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motor neurone disease association

Reading and West Berkshire

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News Letter

Colin's special birthday delivery

We were unable to have a celebration party for my 70th Birthday due to Covid-19, so my wife Shan sneakily and, unbeknown to me, contacted all my Facebook friends. My brother also phoned a few more of my old football mates (not on Facebook) from our Western League double-winning Devizes Town team of 1972-3, who I still meet up with occasionally.

This resulted in a remarkable response and I was shell-shocked and humbled at receiving so many birthday cards (126 in total) containing lovely messages, plus a similar number of Facebook message posts. I even received two beautiful 3-D cards from Japan from ex-work colleague friends.

I have emotional lability due to MND affecting part of my brain that controls my emotions, so some messages brought tears to my eyes and Shan even got emotional reading some of them out to me.

It was beyond my wildest dreams that I would reach the age of 70, when I was diagnosed with MND aged 51, way back on that fateful day of January 28th, 2002. I even have the most common form of MND, affecting both the upper (in the brain) and lower (in the spinal cord) motor neurone activity.

My neurologist can't really explain my very long survival, other than to suggest it must have tended to affect mainly my upper motor neurones.

I have taken 5000mg of natural vitamin E capsules daily, ever since a week or two after my MND diagnosis, based on an article my sister-in-law read at the time in a Sunday newspaper by the actor Joss Ackland.

Joss's wife was in the latter stages of MND and out of desperation was taking that huge daily vitamin E dose based on the report of a German doctor (Dr Carsten Hager), who claimed it had stabilised his own MND and a proportion of the others he had suggested it to and monitored.

Hager's report of over 20-years ago had indicated that some of the people living with MND who he monitored had long survival whilst others had died, so even he wasn't suggesting that it may help stabilise everyone. I think one possibility is maybe it's only effective if taken very early in the disease progression.

I must hastily add that a subsequent **clinical trial on this dosage of Vitamin E concluded** - **no significant effect on survival rate**.

Also, I have no way of knowing whether the vitamin E has slowed my own MND progression or whether I have just been one of the luckier ones, but I continue taking it.

Hager's report was available on the internet for a few years but it appears to have been removed now, although I found references to it.



Tributes pour in for our shining star



Tributes have been pouring in for our brilliant team leader who has stepped down after an incredible 20 plus years of sterling voluntary service.

Now Margaret Moss' outstanding contribution to the MND Association's work has been marked with flowers and many heartfelt messages.

Sally Light, chief executive of the Association, praised her for making such a positive difference to so many people in Berkshire affected by MND.

She wrote: "Carers, families and friends, as well as people living with MND, have benefitted significantly from the work you have done with the branch."

Former treasurer Barry Clouting, who sadly died in April, had also written earlier in the year praising her for "doing an amazing job" with "truly remarkable dedication".

Margaret had intended to stand down as chair in March at the AGM and was thwarted by both the coronavirus pandemic and the lack of a successor.

Thankfully, our dedicated secretary Jane Westwell has nobly stepped up to fill what she describes as "some very big shoes" and Margaret will remain part of the management team.

The branch was regrettably unable to arrange a group presentation recently as face to face meetings are still not allowed for Association volunteers due to Covid-19.

However, Margaret is pictured here with flowers and a gardening gift sent from all her friends on the branch management committee. A surprise bouquet of flowers from the Association also appeared on her doorstep in Caversham, near Reading.

Afterwards, she spoke of how touched she was to receive so many lovely messages adding: "I am so proud of my team."

When the branch Facebook page announced Margaret's retirement it prompted favourable comments from people living with MND as well as families she had supported during the past 20 years.

She replied: "I was not able to speak to all my friends in the branch MND family when the AGM was cancelled due to Covid-19. So now I have this opportunity to do just that and to appreciate all the kind messages.

"It is very pleasing that so many of you have expressed your appreciation of my work over the last 20+ years - it would not have been possible without the amazing team I was working with. I thank them all, the branch committee and supporters as well as all the branch family.

"I have enjoyed working for this worthy cause and It has given me much satisfaction and pleasure to be involved with such a flourishing branch. I am staying around so I will be seeing you at drop-in meetings and events when they all start up again.

"Meanwhile, I leave you in very good hands and know that Reading and West Berkshire branch will continue to work for a World free from MND."



Lin's good news from the fund-raising front

Amazing Lin Jenkins recalls here how even the pandemic has had a silver lining resulting in her incredible record amount of £8k raised for branch funds.

"It has certainly been a year that none of us will ever forget. Much sadness, loneliness and confusion, but, at the same time, such lovely stories of people helping and supporting those around them. Truly inspirational. A new expression has been coined - "doing a Captain Tom", and many of us have joined this movement!

As my events diary became decimated, and the word 'cancelled' appeared multiple times I panicked. What would I do with a whole year's worth of stock? So, I came up with my Garden Gate Community Stall, and we soon set out a target of 100 sales in 100 days. (This eventually kept going for 134 days).

I have some lovely retro items, indeed most decades from the 20th century. These were for numerous V.E. Day events and Steam Fayres etc. Sadly, this still sits in storage and will be used in future years.

No Reading Festival Salvage for me this year. For the first time in about eight years I have no folding garden chairs in stock!

I had boxfuls of odd and damaged china which were all ready for Chapel Row Fayre as well as two suitcases full of teddies earmarked for Padworth Fete. A shed full of garden tools, equipment etc for the Green/Eco Days filled the upstairs room in our annex from floor to ceiling as well as prizes ready for my famous Washing Line Game.

Luckily, I was able to sell masses at my garden gate community stall and car boot sales which started up a couple of months ago. However, with everyone sorting their cupboards and outhouses, and most charity shops closed (and even now only taking limited items) I cannot begin to tell you how much stock has come in this year!

I sold a staggering three quarters of a ton of books and have made numerous trips to local scrap metal dealers.

My husband Paul's elderly cousin passed away in May and we sold the contents of her house, with the proceeds split between the MND Association and a donkey sanctuary. A few things have gone to the auction House and I am building contacts now with dealers whom I deal with directly – things like lamps, cameras, vinyl records and small, solid wood furniture.

All in all, it has been a challenging year, but I am happy to report that I have closed with a record figure of £8,212.00. My season usually ends with the final fete of the summer! (This has also helped to keep my own personal Gremlins at bay).



Lin's garden gate Hallowe'en stall was a spooktacular success

As I write this in mid -October I am planning a Christmas Sale on my driveway in Overdown Road, Tilehurst, Reading, from Friday 20th – Sunday 22nd November. Hopefully, there will be other charities involved running their stalls in local drives and gardens. So far we only have three and lots more would be nice. If we get enough interest Santa may even pop in to see us!

For the next few months we are looking at "alternative ideas - things that can be flexible for both the weather AND Covid -19.

I am currently working on some treasure trails – both walking and vehicular. I will sell these clues and routes for a certain figure. These can be done in your own time and in whatever size groups are allowed at the time. Most, if not all, will end at a pub for a drink or a meal.

I do hope that you are all keeping safe and well both physically and mentally. Christmas and New Year might not be how we usually celebrate it, enjoy them anyway - make the most of every little thing.

See you all in the New Year!

Lin Jenkins

Jacqui's green fingers help our funds to grow







Green-fingered Jacqui Warbey has been helping our depleted funds to grow by selling plants to her local friends and neighbours.

She spread the word with a post on social media and left the cuttings with an honesty box at the end of her drive in Woodley near Reading. All the plants quickly sold and raised a total of £90 for branch funds.

Jacqui writes:

"My friends and family had been very generous in donating to my Teddy Tales and 60 Miles for Richard fundraisers this year but I recognised that if I were to raise further cash in 2020 my supporters had to receive something in return.

I like gardening and realised that if I divided some of my plants and potted up self-seeded primroses as well as some of the excess plug plants I had bought, I might be able to raise funds. I had lots of old flower pots so all I needed was some compost and time.

The next challenge was where to sell them. I live in a quiet cul-de-sac although a few people cut through on their way to the local convenience shop or local school. It occurred to me that I could put the plants at the end of my drive with an honesty box and signs to explain that I was fundraising for the MND Association plus use Facebook to reach out to my local friends to let them know I was selling these plants.

I moved an old rickety bench to the end of my driveway. I had previously turned some old tins into collection boxes for a different fundraiser and now I made some extra holes in the tin so I could wire it to the bench. I now had an honesty box that could not just be grabbed by someone walking by – they would have to cut the wire or spend time untwisting it.

I handwrote some signs, added some MND Association stickers and put the signs inside plastic folders to protect them from rain before fixing them to the bench.

Timing was key. I had mainly plants for winter displays so I knew I needed my friends to see my post before they had spent a fortune at a garden centre. It seems to have worked well and, as an employee of Vodafone, I should be able to double my total through the matched funding scheme. I am now considering what cuttings I can take and which plants I can divide for another sale in the spring."

Since then enterprising Jacqui has been busy making re-usable Christmas gift bags to order in aid of the Association. Sadly, she cannot take any more orders for this year although has plans to repeat the idea in 2021.

The branch is very grateful for Jacqui's dedication to our cause during these tough times and thanks her friends and family for their support too.

If Jacqui has inspired you let us know and if we can help with any fundraising items please email ReadingMND@hotmail.com.

Christmas Cards?

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

A few of the cards available are shown here but If you would like to view the full range of Christmas cards we have available check out our branch Facebook page https://www.facebook.com/mndrwb/ or you can contact Mary Dodds via email MaryDodds@mndrwb.org.

And don't forget that you can also benefit the branch by saving your used postage stamps! Supporter Jill Gaisford has buyers for **used** postage stamps and so raises funds for the Association throughout the year. Jill collects ALL stamps – contact her on 01635 868 834 or by email to jmg1520@gmail.com.



Lantern
10 cards - £2.95



Happy Hedgehog
10 cards - £3.50



Noel & Tree
10 cards - £4.00



Sleigh Ride
10 cards - £3.25

amazonsmile
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:

Sign up for AmazonSmile via smile.amazon.co.uk

Search for the 'Motor Neurone Disease Association' via the charity lookup

Select us as your AmazonSmile charity of choice

Look out for products which are marked as "AmazonSmile eligible"

Enjoy your shopping

To date Amazon UK has donated a total of almost £10,000 to the MND Association out of a total of about £4,500,000 given to UK charities, so come on everyone, sign up and see if we can increase our share.

Generous golfers' winning rounds

Golf club captain Simon Rogers notched up a winning year of fundraising despite the coronavirus pandemic and heavy floods which closed his course.

Thanks to him and the generosity of fellow golfers at Wokefield Park near Reading the branch has now been given a £4k boost which could not have come at a better time.



Simon chose the MND Association for his captain's charity last year in support of popular player Micky Denny who is living with MND.

Micky's friends quickly rallied round to help raise funds and awareness after his diagnosis. One of them ran the London Marathon and others gave generous donations at the annual Captain's Day. When events were cancelled due to Covid-19 Simon had to come up with ingenious ways, including fines, to get them to part with their money.

He said: "The course was closed for four or five months due to flooding so we had a double whammy which impacted on how much money we could raise."

Not surprisingly he was recently delighted to send our treasurer Ed Gryglaszewski a cheque for £4,170.

Our picture shows Simon (far right) with Micky Denny at last June's Captain's Day with the Branch's volunteers Mary Kaye and Wendy Gouldthorpe.

They had been sitting by the tee for the twelfth hole handing out bottles of cold beer in return for a donation!

Jane Gilbert

Rob Burrow: My Year With MND

Following the documentary on Rob Burrow, a former Rugby League player with Leeds Rhinos, as he battles MND, there has been a fantastic response, raising some amazing awareness.



- More than 3 million people have watched the documentary either live or on BBC iplayer (it is still available on BBC iplayer)
- Over £45,000 in donations have been received
- Almost £26,000 was raised through the text to donate code
- 2100 new followers on our social media channels
- 3000% increase in traffic to our website on Sunday
- Tweets by Clare Balding, Sir Kier Starmer, Zoe Ball, Stuart Broad and Sally Nugent
- More than 60 sign ups to the Yorkshire Three Peaks Challenge following in Lindsey's footsteps.

Our Christmas cheer is virtually here

We have very much missed getting together with our MND family at drop-ins and other events this year. Guidance from the MND Association is that we should not be meeting face to face for the time being so we'd like to arrange some virtual drop-ins via Zoom where people can catch up with each other from the comfort and safety of their homes.

The first virtual drop-in will be in early December and we thought we'd make it into a bit of a Christmas celebration by organising home delivered cream teas or a non-food gift to local people living with MND with the option to join us for a virtual get together. If you are living with MND or supporting someone, please look out for further details coming your way by email or post.

Jane Westwell

There is an area support meeting on 25th November 2020 at 11am via Zoom - please join if you are free. If you are interested in finding out more about these meetings but unable to attend this session please contact Adele Petcher on adele.petcher@mndassociation.org or 01604 800610.



Wednesday 25th November 10:00 on Zoom

Talk to people who understand the impact of Motor Neurone Disease. Find out what services are available locally and how the Association may be able to help you.

https://zoom.us/j/94715942026?pwd=WEtHK0IlaWZmTWtmTnhPUlVqRmlGUT09

Meeting ID: 947 1594 2026

Passcode: 1

If you have any questions please do contact Adele Petcher, Area Support Coordinator, 01604 800610, adele.petcher@mndassociation.org

If you need any help with how to work zoom please do get in touch.

www.mndassociation.org
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A warm welcome to these bright new faces

Welcome to our two new committee members, Kerrie Newton and Andrew Wall.

Kerrie has nobly stepped forward to take on the role of branch secretary and will be organising meetings and booking drop-ins when they are able to resume.

Some of you will recognise Kerrie who volunteered for the branch back in 2003-2006 before heading for the USA where she spent 14 years. Her beloved dad George Pearce, who died of MND, enthralled us all at the AGM back in 2004 with a talk on his metal detecting exploits.

Now Kerrie, a busy mum-of-two young children, has returned to Newbury where she lives with her husband and family.

Andrew, who has been our "go to" on all IT matters, will take on the new role of membership secretary and will be dealing with the mailing list and database tasks.

We are delighted to have their skills and enthusiasm – the extra help will enable our former secretary Jane Westwell to become the new branch chair.







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 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.

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