BB&O Flower Media Officer and Lead Designer of 'Deck the Halls'**

If you are unable to come, you can make a donation via: justgiving.com/team/deck-the-halls-flower-festival

Christmas is coming …

Christmas is just a few short weeks away and this is a reminder that you can buy your MND Association cards through the branch.

Three of the cards available are shown here but, if you would like to view the full range that we have available, check out our branch Facebook page www.facebook.com/mndrwb/ or contact Mary Dodds via email promotions@mndrwb.org.

I can post the Christmas Cards to you with postage and packing added to the cost of the cards.

And don't forget that you can also benefit the branch by saving your used postage stamps!

Supporter Jill Gaisford has a buyer for them and raises funds for the Association throughout the year. Jill collects ALL stamps and asks for them to be removed from the envelope leaving about 1cm around them taking care not to damage the stamps. You can contact Jill on 01635 868 834 or by email to jmg1520@gmail.com.

Mary Dodds







35 years on – a time of reflection

We came together to reflect and give thanks for HRH The Queen while marking 35 years of continued support for local families affected by MND.

The branch's anniversary event at Purley Barn on September 10th was a more sombre affair than planned as it came just two days after the end of Her late Majesty's 70-year reign.

It included an homage to her legendary tea with Paddington in volunteer Jacqui Warbey's brilliant teddy bear hunt. A minute's silence was also observed.

COP26 President Alok Sharma, who had planned to attend, sent his apologies as he was called suddenly to parliament.

The branch decided to go ahead with its event, attended by many families affected by motor neurone disease, and a fantastic £1,258 was raised.

Linda Allen, the Association's Director of Fundraising, met volunteers, including branch founder Mary Dodds, and people living with MND – some of whom were meeting our 'dream team' for the first time. For one visitor, it was his only time out of the house, other than to hospital appointments, in a year.

The organisers are indebted to guitarist Simon Williams, who lost his mother to MND, for playing some great tunes, all the star bakers and the huge team of helpers involved both before and on the day.

They felt sure The Queen would have very much approved of the branch carrying on with its vital work.

Jane Gilbert



The MND Association's director of fundraising Linda Allen with Linda Wells, who is living with MND









Publicity Officer Jane Gilbert with Mike Foster, who is living with MND, his daughter Sarah and wife Lin. Can you spot that Goldie Bear even has his own QR code for giving donations to the branch?



Panda Phelan was kept busy painting faces

And they were off . . . to a race night with glitz and glamour

Wedding anniversary couple Lesley and Louis Feinberg turned their celebration into a fabulous £2,500 fundraiser with all the glamour of Royal Ascot.

The sell-out race night at Wokingham Cricket Club on October 1st was held in memory of Lesley's brother Peter, who died of MND in 2018, aged 50.

Their mum Doreen has been a regular supporter of Lin Jenkins's stellar work for the Reading and West Berkshire branch and they decided the funds should be spent helping other local families affected by MND.

Lin donned her Ascot attire and went along to join in the fun with Association Visitors Wendy Gouldthorpe and Debbie Webb.

"My goodness, what an evening we had," said Lin. "So much work had gone into this. Not only were there eight races to bet on, but each race was sponsored, and each horse sold to an owner. As a mark of this each owner wore a rosette.

"We were asked to dress as if going to Royal Ascot. I didn't realize this offered so many options! Yes, posh frocks and hats, morning suits etc. But we had stable lads, trainers, and one jockey, all in a wonderful range of outfits.

"On top of the races we had an auction, large raffle, and a Heads and Tails game which Wendy came close to winning.

"Outside (and for free!) there were hot dogs, pizzas, chips and ice creams, all donated. We did have to pay for our drinks, but they were reasonably priced, leaving more money for funds."

In her opening speech Lin told the racegoers how she got involved with the MND Association - there was a large poster on display featuring her brother-in-law Alec, who is living with MND, and his wife Chris. Alec's legendary sponsored Shortest Walk in Reading's Forbury Gardens proved an emotional story, added Lin.



Lesley is pictured here with two tote sellers



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

About that night . . . .



Jacqui Warbey and Linda Green have eyes for a bargain



Helpers Helen Varley, Kerrie Newton and Linda Pearce



Pretty in pink Macy Gray

It was a feast of fashion, fun and frolics in aid of two great causes – the MND Association Reading and West Berkshire Branch and Sue Ryder Duchess of Kent Hospice.

Hats off again to the dynamic duo Lin Jenkins and Jeannie Briant as well as the glamorous models, helpers and all the fashionistas who bagged some amazing bargains.

As compère Dr Alison Talbot said: "It's a life affirming evening for two charities close to my heart."

Lin and Jeannie, a fundraiser for Sue Ryder, decided to ring the changes after their successful summer fashion show and laid on some entertainment from flamboyant stage performer and singing coach Derry Pope.

Derry, from Pangbourne, was piped into Theale Village Hall with the other models on October 18th by Michael Barnes of Reading Pipe Band.

Lin said: "We most certainly had a fun evening attended by about 80 people with sales of just under £700 and we did lots of networking. Derry was wonderfully entertaining and had us in stitches.

"Due to illness our models had been dropping like flies before the night and Danielle Jenkins, Macy Gray, Linda Green and Derry all did a wonderful job"

Dr Talbot, a former Associate Specialist at Duchess of Kent Hospice, introduced the models who wore an array of donated outfits, some still with their shop labels.

Many of them were sold later at bargain prices while others will go into next year's fashion show and sale planned in the spring, this time in Tilehurst, near Reading. A raffle, refreshments, stalls selling Avon, Body Shop, handmade cards and MND Association Christmas cards, all helped to swell the proceeds.

Stop Press: Lin and Jeannie have now donated some of the left-over winter coats to the people of Ukraine.

Jane Gilbert



Well hello!



Danielle Jenkins is Ascot ready

A holiday postcard from Deborah and Ray

We're delighted to hear that our free holiday prize draw winners Deborah and Ray Hayhurst had a great time in Cornwall.

Deborah, who is living with MND, and her husband and carer Ray, were out every day enjoying the sea air and West Country attractions.

Ray said: "We both loved Cornwall and are very grateful."

The free week-long stay at Tudor Lodges in Looe (www.tudorlodges.co.uk) was kindly gifted to the branch by the owners Michael and Julia. It followed a review in the Newsletter by Alec Jenkins, who is living with MND, and had a great time staying there.

Ray said: "Deb really enjoyed it and we were very lucky with the weather. The Eden Project was great, really accessible."

The couple, from Earley, were joined by Ray's sister Deb and Deb's sister Judy who, he says, were a great help. Pasties, fish and chips, ice cream and Cornish ale were all part of the experience, of course.

Ray said: "Tudor Lodge was excellent, it covered everything we needed with a hoist, wet room, accessible bedroom, profile bed and pressure mattress. Mike and Julie were very accommodating. I'd certainly recommend it."

He is also delighted to have had a good cycling break in Mallorca recently thanks to a Carer's Grant funded by the branch.

Ray added: "I loved getting back on my bike for the first time since May.

"I managed over 200 miles and about 14,000 ft climbing in four days of cycling, I was quite happy with that but, my word, I'm not as fit as I was two years ago.

"I really felt the benefit though, feeling relaxed and rested when I got home."

Below are some of Ray's pictures taken at the Eden Project and on his Mallorcan break.

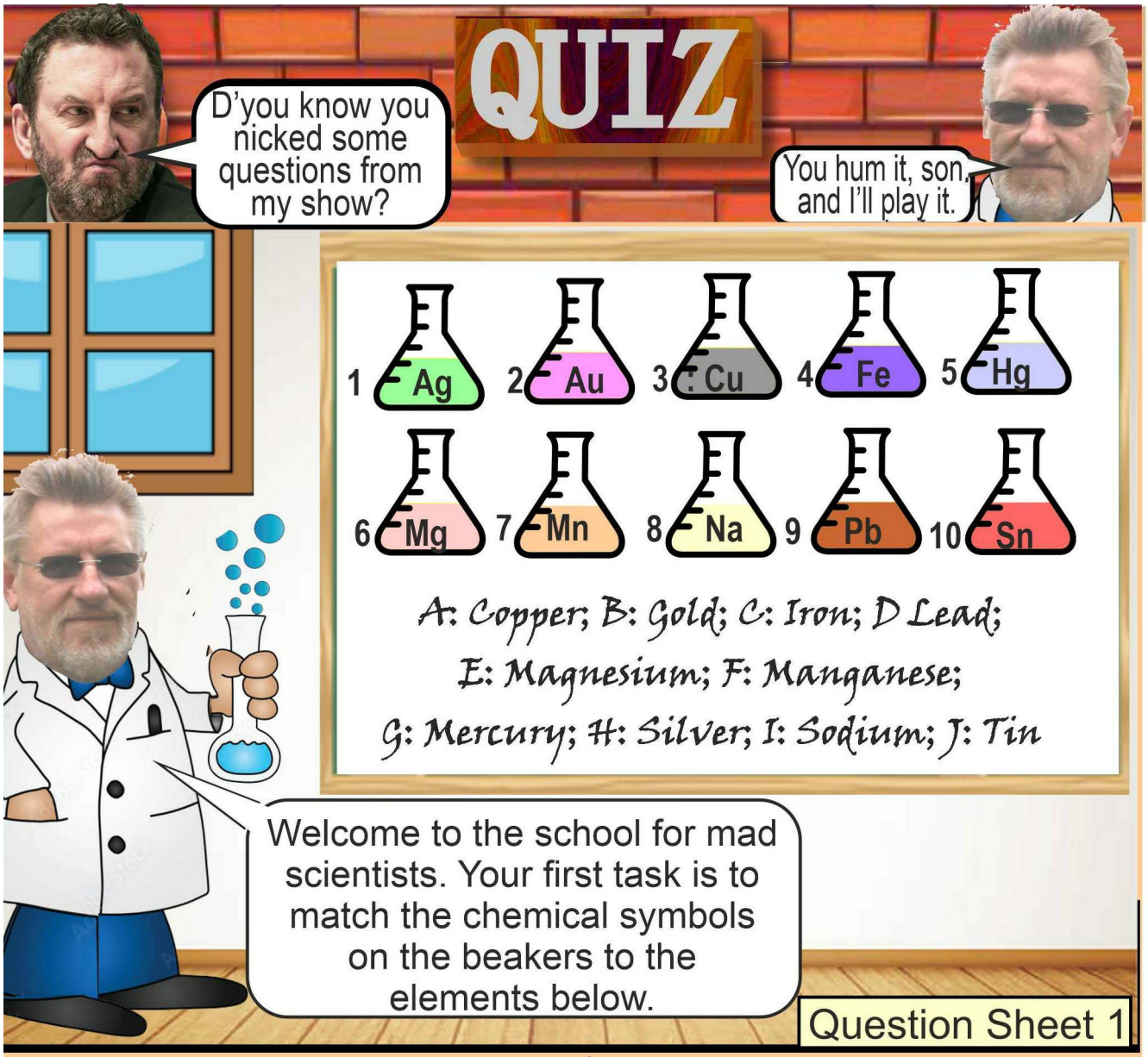
Jane Gilbert

Editor's Note: Carer's, Quality of Life and Support Grants are some of the ways the Association can make a difference to families affected by MND. People can apply for this funding via their Association Visitor or by contacting the branch directly.



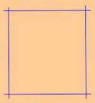
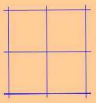






11: What do the following have in common? [a]:  ; [b]:  ; [c]:  ; [d]: 

12: Which singers real name was/is Henry John Deutschendorf Jr? [a]:Jack Jones; [b]:John Denver]; [c]:Harry Connick Jr; [d]: John Legend

13: Crack the code: [a]:  = 4; [b]:  = 1; [c]:  = ?

14: Which leader reportedly said: "It is true that liberty is precious - so precious that it must be rationed"? [a]: Adolph Hitler; [b]: Vladimir Ilyich Lenin; [c]: Mao Zedong; [d]: Fidel Castro

15: If the 3rd of March, the 8th of November and the 9th of September are all the same, then what in October is also the same?

16: How many pets does Tess have in total if all except two are cats, all except two are rabbits and all except two are hamsters?

17: Fill in the blank: Jessica is Mandy's only sister. Mandy is the ___ of Jessica's sister.

18: John was born on 29th of February 1980. As of 1st January 2022 how many birthdays has he had?

19: What number between 1 and 100 has the most syllables when said out loud?

20 What well-known three-word expression is this? **THODEEPUGHT**

Question Sheet 2

Footnote: Please excuse the **very** old joke at the top of the page. *Alec Jenkins*

Lin is our hero!

Our A-mazing Lin Jenkins has triumphed again by raising an incredible £8,500 to help in the fight against MND.

The cash comes after Branch Fundraiser Lin, from Tilehurst, worked tirelessly most weekends selling donated items at fetes, fairs, and car boot sales from October 1st, last year, whatever the weather. She even joined the salvage team again down at the very grim aftermath of this year's Reading Festival and braved a scrap metal yard trading in unwanted electrical cables amongst other things.

Now, Lin has delighted the committee by giving half of her funds to be spent on supporting local people living with MND. The remainder will go direct to Professor Kevin Talbot's research fund at the University of Oxford.

Lin was "very impressed and inspired" after attending an open day at the clinical neurosciences department before the Covid pandemic.

She wrote to Professor Talbot: "Recently, seeing all the publicity on progress being made in the research into MND, I have decided that half of the money raised this year should go to you, with the remaining half going to my branch."



Lin presents her cheque to Branch Treasurer Ed Gryglaszewski watched by some of the branch committee.

Lin's valuable research donation will allow the team to support promising PhD students and to explore exciting and more high-risk ideas providing pilot data for large grant applications.

Watch this space to see what fantastic fundraising ideas energetic Lin comes up with for next year!

Jane Gilbert



Answers to quiz on Page 10

1: H, Silver; **2**: B, Gold; **3**: A, Copper; **4**: C, Iron; **5**: G, Mercury; **6**: E, Magnesium; **7**: F, Manganese; **8**: I Sodium; **9**: D, Lead; **10**: J Tin
11: They are homophones for letters of the alphabet: B, P, Q, J; **12**: b: John Denver; **13**: 9: It's the number of times that lines intersect; **14**: Vladimir Ilyich Lenin; **15**: 7th: It's the position of the letter 'r' in each month; **16**: 3; **17**: Name; **18**: 1, the same as everyone. The rest are anniversaries of the birthday; **19**: 77 - 7 is the only single digit number which has 2 syllables; **20**: Deep in thought

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

Paddy's Bakeit!

Star baker and committee member Paddy Lunn is back with her legendary cake and card sale in Sonning Common on Friday, November 18th, from 2-5pm.

She has also been busy making marmalade and chutney as well as producing more beautiful cards illustrated by her husband Rod, who died of MND.

For more details contact secretary@mndrwb.org.

Christmas Tea-time

Everyone is welcome to join us at the

Branch Christmas Tea
on December 6th, 2.30pm-4.30pm
at the 17th century Purley Barn,
RG8 8DR.

RSVP secretary@mndrwb.org or call 07760 854975.

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.

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You shop. Amazon gives.

Sign up to AmazonSmile and you can support the MND Association as you shop, at no extra cost to yourself.

The Association is excited to partner with AmazonSmile. By signing up to shop via AmazonSmile, you'll still be able to enjoy the same range of products and prices just like you can with a regular Amazon account.

However, you'll now be able to select the Association as your chosen charity – which means that 0.5 percent of the price of every eligible product that you buy will be donated to the association. This will have no effect on the price that you pay.

Shop and support the MND Association today:

1. **Sign up for AmazonSmile via smile.amazon.co.uk.**
2. **Search for the 'Motor Neurone Disease Association' via the charity lookup.**
3. **Select us as your AmazonSmile charity of choice.**
4. **Look out for products which are marked as "AmazonSmile eligible".**

Enjoy your shopping!

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