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motor neurone disease association

Reading and West Berkshire

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News Letter

Our hero Lin is A-MAZ-ING!



Mary Dodds, Lin Jenkins, Jane Gilbert, Margaret Moss, Jane Westwell, Russell Spivey, Barry Dodds

Many congratulations to big-hearted Lin Jenkins who has raised nearly £6,000 through her relentless hard work during the coronavirus pandemic.

Our volunteers turned out in their MND T shirts to surprise Lin on her 100th community sale in 100 days outside her home in Tilehurst, near Reading.

They said: "We are truly astonished at the amount of MND awareness raising Lin has been doing single-handedly and are very grateful for the generous donations from all her many supporters.

"She is a legend in her community – and ours!"

Lin was given a massive socially distanced round of applause as well as a well-deserved bottle of whisky by the branch committee.

The MND Association's regional fundraiser Russell Spivey also presented her with a Certificate of Appreciation for such an awesome achievement.

Lin started selling donated items from her driveway and garden when all the fetes and fairs she had planned to attend this year were cancelled due to Covid-19.

She was overwhelmed by support from her community saying: "I believe we have all helped each other through one of the most difficult periods of our lives".

Lin has no plans to shut up shop just yet and will continue her garden stall on a smaller scale until August 16th – her 150th day.

Don't think she will be putting her feet up; as lockdown eases our hero is also attending three car boot sales a week and organising a house clearance sale! (see separate story on page 5).

She said: "We want to go out with a bang on August 15th and aMaNDA the bear should be making an appearance again. We also have half the proceeds of Cousin Betty's sale to come, so fingers crossed for a record year."

For the record, Lin's community stall had raised £4,443.00 as the Newsletter went to press and her fundraising total for the season so far stands at £5,909.00.

What a star!

Jane Gilbert

Police probe charity's £120 loss

Police are investigating after a man drove off without paying for £120 worth of items being sold to raise cash for the MND Association.

Fundraiser Lin Jenkins asked her husband Paul to take a note of the car registration number when she became suspicious about the driver's behaviour.

He had visited the community stall at her home in Tilehurst twice before when he paid for all the items he bought.

She said: "The third time he came and stayed for such a long time. There was something about him that I didn't trust."

The loss came as a big blow to Lin who was so close to reaching her 100th sale at the time. She has been told by the police that a man in his 60s has been arrested for another similar alleged crime and investigations are continuing.

Registered Charity No 294354

My life under lockdown

Inspirational Alec Jenkins from Newbury has been living with MND for 22 years. He writes here, with his renowned humour, about the ups and downs of being shielded.



"I have been asked to write an article about my life under lockdown.

We are far luckier than many others: we live in an extended property in which both floors are fully self-contained. My wife (whose name continues to elude me) and I live with our son downstairs, whilst our daughter, son-in-law and our two grandsons live upstairs. The fact that our son and son-in-law are both called Phil does lead to a bit of confusion.

The good thing about living like this is that our grandsons can come down to see us whenever they like. The downside is that our grandsons can come down to see us **whenever they like**! Seriously, it's great that we get to see the whole family every day. Our son and our daughter both work from home whilst our son-in-law is furloughed.



I have to admit that, coming from a long line of cowards (I'm joking about my forebears), COVID-19 does scare me, especially when I see just how stupid some people are: as we saw with the crowds on Bournemouth beach recently. Many seem to have no idea about 'social-distancing' - they seem to think that two metres is about two feet. I am aware that, should I contract the virus, my chances of survival are slightly less than my chances of getting the lead in the next super-hero film!

On hot sunny days I am 'forced' to sit out on the patio either sipping an ice-cold cider or licking an ice-lolly. The cider is Swedish - Rekorderlig - and I order it online in a case of 15 bottles. The ice-lollies are frozen rum Mojitos. If this continues I may decide never to come out of lockdown!



However, when the weather is not so good I can usually find things to do in the house to pass the time. I read quite a lot - my favourite non-fiction books are about guitars (I used to play) or the history of native Americans and my current favourite novels are the Jack Reacher books by Lee Child; I do cryptic crosswords; I spend a lot of time on my laptop (e-mails; downloading/organising music; getting to grips with a new text-to-speech programme; playing around with pictures and text on a programme called Coreldraw to produce things like the quizzes that I compile from time to time and t*his* article); I've made a couple of jigsaw puzzles, one of which was a 3D of a German castle, or should that be a schloss? I was particularly pleased that, after about 22 years living with MND, my fingers can still manage something like that.



I said at the start how lucky my wife and I are to be able to mix with our immediate family. Unfortunately it's a bit of a double-edged sword: as we move out of lockdown we will have to return to self-isolating as our grandsons return to school and our son, daughter and son-in-law return to work, particularly if others don't observe social distancing. I recently left my premises for the first time since we first started social distancing - even before the official lockdown - and took a spin round the block in my wheelchair which I call my 'cripmobile'!

I am lucky in other ways; I haven't had the problem of needing a carer. My wife was working as a carer and then when she retired she took on her most demanding charge - me! It means I get **exemplary** care. Jane Owen, the clinical nurse specialist for rare neuro conditions,has arranged for my next consultative appointment to be via Zoom, which I recently installed on my laptop. My local pharmacy delivers my many pills and potions, and we have a weekly Sainsbury's delivery slot, so we don't need to go out. On top of that, as I was missing Caffe Nero's frappe lattes we bought online a frappe/milk-shake/smoothie maker plus the various ingredients. So now I've got my own Barista!

I want to finish on a serious note: I keep hearing that things/people will be better when it's all over. I wish I shared that optimism. Unfortunately, Soho and Bournemouth have shown that too many people are as selfish and thoughtless as they ever were. Their overriding thought seems to be for the flights to 'get back to normal' so they can get away on holiday again and two fingers to the environment!"

Alec Jenkins

AV's award for her unstinting support

A former dedicated volunteer for the MND Association's Reading and West Berkshire branch has been honoured after chalking up an impressive 16 years of service for the charity.

Association Visitor Joanna Knott received a prestigious Paul Harris Fellowship from the Rotary Club of Newbury for her tireless work visiting people affected by motor neurone disease in their homes.

She trained for the important volunteer role after retiring as a local speech therapist and was also a leading member of West Berkshire Neurological Alliance.

Joanna, who now supports families in Devon where she lives, described her award as an "incredible honour."



Joanna is pictured with the award pin and a certificate signed by the International President of Rotary

She said: "I am rather embarrassed as I feel there are several others within the Association's Reading and West Berks Branch who have done considerably more than me. However, I would like to accept this with my heartfelt thanks on behalf of all my colleagues who have done so much for so many people living with motor neurone disease over the past 20 or more years."

The award was posted to Joanna due to the Covid-19 restrictions by Chris Philip, Newbury Rotary Club's chair of International and Foundation, who is herself a Paul Harris award holder.

She said each year Rotary members can nominate others who have reflected the club's motto of Service above Self.

"It's our way of saying Thank You for thinking of others. It is quite prestigious to have one."

Joanna's award coincided with Volunteers' Week in June which is an annual celebration of the contribution millions of people make across the UK through volunteering. The network of MND Association volunteers provides support, help and signposting to people living with the disease and their families and carers.

If you would like to know more about volunteering locally in a variety of ways for the MND Association, please email: ReadingMND@hotmail.com.

For more information about MND and the MND Association please visit www.mndassociation.org

Jane Gilbert

Voice banking in a pandemic?

If you want to bank your voice then we can help, even in the middle of Covid-19, by lending you a headset microphone and giving you remote help to record your digital voice. There is no need for face to face contact.

You can create a digital version of your voice by recording 350 short sentences using Acapela's website for their "My Own Voice" software. All the cost is covered by the MND Association. The process is easy, and you can start and stop at any time. Your completed voice can then be downloaded into software that is usually recommended by your speech and language therapist.

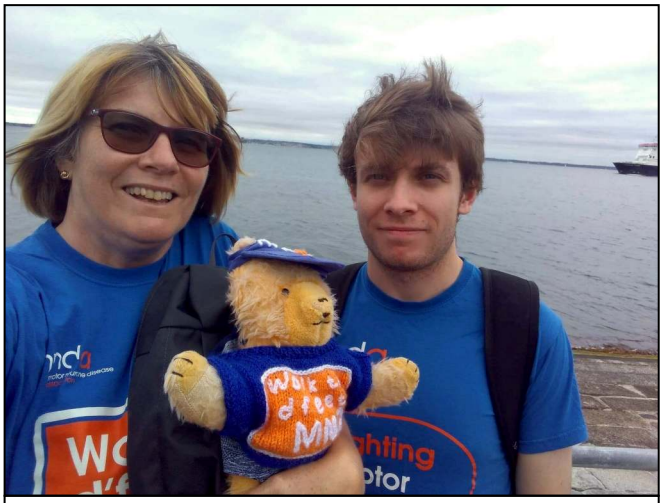
All you need is a good internet connection, a reasonably up-to-date PC or Mac and a headset microphone. The built-in microphones are not up to the job, so it is essential to use a USB headset microphone. If you can watch films on Netflix then your internet connection is fast enough to bank your voice using the online software. And that's it - simple.

For more details check out this video on YouTube: https://youtu.be/0WLs7iZuPNY

If this is of interest, then please contact our local Voice Banking volunteer Michael Morrison via the branch email address: ReadingMND@hotmail.com.

Michael Morrison

60 miles for Richard



Jacqui and Christopher with Goldie the bear

Supporter Jacqui Warbey was determined not to be beaten when her fundraising plans were scuppered due to Covid-19.

She and five of her family had hoped to be walking 60 miles between them around the main lake at Dinton Pastures in May to mark her late husband Richard's 60th birthday.

Now Jacqui and her son Christopher are doing a series of shorter walks from their Woodley home to raise vital funds for the Reading and West Berkshire branch.

They will be accompanied once again by Richard's old teddy bear Goldie dressed in his Walk to d'feet MND knitted top.

Jacqui said: "I'm fundraising again. As other MND Association events have had to be cancelled or postponed your donation is even more important this year.

"The Association helped me and Richard through his illness so I want to do my part and ensure that other families continue to receive this support."

A big incentive for Jacqui is that her employer Vodafone will match her funds and she can apply for up to £350 each quarter.

She said: "I have just had a letter confirming that £350 is on its way to the branch after my Teddy Tales' fundraiser on social media." Christopher is also hoping to get match funding from his bosses at healthcare company GSK.

Jacqui created her delightful Teddy Tales in memory of Richard who died three years ago from MND aged 56.

During Lockdown she was unable to run her usual cake sale and raffle at work and decided instead to post photos on Facebook of her cute teddies dressed in various outfits to make people smile.

During the second half of July Jacqui and Christopher will be walking six to eight-mile routes locally as their Guernsey holiday was cancelled. They will be joined on some of them by Jacqui's other son James and, as a smaller group, they are aiming to minimise the Covid-19 risk.

Pledge your support to Jacqui and help boost our funds here:
www.justgiving.com/fundraising/jacqueline-warbey2

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 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: ReadingMND@hotmail.com **Tel: 07760 854975**

Generous legacy from 'Cousin Betty'

This lovely woman's family is generously giving half the proceeds from the sale of her house contents to the MND Association's Reading & West Berks branch.

We are very grateful to fantastic fundraiser Lin Jenkins and her husband Paul for this kind gesture in memory of their beloved 'Cousin Betty' who died in May, aged 92.

For many years Paul looked after his cousin and Godmother Betty Morris who broke her hip before lockdown and spent the last few months of her life in a care home.

As the Newsletter went to press Lin was busy organising the clearance and dispersal sale of the entire contents of Betty's house and outbuildings at Cresswell, Goring Road, Woodcote, near Reading. (RG8 0QE)

She said:" The house is being sold and we are selling all the contents mostly from the back and front gardens. I'm hoping the branch will do nicely out of it."



The sale was planned for 24th, 25th and 26th July from 9am-5pm each day.

All the takings were being shared between the Motor Neurone Disease Association which supports Paul's brother Alec Jenkins and the Island Farm Donkey Sanctuary at Brightwell-cum-Sotwell – a cause close to Betty's heart.

Lin was hoping some of our supporters would turn out to help her and Paul with the sale.

For more details contact Paul on 07391 653064, Lin on 07796 783835 or email rlpjenkins@tiscali.co.uk.

Jane Gilbert

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

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

Alec's Lockdown Mini-Quiz

(Answers on page 8)

PUZZLE #1



Jasper Jason works for local radio.

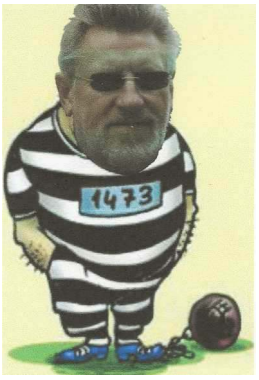
This is his business card.

Can you spot the pattern?

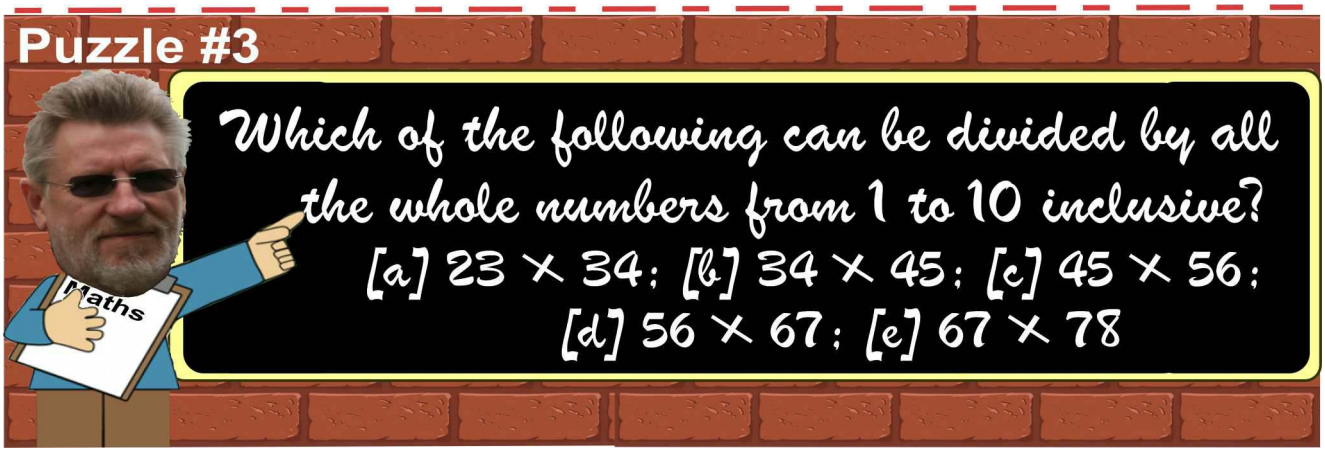


PUZZLE #2

A condemned prisoner was offered a chance of freedom. He was led into a room which had 2 doors. He was told that 1 door led to freedom and 1 to death, but not which, and that one guard would always lie whilst the other would always tell the truth, but not which. He was allowed to ask **one** of the guards **one** question only. He could choose which one. What question did he ask to gain his freedom?



Puzzle #3



Hints: If needed hold page to mirror

H1: Count the number of letters

H2: Right + wrong = wrong

H3: If a number is divisible by 5, for example, and you multiply it by a whole number then the answer will also be divisible by 5. Start by eliminating any one (s) it can't be

Outgoing branch chair Margaret Moss looks back on her remarkable 20 years at the helm



As you know I have been chair of the branch for 20 years and decided it was time to look back and to celebrate this period. I have met and worked with a lot of great people. The majority have been closely connected to or have been affected by motor neurone disease. This has created a common bond and I think that it is from this that the phrase 'the MND family' was coined.

I joined the group initially to find out about MND as my brother had been diagnosed in Newcastle upon Tyne. Lady Hallifax was a leading figure at that time - she had an amazing talent for recruiting likely souls and that has continued over the years.

Another key person was Dr Monnica Stewart, a retired geriatrician with her own physical disability, who was a moving force in the branch. It was under her influence with John Holt of the West Berkshire Neurological Alliance that the post of Nurse Specialist in Rare Neurological Conditions was initiated and funded, partly by the branch, for a two year pilot before being taken on by the Royal Berkshire Hospital Trust. Other committee members have come and gone and all contributed to the success and high standing of the Reading & West Berkshire Branch which is highly regarded and recognised by the Association.

Over the years branch activities and ideas developed.

Perhaps you can remember some of these?:
The Thank You Lunch held at Ufton Court initially which became a two-yearly regular event; successful drop-In meetings; summer tea parties, at first in the Canoe Club in Caversham and latterly at the Burghfield Sailing Club; open meetings with interesting speakers; the moving Free Spirit balloon release with actor Simon Williams; a collection and race day at Newbury Race Course; Welford Park Snowdrop Sunday; various events at Englefield House including the garden open day, the branch's 25th anniversary in the Long Gallery, the Association's 30th anniversary lantern event in the grounds of the stately home with actor Joss Ackland, the branch's 30th anniversary in St Mark's Church and the Long Gallery – all thanks to the generosity of the Benyon family; pub games at Avington Manor Tithe Barn; the Royal Berkshire Show (10 years on); Caversham Rock'n'Ale Festival; Chapel Row Charity Fayre; Alec Jenkins and Colin Moss's 'Shortest Walk' in Forbury Gardens; 'Cycling for Brian' in Palmer Park; a conference for GPs and health care professionals (because many GPs know little about MND); conferences for carers; barge trips on the Kennet & Avon Canal with The Rotary Club of Newbury; the open day at Reading University's Harris Garden; the 'Fighting for Life' play; Christmas teas and lunches ..... and many other events which have kept our volunteers and committee members involved and strong.

When I joined the branch, the Newsletter was a simple two-page occasional happening and now look at it - a regular eight or ten pager! There is a website, an active Facebook page and a Twitter account with dedicated volunteers who look after all these.

Alongside these events the valuable Association Visitors have done amazing work, of course, supporting, in a practical way, families affected by MND. We will always need these special people!

And all this without mentioning the individuals, friends and family of those living with MND, who ran their own events raising awareness and funds either for the branch or the Association nationally – all working towards our mission of a World Free of MND.

Thank you everyone – it has been a great privilege to have worked with you for all these years!

Margaret Moss

Editor's Note: Margaret is hoping to hand over the reins this year to Jane Westwell, our current secretary, if a replacement can be found for that role.

Interested? Do contact the branch email for more details: ReadingMND@hotmail.com

We need to hear from people with new ideas and energy to enable us to continue the vital work of supporting local people living with this devastating disease.

Michael tees up funds to help fight MND

Keen golfer Michael Miller will be driving off his fundraising ideas for the branch despite the limitations imposed by the coronavirus pandemic.

Michael, aged 73, says: "It's going to be quite difficult but, not impossible, organising competitions what with all this social distancing business. We'll do our best."

He will be supporting the branch this year during his captaincy at Deanwood Park Golf Cub near Newbury. Michael says it wasn't a difficult decision to choose the Association to benefit from the club's fundraising activities.

"I've lost a few friends to this awful disease. We also have a golfing friend whose husband has motor neurone disease."

The Christmas raffle at the club will go ahead and Michael, who works part time with autistic adults in Newbury, will be finding ways to get fellow golfers to part with their money.

He added: "Between now and then we hope to have the odd competition, these are good fund raisers.

"My wife is making cakes and other delicious delights for the Saturday group which is very generous."

Jane Gilbert



For further information and support contact our **MND Connect helpline** mndconnect **0808 802 6262**

Answers to quiz on page 6

Puzzle #1: The letters of his card are the initial letters all of the months of the year beginning June and ending May

Puzzle #2: The question he asked one guard - it could have been either one - was, "If I had asked the other guard which is the door to freedom which one would he have said". He knew that the door indicated was the door to the gallows, and therefore walked out the other: the door to freedom. (If the guard was the one who always lies he would lie about the answer the honest guard would give. If he was the guard who always tells the truth he would tell you honestly what the other guard would say, but the other guard would lie).

Puzzle #3: c (45 x 56) NB: You do not need a calculator!! Firstly, work on prime numbers. If one of the two (whole) numbers being multiplied is divisible by 5 (ie ends in a 5 or 0) the answer will be divisible by 5. You could therefore ignore a, d & e. Next turn your attention to 7. In the same way if one of the two (whole) numbers being multiplied is divisible by 7 the answer will be divisible by 7. 56 is the only number divisible by 7 (7 x 8). Therefore the answer must be c (45 x 56). You can easily check your answer:

[a] Any two whole numbers multiplied together will be divisible by 1;

[b] 56 is divisible by 8 (7 x 8), and will also divisible by 8 if multiplied by a whole number. If it is divisible by 8 then it will be divisible by 2 & 4, as well

[c] If you add the digits of a number together and the answer is divisible by 9 then that number is also divisible by 9 (4 +5 =9). It's also divisible by 3 and if you multiply it by an even number (56), it will also be divisible by 6

[d] 45 is divisible by 5. When multiplied by an even number (56) the answer is divisible by 10 You've now shown that c is divisible by **1, 2, 3, 4, 5, 6, 7, 8, 9 & 10.**

Could you be the next Branch Secretary?? …

If you have administrative, organisational and IT skills you could be the perfect person to help our friendly and effective team. Our current Secretary Jane Westwell is stepping up to become Branch Chair - when her replacement comes forward!

The Branch Secretary provides secretarial support to the committee to help manage effective communications within this successful Branch.

What does this role involve?

- To prepare, with the chair, agendas for committee and other meetings
- Take notes of branch member's ideas as they arise and make sure they are brought forward onto the next agenda
- To book venues and speakers for meetings
- To respond and deal with all branch correspondence
- To circulate appropriate information to committee members, regional staff and our national office
- To ensure the effective and accurate communication and updating of group information including branch membership list
- To keep and file appropriate documentation
- To take part in branch or Association training and attend meetings as required

You will be a crucial member within the branch team and will be helping ensure that we are keeping accurate documentation.

We are looking for someone to commit to approximately 2-3 hours a week including willingness to attend monthly committee meetings.

Full training and induction will be provided and travel expenses will be reimbursed.

Interested? Email the branch: **ReadingMND@hotmail.com** and we'd be delighted to talk about the role.

… or the Branch Events Co-ordinator??

As you might imagine, any event the branch runs needs to be planned and organised - whether it's the venue, the t-shirts, balloons, the tablecloths, invitations or the myriad other things!

In order that the event actually happens, all this needs someone to mastermind it. Not to **do** it all but to organise and delegate the separate items to individuals - either the committee or supporters.

Those of you who were at the Summer Tea Party or the recent Thank You Lunch will appreciate the work done by our dedicated team. We are very grateful for all that everybody does but things could be so much better if we had an Events Co-ordinator.

As the branch has only occasional events, this is not a full-time job! Nor would it require attendance at the monthly committee meeting; it only requires a person with a tidy and organised mind who wants things to go well.

Could you or someone you know be this person?

The branch has been without an events coordinator for some time now and it would make for the smoother running of events if we could now fill this role.

For further information contact any of the committee on the branch phone 07760 854975 or email **ReadingMND@hotmail.com**

We look forward to hearing from you!

Margaret Moss, Branch Chair

Fundraising during the pandemic (and beyond)

There is no doubt that the Covid-19 pandemic has resulted in a strange three months for most people and been down-right difficult for others. Lockdown and subsequent gradual (socially distant) reopening of our society has also had a profound effect on many organisations in the UK. Charities are no exception, with donations standing at millions of pounds below usual levels because of cancelled events.

Our Branch is no different, with funds down by about one third for the time of year. However, we count ourselves lucky to have the support of some dedicated and inventive people who have continued to raise money to support our activities. I think that Lin Jenkins is an absolute legend, running her community stall for over 100 days and Jacqueline Warbey's "Teddy Tales" brought some fun and laughter during a difficult time. I also really admire the inventiveness of her photos. I'm sure there is potential for a calendar there!

So, what about if your original fund-raising plans were stymied by Covid-19 and you are starting to think about doing something? The MND Association has a supporter information website (https://www.mndassociation.org/get-involved/fundraising/home-fundraising/) with ideas for fund-raising at home or via virtual events. Around the time of the (cancelled) London Marathon, charities launched the idea of fundraising activities on a theme of 26.2. It has been inspiring to see people round the country devising their own "26.2" challenges from 26.2 laps of the garden to walking marathons where individuals pound the streets to complete the 26.2 miles.

A plea to future fund-raisers

If you do decide to fund-raise for the Reading & West Berkshire Branch, please get in touch with us at the start of your plan. We will help with publicity and materials to help you achieve your aim. To help fund-raisers pay money direct to the Branch we have a page on Localgiving https://localgiving.org/charity/rwbmnda/. It is also possible to set up a fund-raising page on Localgiving to collect on-line sponsorship payments.

If you prefer to use a national site such as JustGiving, please make sure that your story mentions that you are fundraising for the Reading & West Berkshire Branch. We hate to ask this so directly but if you want funds to come to us, and don't say so on the fundraising site, we can't receive the money because it would breach the fundraising code of practice. This can be very frustrating for the fund-raiser, or worse, they never know that the money didn't get to us. It also means that we aren't able to express our appreciation for the donation because we don't know about it.

As for me, I'm thinking about my own 26.2 themed challenge. Anyone want to join me walking 26,200 steps one day later this year?

Jane Westwell, Branch Secretary

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