

# NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch



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Maxwell Thorpe Concert  
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## Welcome to the Winter Edition of the South Yorkshire Branch Newsletter

As we approach the end of 2022 it gives the Branch Committee an opportunity to thank all those generous people whose efforts holding fundraising events, large or small and in whatever capacity over the past year have enabled us to meet all the varied requests we have had for support. And we have had more such requests this year. Despite the current financial situation so many are facing, people have dug deep. Thank you to all of you.

There are details in this newsletter giving information about the grants available to people living with MND, so please do speak with your Association Visitor or contact Brian Jackson if you need help in understanding or accessing any of the grants outlined. We are here to help in **any way** we can.

I'm sure you will agree that the sterling efforts of Kevin Sinfield in raising funds towards the planned Rob Burrow Centre in Leeds and the support for the wider MND community which will come from his fundraising, has done so much to champion the

awareness of MND, and we must applaud him for that. However, we have news of a South Yorkshire Branch committee member who has undertaken challenges in the past and who is due to embark on his next one – yes, Bare Legs Brian is back on his bike again at almost 80 years young. Read a bit more about his challenge elsewhere in the newsletter and how to support him. Good luck Brian, we know you can do it!

Once again, a huge thank you to everyone who has supported the Branch. Amongst those thanks are Mensa Printers for the professional production of the newsletter and to Sutton McGrath Hartley for their ongoing funding of it. Last but not least, thanks to the health care professionals who work tirelessly not just to support people living with MND but in their work towards finding a cure for this disease.

On behalf of the Branch Committee, Merry Christmas and Happy 2023.

## Chairman's Report

Dear All

Welcome to our end of year Branch Newsletter. At this time of year, we tend to be reflective about the year that's coming to an end and what an astonishing year it has been! It's not often that you get three prime ministers in the space of six months!! It has been intensely sobering at times but with much to celebrate, despite very often being overshadowed by international events.

Closer to home we read daily about how very difficult things are as a result of the economic crisis and PLWMND are not immune to all of this. Thankfully, and due to the enormous generosity of our local people, we have continued to be able to raise substantial funds to enable us to support as many PLWMND as we are able. Indeed, fundraising at the MNDA has been very successful throughout 2022 and the South Yorkshire Branch has played its part in that work.

Highlights of the fund-raising events we have held in 2022 include fabulous concerts from the award winning Stannington Brass Band and Sheffield's superstar singer Maxwell Thorpe. Golf days and the

Folk concerts were also highly successful and well attended. We are already well into the planning of next year's events thanks to the tireless efforts of the Branch Committee members. As you will read elsewhere in the newsletter, we have also held a very successful event for families and friends living with MND at Gulliver's Valley in Rotherham which we intend to repeat next year. So watch this space.

We continue to look at ways to ensure the Branch remains buoyant and sustainable and are still keen to hear from anyone who might wish to join the group. So do contact us if you are interested.

Finally, I would like to wish everyone the very best for the festive season and hope that you all have a very happy and prosperous 2023. **Andrew**

## Treasurer's Report

Our income for the third quarter of the year was £10,385. Income is beginning to recover, and due to a number of successful events that have taken place since September, I expect that level of income to be at least maintained in the final quarter. Income will definitely be down on usual annual figures though. Our available funds, which reached a low point in August this year at £3,431, have now recovered to £6,885 at the end of October, a much more comfortable position. The amount spent on care and equipment in the quarter was £11,038. The grants needed by people living with MND continue to be high, and are expected to remain so in the current economic climate, but we fully expect to be able to meet all needs for the foreseeable future, assuming income remains steady. Your support either by way of attendance at events or by donation would be appreciated, particularly if you can set up a direct debit to give us a regular income. If you can Gift Aid this, even better, as it adds 25% to the value of your donation. Cheques should be made payable to MND Association South Yorkshire and sent to Mr P Hebblethwaite at 55 Newfield Lane, Sheffield S17 3DD or you can pay directly to

our account 02972378, sort code 30-96-09. If you would like to set up a monthly direct debit, then I would be delighted to hear from you. You can call me on 07729 118 590 or email me - treasurer.mndasy@gmail.com. **Paul**

## MNDA grants for people affected by MND

You may not be aware the Association have several financial grants which can be used in a variety of ways. For people living with MND there is a Support (Care) Grant which is to be used once to help with after assessment by a HSCP and if all statutory options have been explored. It can be used for adaptations, stairlifts, respite care costs, washer dryer toilets and riser recliner chairs. There is also a Quality-of-Life Grant which is designed to help maintain independence, dignity, comfort and social connections. This is the widest reaching grant as it can be used for adaptations and equipment not needing assessment, as well as for hobbies and interests including gardening and even home maintenance, transport costs, tablets for accessing social media etc, and accessible/adapted holiday venues.

For people affected by MND there is the Carer's and Young Carer's Grant which again can be used for hobbies and interests, keeping connected and short breaks such as pamper weekends or activity weekends.

The Children and Young Person's Grant which is for those under 18 affected by MND can again be used for hobbies and interests as well as driving lessons, keeping connected, and holiday and school trips.

All of these grants have limits on the individual request and on the amount in any one year.

The examples given for the use of the grants are a few of ways in which the Branch and the Association can help.

If you would like to know more about how to apply and who can apply, please, contact Brian Jackson at **associationvisitor.bj@gmail.com** or on **07794 480110** or ask your Association Visitor if you have one.

## Bare Legs Brian's 2023 Challenge

December 5th saw the launch of BLB's latest challenge. In 2019 BLB missed out doing a challenge because of the pandemic and subsequent restrictions. In 2023, the year Brian reaches 80, he has decided to take on a slightly more daunting task by taking part in the MNDA London to Paris Cycle Challenge! This is a 311-mile ride undertaken over four cycling days with one of the days just short of 100 miles and one over. All the money raised in sponsorship will be coming to the South Yorkshire Branch to aid us in our work to help people affected by MND. If you would like to know more about BLB's challenge for next year, do contact him at **associationvisitor.bj@gmail.com** or on **07794 480110**. If you would like to support him, go to his JustGiving page at **www.justgiving.com.fundraising/BareLegsBrian**.

By the way, the choice of December 5th was because that was 80 days before BLB's 80th birthday.



## Sarah's Experience of Dragon's Back

Rewind to July 2015. I'm doing a summer research placement at the University of Sheffield. Except instead of doing my lab work, I'm glued to my laptop screen, watching a GPS tracker inch slowly down the length of Wales. Matt, my boyfriend (now husband), was running the length of Wales in an event called 'The Dragon's Back'. What an idiot. Yet the seed was planted, and I spent the last seven years as a 'Dragon-in-training'.

Fast forward to September 2022. It's 5.45am and I'm stood in the ruins of Conwy Castle with approximately 300 other idiot-sorry... runners. The atmosphere is electric with anticipation and nerves, and everyone is silent; lost in their own thoughts and listening to the Welsh Male Choir. I'm chuffed to even be on the start line. Training for the Dragon's Back did not come without its challenges, mentally and physically, and I had to make a lot of personal sacrifices to get to this point. The Welsh anthem is sung, and we set off along the castle walls. Egos are left in the castle grounds, and we're on our way to Cardiff. 380km to go, and just a few mountains in the way...



Going into Dragon's Back, I had no expectations on what the outcome of this race would be for me. Earlier in the year I had fallen 10 km into a 100 km race, so I knew first-hand just how quickly this could all be over with one wrong step, regardless of the amount of training and preparation. I also didn't know how my body would cope with six back-to-back days, averaging 65 km and 3000 m of height gain per day. Would I get injured? Would I get timed-out? Could I cope with the lack of sleep? I promised myself that I would smile, enjoy it (as much as possible) and keep moving until I was told to stop.

The Dragon's Back Race is

supported by a 100-strong volunteer team responsible for moving a small tented village southward through Wales with all the amenities required to support 300 runners: 35 eight-man tents, a catering tent, a medical tent (complete with qualified medics, physios and emergency response team), a drying tent (crucial after a day in the Welsh mountains) and a participant information point, where runners could collect their treasured DRAGON MAIL!

Each runner was required to carry a tracker, primarily for our safety, but with the bonus of family and friends being able to view this tracker and follow our progress. The tracking interface was also linked to Dragon Mail, a one-way messaging system where family and friends could send messages of encouragement to runners. These messages will be a permanent reminder of the humungous quantities of support I received during my Dragon's Back experience. The messages from people living with and affected by MND who heard about my challenge did not go unnoticed – THANK YOU!

I soon settled into a routine. Up at 4am. First breakfast. Back to the tent to pack my kit away. Second breakfast. Kit check. Ready to start at 6am. There

were defined start and end points to each day, with a maximum time limit of 16 hours (6am – 10pm) and three cut-off locations each day. Runners could choose their start time between 6 and 9am - but arrive at the cut-off location one second after course closure, and you would not be able to continue with the race. Matt, a glutton for punishment, had decided to come back for a second dance with the Dragon. Being a faster runner than I, Matt enjoyed the luxury of a later start time, having more confidence in getting through the checkpoints in time. This meant we enjoyed a daily game of cat and mouse; how far could I get before Matt caught me up and overtook me? As one friend kindly noted in a Dragon Mail, I simultaneously wanted to hug him and hate him. But nonetheless, it was the highlight of each day for me and a large contributing factor for me getting to the finish. Evenings also followed a similar pattern: arrive at camp (hopefully before dark, but not always), straight to the tent for dry clothes, first dinner and dragon mail, back to the tent to repack bag for tomorrow, second dinner, bed. Repeat. Whilst I appreciate this would be a holiday-from-hell for most people, I viewed this as

an all-inclusive holiday, with a mobile all-you-can-eat buffet; six-days of mountain running in Wales with an endless supply of cake – perfection! This was as much an eating challenge, as a physical one.

Each day on the Dragon's Back course has its own character: from the rocky summits of Snowdonia; the rolling and ankle-twisting bogs and tussocks of mid-Wales; into the steep, grassy slopes of the Brecon Beacons; and finally, the urban trails of Cardiff. Some days suited my peak-district trained legs better than others, with my shortest day out being 11 hours 40 minutes, and my longest being 15 and a half hours. One way or another, 81 running hours after leaving Conwy Castle, I shuffled into the grounds of Cardiff Castle, crossing the finish line with Matt to receive our coveted Dragon trophies together!

### **My final race statistics stood at:**

- 6 days
- 388 km
- 18,496 m height gain
- 8th woman / 81st overall

As much as I would love to say is it was all smiles and cake-eating, it wasn't. As I write this, two months after crossing the finish line, I still can't describe what it was like to compete in (and complete) the Dragon's Back Race. I felt every emotion possible, often simultaneously.

I am incredibly proud of what I achieved, and exceptionally grateful to my body for enabling me to take on such a ridiculous challenge. But most of all, I am honoured that I was able to make even a small difference to someone living with MND. I have had the pleasure to meet and work with some wonderful people living with MND, and I know how much difference these grants will make to their lives and the lives of their families.



## Love Story



A couple who met on the TV show *First Dates* have got married after one of them developed motor neurone disease.

Mike Sumner and Zoe Welch appeared together in 2020 on the Channel 4 programme, which sees single men and women go on blind dates. In their TV encounter, Mrs Sumner Welch said it was “not love at first sight” but the couple’s relationship developed over the following months.

“At the end of meeting each other, we knew we had a connection and we knew we wanted to stay in touch,” she said. “But we weren’t ready to say ‘yeah that’s my forever person’ at that stage.”

Mr Sumner, 38, from Grimsby, proposed during a Florida holiday in March 2022, two years to the day since they first met. Mike was diagnosed with MND and the couple brought their wedding date forward, tying the knot in September.

Mrs Sumner Welch said it was so they both “could celebrate as much as possible”.

“It was originally planned for early next year, but we brought it forwards so Mike was able to do as much as he can to participate in it,” she said. “It can always get worse and there is no set timeframe with when it can get worse”

He arrived at the ceremony near Bradford in a DeLorean car, as featured in his favourite film *Back to the Future*. The couple had a mini-honeymoon in York and are planning a longer one in Italy next year.

They live in Sheffield and say they are being given “brilliant support” by the MND Association. Mr Sumner said the couple aimed to “live life as much as possible”.

“You’ve got to laugh, although it will get you down,” he said. “Zoe looks after me really well. I think I face it so well because of her.”

## An Evening with Maxwell Thorpe



On Sunday 13th November the Niagara Centre resounded to the superb voice of Maxwell Thorpe. A classically trained singer from Sheffield, for many years he could be found busking around Yorkshire and Derbyshire.

He was persuaded to enter the "Britain's Got Talent" competition on ITV where he quickly became a favourite with the many thousands of people who voted for him, winning the semi-final and appearing in the final.

His repertoire on the evening appealed to all tastes in music, from beautiful classical arias to favourites such as Bring Him Home, You Raise me Up,

Impossible Dream and Can't Help Falling in Love.

Thanks go to the Rev A Platts for supporting Maxwell with the sound system, the Manager of the Niagara Centre who provided the venue free of charge, and to the staff who helped on the night.

Special thanks go to Trevor Peacock and his wife Doreen for all the hard work they contributed into making this musical evening a success.

Our thanks must also go to Maxwell who has supported the Branch previously and who is now launching his professional career. We wish him well. The concert raised £1,200 for the Branch.



## Family Fun Day at Gulliver's Valley

On Saturday, 17th September, the South Yorkshire Branch held a Fun Day at Gulliver's Valley. Six families enjoyed a day of fun along with warm sunny weather. The ages of the twenty-three children ranged from little ones in prams to teenagers and all were given some money to spend. This was all made possible by the donation of a sum of money which was to be used for the children and young people affected by MND. It was such a success that the event is to be repeated on June 17th next year. Look out in the New Year everyone for further details and the opportunity to register for our next Fun Day.



## Folk Night

Another successful evening of folk music was held on Sunday 6th November at Crookes Working Men's Club. Artists who performed included Union Jill, Roisin Ban, Keith Kendrick & Sylvia Needham and Hilary Spencer from Artisan. Sheffield Steel Rapper also took to the floor with their remarkable dancing. Thanks to Crookes Social Club who provided the venue free of charge; to Mel White, our past chairman, who organised the night, and to all the artists who performed who also gave of their time freely to support the event, which raised £915 for the Branch. If you're a lover of folk music there will be a similar event as last year, taking place on Sunday 23rd July 2023 at Upper Denby, with lots more artists taking part but hopefully not a repeat of the weather! Please make a note of the date and come along to help raise funds for the Branch. More details will be available nearer the time.





## Fantastic Fundraisers with a Sad Story



In 2007 Jeanette Bonser's dad John was diagnosed with MND. His symptoms had started a few years earlier and he deteriorated quickly and passed away aged 66 years. Jeanette and her husband Derek started fundraising and subsequently joined the South Yorkshire team to run the Sheffield Half Marathon. The brilliant Fun Run and Half Marathon event started and ended in the Don Valley stadium in those days, and their participation and sponsorship, along with many others, helped to make this one of the biggest events in the Branch calendar.

Jeanette recently told us that her Mum Patricia had been diagnosed with dementia quite a few years ago. She said "Around 2020 my Mum started slurring her words, very similar to Dad. I kept asking doctors

if this was to do with dementia, and they said "quite possibly". Then I noticed Mum coughing a lot whilst eating so the doctor got a speech therapist to visit mum and she quickly got Mum further tests with the neurology department. I said to her "you're not thinking MND" cause my Dad passed with this. She told me it was one of the things they would be looking at, but the chance of both Mum and Dad having it was very rare. In May 2022 my



Mum was diagnosed with MND and we were in total shock and heartbroken. Mum's consultant said that he had never known this in all the years he'd been a doctor."

Jeanette tells us that they are now making lots of memories with her Mum, and in October she and Derek entered and ran the London Marathon. "We took my Mum and daughter Sophie along to watch us. They were on the Tower Bridge halfway point

## Thank you to our Fundraisers

Tori's friend Sophie lost her Mum to MND last year. Sophie's family have been fundraising for some time and Tori Frances wanted the sponsorship from her first ever Great North Run to help local families too. The run was hard but raising nearly £1000 made it all worth it. Congratulations.

Angela Burns handed over a cheque to Bare legs Brian and Branch Chairman Dr Andrew Gibson at the committee meeting in September. £500 raised from Ladies' Day 2022 was donated after a good friend of Angela's was diagnosed with MND. Thanks for helping our branch.



to cheer us on and it was very emotional.”

Jeanette set up a Just Giving page and along with her sponsorship form has raised a fantastic total of £2,693, with nearly half coming directly to the Branch. Jeanette and family would like to thank everyone for their kind words and donations, and we would like to offer Congratulations on their achievement and thank them for remembering the Branch.



## Julie's Story



*"I want to share something positive with you"*

My brother Andrew Herbert was diagnosed with Motor Neurone Disease at the end of June 2022. The company he works for, Novuna, have been fantastic in their support for Andrew, adapting his work to his needs. When the diagnosis was made the company arranged a massive fundraiser, called 'Miles for MND', which Novuna guaranteed to match fund.

Andrew's love of outdoor activities and his commitment to cycling led to the idea of 'Miles for MND'. The target was 20,051 miles, which was the amount that Andrew cycled from Skipton to Leeds once a week for 7 years and they added his age at diagnosis 51. The main fundraiser was from 5TH to 11th September 2022 and Novuna colleagues along with Andrew's family and friends planned to run, cycle, swim, walk the dog, horse ride, row or jog.

My daughter Emily and I swam a marathon together (26miles), I really enjoyed pushing myself and when I got tired, I would think of my brother and that would spur me on. I felt a sense of achievement and encouragement as everyone pushed together, and of course the money raised kept going up.

Some of Andrew's work colleagues 'Andrews Angels' arranged an interview about the fundraiser on the BBC Friday night request show and a few of his favourite songs were played. He was also mentioned on local radio, again playing some of his favourite songs and there was also an article in the local paper; these moments were very touching and special.

In total a massive 22,245 miles were completed as a team and an amazing £60,877 was raised for MND, an incredible achievement. Our family is very thankful for everyone's incredible effort and support.

Although the diagnosis of MND for my brother is so sad and it's difficult to see the disease progress. I am immensely proud of Andrew, he keeps striving every day, he is a lovely brother and his humour and personality keep shining through.

Thanks so much Julie for sending this to us and Congratulations on swimming a marathon.

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# The Motor Neurone Disease Association

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## South Yorkshire Branch

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## Events for 2023

The Branch have the following events planned for 2023, with some dates still to be confirmed and further details to be announced in future newsletters.

Thursday Carers' Meetings	United Reform Church, Wickersley Road, Rotherham S60 2JN 2.00 pm – 4 00 pm 26th January 2023 and 30th March 2023
Sheffield Half Marathon	Sunday 26th March 2023
Stannington Band Concert	May - date to be confirmed
Gulliver's Valley Fun Day	17th June 2023
Folk Event, Upper Denby Village	23rd July 2023
Hallows Golf Day	4th August 2023
Walk to D'Feet	August/September – date to be confirmed
SHM Golf Day	September - date to be confirmed
Quiz Night	20th October 2023 @ Tapton Hall
Murder Mystery Night	date to be confirmed
Cannon Hall Treasure Hunt	date to be confirmed