

**OUR NEW PATRON
 WELCOME TANYA ARNOLD**



We are pleased to announce that Tanya Arnold, BBC Look North and Super League Show presenter has agreed to become patron of the West Yorkshire Branch. This picture is from earlier this year when she was with our CEO Sally Light and Leeds Rhinos Rob Burrow at the Leeds Sports Awards. Tanya is keen to support our branch after interviewing Rob following his diagnosis. She will be pledging some miles to support the branch with Mission 5000 later this month.

BIG STEPS OF HOPE



Michael and Jill, together with their children, daughter and son-in-law, 8 grandchildren, and two dogs, completed a 7km socially distanced walk along the Trans Pennine Trail on 3rd August for Big Steps of Hope. The medal ceremony was

curtailed due to a plague of midges!

**MISSION 5000
 SUPPORT THE WEST YORKSHIRE BRANCH**



5,000 people with motor neurone disease. 5,000 miles to complete. A community uniting to cover the distance. How far will you go?

The Association expects to lose over £2 million this year due to the cancellation of community and sporting events as a result of the COVID-19 pandemic. But our fight against MND cannot be delayed. People affected by the disease need our support now, they need their voices heard today. People facing MND in the future need our vital research to continue. That's why we're on a mission, and we need you to join us.

Together we want to cover 5,000 miles, that's a mile for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot however far you can. Every penny you raise will bring us closer to achieving our ultimate mission, a world free from MND. Sign up here:-

www.mndassociation.org/mission5000

YORKSHIRE DAY QUIZ

Thank you to Jenn Dodd for organising the quiz on Facebook Live. It was easy to log in via the link provided, we didn't even need to comb our hair or tidy the room behind us as we could only see Jenn. Good questions too, made us think, not sure who got the most right, we were just challenging ourselves. The Branch benefitted from the £67 in donations so thank you also to those who took part.

LOTTERY COMMUNITY FUND

The West Yorkshire Branch has been awarded the fabulous sum of £5,700 by the Lottery Community Fund to spend on keeping in touch with our members at this difficult time. We are very grateful for the extra funds. Thank you to Jenn Dodd for completing all the paperwork.

DEBORAH MERCER'S LOCKDOWN STORY



I'm 58, married with three sons 21, 19 and 17yrs and we live in Leeds. I'm also a registered nurse but retired through ill health recently as I am living with motor

neurone disease. My husband is a primary school teacher, also retired early because of Parkinson's Disease.

Having lived with confirmed MND as an unwelcome companion for the past year I've found lockdown to be a leveller - everyone is restricted in what they can do. Personally, it's felt like just the next issue to deal with in a continuous stream of things I've had to adapt to. With MND you are best to learn fast how to swing the direction of your thoughts back to the present, don't dwell on what you can no longer do, don't think too far ahead.

I think my boys have the toughest time of it. The essential need for their friends and those summers around 6th form and university so special. The uncertainty about what lies ahead for them. Having to navigate through it all with the pressure to keep us safe. The eldest son in his final year at university, finished without the proper ending, no goodbyes. Such a loss to deal with as well as all the rest of it.

The MND nurse specialist phoned early on to catch up and explain how things would be for the foreseeable future; no visits or MDT clinic appointments and that her role as my single point of contact would be transferred to the physiotherapist when she was needed to work on the covid wards. There would still be someone on the end of the phone. Thankfully, the regular sessions with a psychologist continued by video. It seemed very sensible but was strange to listen to and I could only imagine how difficult that plan was to enact by the healthcare team. Every conversation I had with a health professional during lockdown had changed in tone compared to before covid. I felt for them, what do you say to a person with limited time when previously the advice was to get your affairs in order, then make the most of each day with your loved ones, making memories?

At first, I wasn't on the extremely vulnerable list as motor neurone disease isn't mentioned specifically. I was shocked at how personal and discriminatory that felt. Despite my awareness of the unprecedented nature of all this, I struggled initially feeling of less worth than those in good

health. I self-registered as extremely vulnerable – not because I needed help, but rather to not be ignored. I could rationalise that the NHS (my beloved NHS!) may not be able to offer me treatment on a ventilator. I knew that some of the MND care team who had surrounded me with care and support since diagnosis were reassigned to care for people with covid. It was however, both disproportionately upsetting to be overlooked when publicly classifying the vulnerable and sobering to experience and want to change that. Both my neurologist and GP had already confirmed the need to shield in writing - it was extra work for them and distressing for me and others with MND during an extraordinarily difficult time for all.

We had building works ongoing at lockdown to make the house accessible, so it's been tricky as everything slowed down and stopped for a while. Looking back, we began to see logistical problems supplying some of the medical equipment and building in late January. Our builder continued alone during lockdown to try to get us back up and running, but supplies were difficult to get hold of, so it was slow going. It was an anxious, stressful time. I had chosen to self-isolate quite early before the official restrictions as covid was obviously very risky for people with MND. Having spent my working life in an acute NHS hospital, and now as a palliative patient, I was uncomfortably aware of the triage priorities in a mass incident. I understood, but it didn't make it easier to manage. I decided to take action myself. I contacted my MND nurse and GP to request 'Just In Case' anticipatory medication – if I got covid I was going nowhere, and I'd have helpful drugs ready for the end of life.

Of course, plan A was not to get the virus, so my husband and I strictly isolated using a camper van parked outside the house. Our retirement plans had always been to buy a camper and travel once the boys were up and off. We'd gone ahead anyway and bought one despite our health issues, little realising how useful it would be during lockdown. Amidst the chaos I felt safe in the van. Being in there enabled two of our boys to come home early from university and quarantine in the house. After 14 days of official restrictions, and with little footfall in the house all felt calmer and, ensuring a daily clean, we started sleeping in the house. Daytimes were spent in the now catering van. The boys needed no excuse to stay mainly in their rooms. It was another four weeks until the house was liveable. The van remained ready to move back into as my insurance blanket. Food wise we've been fine although initially I couldn't get my usual online delivery, I contacted local businesses who delivered, and friends

helped. We get through a lot of food though, so I phoned Sainsbury's who were great, they prioritised me and phoned my local store to ensure regular slots. I found cooking lovely meals for my family became even important to me at the start of lockdown, I've calmed down about this now but hopefully the food is still good. We're fortunate to have a decent sized garden with trees at the far end. I've always loved nature but have found I really see the beauty in it all so much more now. People ask how I'm doing not going out, and it's hard to explain the pleasure I get from just looking at nature. A strategically placed chair by the apple trees, birdsong, a gentle breeze, and the breath-taking beauty of the apple blossom, just exquisite. The garden has also been well used by our boys. As well as a training ground and rugby pitch, they created 'The Prince', a very local hostelry named in memory of a beloved family pet. Tucked just under the canopy of trees; chairs, fairy lights, a fire pit, The Prince has proved an invaluable social space for our boys and their friend next door, suitably social distanced over the fence. Two of my boys had 21st and 17th birthdays the same weekend in May. I was worried about how we could make it special for them. In fact, our plans created a special, unique time that the 21-year-old declared the 'perfect day'. Result. I think the challenging times for people like me and our loved ones is now, when the restrictions are easing, and the virus is still around. A new normal likely for the foreseeable future. I want my boys to be able to meet friends and attend 6th form college, university and work. I know they are conflicted, and we continue to tread carefully. The extent to which we isolate will be, and is already, a deeply personal decision. A continuous risk assessment on constantly shifting sands. Choosing highlights of my lockdown I realise there have been many; the kindness of friends, the birthdays, our eldest son completing his dissertation despite the chaos, the phone call from Leeds Rhinos checking I was ok, the help of the local covid action group/MP replacing a recently purchased washing machine when my voice tired of explaining it and I was getting nowhere, an experienced OT from the Disability Services Team who knew just what I needed, a friend's weekly quiz, my brilliant GP who phoned quickly and sorted a video link for future

arrangements when neither of us had done that before. Mostly, time at home with close family. And what of my future plans? Well, like everyone else we've had a rethink, we intend to continue using our own judgement, not breaking the rules, but being cautious and decide what we do ourselves. I have a virtual graduation celebration to attend and one other thing's certain - I've got time arranged with a couple of apple trees.
Deb Mercer 15/07/20

SARAH LEE'S 1,000,000 STEPS



Sarah Lee has completed 728,000 steps out of 1,000,000. She has 2 weeks left to do the rest. Good luck Sarah.

ART COMPETITION ENTRIES



STEVE'S STORY

As lockdown started in March we found ourselves shielding because of our medical conditions. We decided to stop all carers apart from the morning team who come in at 7 o'clock to get me up and ready for the day. Karen would do everything else for the duration and we thereby minimised the number of people coming into the house. With the better weather coming along we were able to spend many days out in the garden where Karen could relax with some therapeutic horticulture and I could watch from the sidelines, occasionally throwing in helpful suggestions (and ducking quickly if they were thrown back!). I was also able to watch the birds in and around the various feeders in the back garden. There are regularly 14 to 18 different species on any one day and they are a delight to watch.

When not outside, my usual place is overlooking the garden, so I can keep an eye on it while reading, doing crosswords, jigsaws or other puzzles. I am also happy to watch DVDs and films we have recorded, as well as playing Scrabble with a number of others on-line.

After a few weeks of isolation Karen was able to take walks around the fields and the change of scenery was very welcome. We are, though, very lucky to be happy with our home and garden so lockdown has not felt restrictive at all.

Once we had self-registered as "extremely vulnerable" we were fortunate to get a weekly Asda delivery slot and have also been able to call on neighbours and Karen's son for regular top-ups as required. We have therefore been able to take full advantage of Karen's considerable culinary talent. We also have regular ingredient deliveries from Hello Fresh, which further vary our eating experience.

Because of shielding we cancelled all weekly day care and occasional respite at a local care home. After about 8 weeks we decided to try and reduce Karen's considerable burden by reinstating evening care. After much research drew a blank, my morning carers surprised and delighted us by offering to add me on at the end of their shift and this welcome arrangement with trusted providers is working very well.

During lockdown we have kept in touch with friends and family by telephone and email much more than usual. More recently we have had a few "garden visitors" but as lockdown is easing we have formed a social bubble with Karen's daughter and family which has led to some much-missed in-home visiting. While we are still a long way from the old "normal" I think we are getting nearer to a "new normal" with slowly increasing freedoms. We will look critically at emerging situations and apply our own common sense in order to progress safely.

Steve Merrey

STILL PLENTY OF TIME TO ENTER THE BRANCH ART COMPETITION



ILKLEY MANOR HOUSE

Art for MND in the Manor House
Art competition

WIN your work on display in Ilkley Manor House

Later this year the West Yorkshire Branch will be hosting an art exhibition in Ilkley Manor House featuring several local artists. We are offering you the chance to be a part of it by entering to WIN the chance to have your work displayed in the exhibition. All entries will be posted online alongside the title of the piece, first name of the entrant and category they have entered. Winners will be picked from the following categories by artist Matthew Evans: Children aged up to 8 years, children and young people aged 9-18 years and those over 18 years old. All you need to do is create a piece of art inspired by your local area, Yorkshire, for example. For full terms and conditions visit the West Yorkshire Branch page of the MND Association website.

All entries must be scanned/photographed and emailed by a responsible adult to jenn.dodd@mndassociation.org along with the title, your name and age. Entry is FREE, but we are asking for a suggested donation of £2 to the West Yorkshire Branch JustGiving page www.justgiving.com/fundraising/mndawestyorkshire

 West Yorkshire Branch  @MND_A_WestYorks

www.mndassociation.org
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Spot some of the entries in the newsletter.

VIRTUAL GET-TOGETHERS on ZOOM
11.30am – 1.00pm

September	Friday 18th
October	Friday 16th
November	Friday 20th
December	Friday 11th

Contact Sue Starkey for joining code or link. It's good to keep in touch with the West Yorkshire Branch Family. If you've not zoomed before it's quite easy to do – we are all learning new skills.

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