

# NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

SUMMER 2023



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## Welcome to the Summer Edition of the South Yorkshire Branch Newsletter

As the time comes around to begin to collate items for inclusion in our next Branch Newsletter it never ceases to fill me with gratitude towards the many generous people who go the extra mile to support people living with MND. No-one can remain unaffected by the commitment of Kevin Sinfield towards his friend Rob Burrow and also by his determination to continue to raise awareness and funds for the wider MND community. Closer to home we have our own heroes who take on their own acts of quiet support, whether this be by fundraising in all its many forms or doing the caring of a loved one, so it is important to recognise the commitment and dedication they all give. A huge thank you to you all.

### Open Meetings

The Branch Committee are looking to resume the Open Meetings which used to take place regularly before Covid. For those of you reading this newsletter for the first time, the "Open" meetings were so named because they are "open" for anyone to attend, not just people affected by MND. Their format was in the guise of people meeting together for a chat and refreshments, and on occasions there would be a speaker in attendance, such as

a SiTraN scientist, a Scottish Laird who gave a talk on the history of kilts, to the Duchess of Devonshire. The meetings were informal and attended by Committee Members so there was the opportunity to meet with them. There was also a Summer Evening Meeting to the Botanical Gardens or other local garden venues. We are now seeking your opinion on how you would like to see the format of these meetings in the future. Please let us know of your thoughts and ideas; you can do this by contacting any member of the committee, see details within this newsletter, or directly to me either on [Christine.Naylor@mndassociation.org](mailto:Christine.Naylor@mndassociation.org) or [Chris222@sky.com](mailto:Chris222@sky.com) or 0114 2653774.

Please also let us know of any fund-raising events you would like to hold or would like someone from the Branch committee to assist. We also value your articles for inclusion in the newsletter, so please keep them coming and send us anything you feel will be of interest.

I look forward to hearing your views on the Open Meetings and receiving anything for the next newsletter.

**Christine**

## Treasurer's Report

In the quarter to 31st March 2023, our finances improved a little, but we are still working on relatively small margins. We are grateful to the Swann Morton Foundation who generously donated £1,000 to our cause. We also raised £1,100 from the Unite the Union Brass Band concert and a good night was had by all. We thank Trevor Peacock for organising this. Lloyds Bank have agreed to match fund the total raised on this night, for which we are most grateful. Our total income for the quarter was £9,433 and the amount spent on supporting people living with MND was £8,218. In April, we received £2,105 from the Concrete

Society and we thank all those who contributed. This was again most welcome and gives us a good start for the second quarter. At the end of the quarter, we had available funds of £7,574, but we also had grants in progress amounting to £3225.

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. You can call me on 07729 118 590 or email me - [treasurer.mndasy@gmail.com](mailto:treasurer.mndasy@gmail.com)

**Paul**

## Chairman's Report

Hello Everyone

I am writing this in the week that saw the inaugural Rob Burrow Leeds Marathon. The event was a phenomenal success and raised both increased awareness of, and huge sums of money for, Motor Neurone Disease research and support.

For me, the image of Rob Burrow being carried over the line by his great friend and mate Kevin Sinfield was perhaps the most moving element of how the day was reported. The action in context of the dreadfulness that is MND encapsulated everything that is phenomenal about the human spirit and showed such empathy from one human being to another that I suspect that it brought more than a tear from all who saw it. Deservedly so. It will, I believe, become an iconic image to represent all that is positive about the fight against this dreadful condition.

The whole event and all those involved also shows how the awareness on MND has risen in the last decade and that of course is not due to any one single act but also due to the hard work of everyone that has been touched by the illness.

Every branch of the Motor Neurone Disease Association has many "Kevins" in their ranks. The South Yorkshire Branch is no exception. If when you read this, you would like to get more involved in the branch and our activities, in as little or as much detail as you want, then do contact us on the email addresses and telephone numbers in the newsletter.

I wish you all the very best until next time.

**Andrew**

## Concrete Society Winter Ball



On Friday 3rd March the Yorkshire Concrete Society held their Winter Ball at the Holiday Inn in Rotherham. Branch Chair Andrew Gibson and our Regional Fundraiser Jenn Scribbins attended the event and were invited to commence the evening by speaking about MND and the work of the Branch. This was followed by live music and a luxury raffle with prizes including bottles of champagne and the prize everyone wanted to win – an air fryer! A grand total of £2,209.30 was raised with several kind donations from guests to take the total over the £2,000 mark. The Holiday Inn will also be kindly supporting with a

donation from the takings of the bar on the evening. Our thanks go to all members of the Yorkshire Concrete Society for choosing to support the MND Association as their charity on the night.



# The First Leeds Rob Burrow Marathon May 14<sup>th</sup> 2023

Some of our Fantastic South Yorkshire Runners and their Stories.



Sunday 14<sup>th</sup> May was such an important day in the MND community calendar. Rob Burrow MBE a patron of the Association and the first marathon to be held in Leeds for 20 years was held in his name, with the Association as the charity partner.

His story and particular the activities of his friend Kevin Sinfield inspired so many runners to take up the challenge of running around the hills of West Yorkshire. 57% of the people who took to the streets on that hot and sunny morning had never run a marathon before and many were not regular runners.

They all felt it was not an opportunity to be missed and with miles and miles of training and incredible determination our South Yorkshire runners somehow got round the 26.2-mile course. They raised thousands of pounds in the process. It was a very emotional day.

Natalie Cawkwell from Rotherham ran with her brother Damian and sister and brother-in-law Deborah and Daniel, as "Team David." She took on the challenge to run on what would have been David's 48<sup>th</sup> birthday. David died from MND in 2017. Natalie said "he would be very amused to see me



tackling this challenge but although nervous I've trained well, and my daughter Heidi will be there to cheer me on. Team David raised over £3,300 specifically for the South Yorkshire Branch.

Music student Reuben Cole took on a marathon challenge inspired by Kevin Sinfield's 7 in 7 events. Reuben's uncle Glenn had MND. Reuben explains "He was a keen sportsman all his life which made it difficult to see him struggle physically, he would have loved to have seen Kev's challenges, but he died in October 2020 a couple of months before Kev's initial one. It seemed very fitting to do the challenge at this time as Glenn was also a lifelong Leeds Rhinos fan."

Reuben aimed for 7 Marathons in 7 days. Five of them went really well. Day 5 would have been his uncle's birthday. Day 6 saw him pull up with a knee injury half way round and he was devastated to have to watch his dad Peter complete Day 7. Reuben has said he will definitely be back in Leeds to do it in 2024. Reuben's story was featured in the local press which helped both raise



funds and awareness. Running nearly 150 miles in 6 days and raising over £4,500 for the Association was a very fitting tribute to Uncle Glenn.

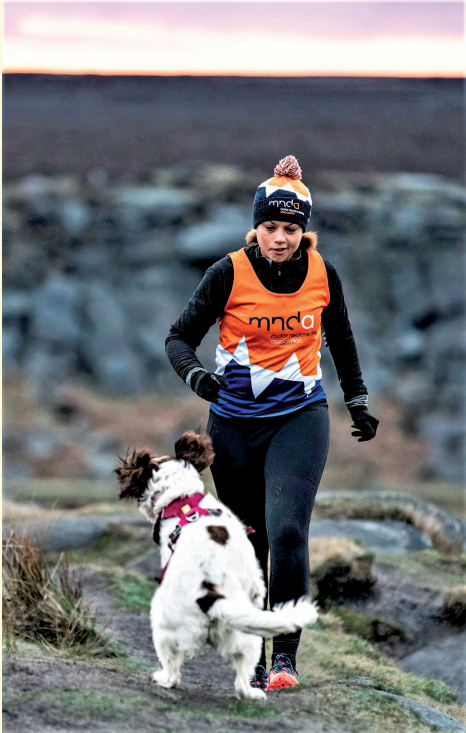
Tracy Woodward from Barnsley has taken up countless running challenges for the MND Association and particularly the South Yorkshire branch for many years. She joined our Half Marathon teams on several occasions when the event was held in the Don Valley stadium, and she's helped train others along the way. She said "I'm coming out of marathon retirement to do this one! I lost my sister to MND and when I heard the news that Leeds Marathon would have the backing of MNDA and be a fitting tribute to all that Rob Burrow and Kevin Sinfield have done in raising awareness, well it was an opportunity I just couldn't miss and didn't hesitate in signing up. Come race day it's going to be emotional, but such an amazing atmosphere and I can't wait to be with all of the other MND runners."

Allan Shaw is a third year PhD student at SITraN supervised by Professor Dame Pamela Shaw. "In my research I generate



brain cell models using skin cells kindly donated by individuals living with MND, as well as their relatives. I am using these models to try and understand why individuals live long, healthy, and happy lives before the onset of symptoms, determine what the triggers are for developing MND, and use this knowledge to find targets for new therapies. I began running seriously in January 2020 after being challenged to participate in the Sheffield Half Marathon. Despite having to wait 18 months for the race to occur, I never stopped training and have developed a lifelong passion which plays a central role in my work/life balance. I'm honoured to be participating in the inaugural Rob Burrow Marathon, which will be my first competitive marathon and look forward to continuing to fundraise in the future. I am grateful for the support from the MND community and encouraged daily by their positivity to keep working and make new breakthroughs in the lab". Allan was one of the first home on the day with an amazing time of 3 hours 30 minutes.

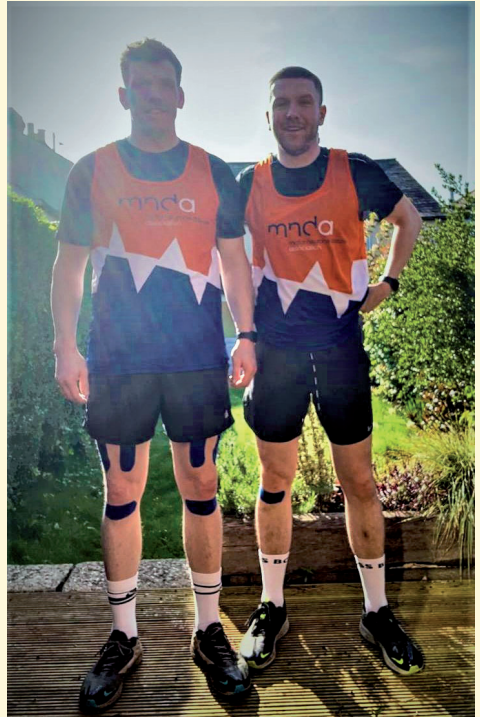
Rachel Sinclair lost her Mum to MND in 2018 and decided that 5 years on was the ideal time to take on the challenge of her first marathon, particularly the Rob Burrow



Leeds event. Rachel set a very ambitious fundraising target, but she was determined to make a difference and like so many others exceeded her £5,000 target. Rachel understands just how much money is needed for essential research into the devastating disease that affected her family's life.

Rachel joined the MND runners in the Sheffield Half Marathon as part of her training. She's found running helped her both physically and mentally to cope with her grief and the excellent video Rachel's created on her Just Giving page explains this particularly well. [Rachel Sinclair is fundraising for Motor Neurone Disease Association \(justgiving.com\)](https://www.justgiving.com/fundraising/rachel-sinclair)

Peter Booth has been involved in our charity events for some time. His aunt Ann Quinn has been running for MND for years and is very proud of the fact that so many friends and family members have joined her and raised funds and awareness in different ways, but especially running."



This time Peter and his older brother Tom came home to Yorkshire to run their first ("and last" said Tom!) marathons.

Back in 2010 and 2011 Peter proudly joined the big Fun Run team at the Don Valley stadium while his aunt and older cousin ran the Sheffield Half Marathon. Peter and Tom did their training runs together for many months, in London, and gradually increased their miles ready for the challenge. They know Yorkshire though and knew it would be tough. Having run 26.2 miles in the heat they then needed to get themselves back to London for work the next day. Ann was immensely proud of them.

We know there were other South Yorkshire runners at this event and we'd love to hear your stories too, so please do get in touch. Thank you again to the runners, donors and supporters. Sunday May 12<sup>th</sup> 2024 will be the next one. Register your interest now.

## Welcome to our Grant Volunteers



Hi, I'm Daisy Joustra, I live in Barnsley and my role is as a grants volunteer. I'm also a masters student at the University of Sheffield, and through studying Public Health, I learnt about some of the health inequalities that are experienced all over the UK. I really wanted to be part of an organisation that made a meaningful difference to people's lives, so the opportunity to be a grants volunteer at a the MND association seemed perfect. As a grant's writer, I work within a small team to research and apply for different grants and pots of money that are available to the organisation.



Hi, I'm Esme and I have joined the team of Volunteer Grant Writers at the South Yorkshire Motor Neurone Disease (MND) Association this year. I work as a Project Support Officer within Health and Social Care in Sheffield and was drawn to this volunteering opportunity as a way of utilising and progressing my research and writing skills in a field of healthcare that would go towards making a genuine difference.

I have thoroughly enjoyed the first few months of this position with getting to know the fellow Volunteer Grant Writers joining alongside the other volunteers at the South Yorkshire branch who will be supporting our role, to learn about the important support grants can provide to those with MND, their family and carers.

I am looking forward to continue learning about the wonderful work of the branch and association to date and participating in fundraising activities organised.





Hi, I'm Siobhan, a mother of 2, a granny, retired since 2019. I love travelling, holidays and spending time with my family.

I recently joined the South Yorkshire Branch of the MND Association as a member of the grant's team, researching potential charities who might be willing to fund the numerous projects the branch is involved with.

I chose MNDA for volunteer work as I have experienced first-hand the impact a rare neurological condition can have on a person's life.

Four years ago I was diagnosed with a rare neurological condition causing muscle stiffness, affecting my balance and ultimately my mobility. It took four years of testing, monitoring and clinical examinations to get my diagnosis. Like MND there is no treatment or cure but unlike MND it isn't life shortening.

My condition has changed my life and made everyday things I once took for

granted more difficult but I consider myself lucky, my challenges pale into insignificance compared to the challenges people living with MND experience.

I can't help out with research into a desperately needed cure but I can use the skills I have acquired from a long career in various senior management positions to help raise vital funds for people living with MND and their carers to improve their quality of life.

In 2019 I walked 100 miles and raised £4683 for MNDA, I intend to keep fundraising and am delighted to join the South Yorkshire Branch as a volunteer.

## Memorial Service

On Saturday 18th March a Memorial Service was held in St Andrew's Church on Psalter Lane. This is a bi-annual event organised by SiTraN and was the first to be held following lockdown and had the largest attendance to date. A non-religious event, it was an opportunity for people who have been bereaved by MND to come together to reflect and remember in a positive way those we have lost to MND. Professor Dame Pamela Shaw gave an inspirational speech, as well as mentioning the work that goes on at SiTraN towards finding a cure. Tea, coffee and biscuits were available at the close of the afternoon with the chance for a chat with friends.

## High Sheriff of South Yorkshire Awards



An awards ceremony was hosted by the High Sheriff of South Yorkshire, Professor Jaydip Ray and the Mayor of Rotherham, Councillor Tajamal Khan, on Wednesday 10th May at Rotherham Townhall.

Professor Ray presented an award to the South Yorkshire Branch of the Motor Neurone Disease Association for providing outstanding service to the MND community in South Yorkshire. Branch Committee members are pictured below receiving the award. They were treated to a tour of the Town Hall by Mayor Khan, who talked enthusiastically about the history of the building and his work over the past year in office.

A huge thank to everybody involved in making the South Yorkshire Branch such a special organisation to be involved with.



# Making a Difference with Lloyd's Bank



We are delighted to be working in partnership with Lloyds Bank in Sheffield to raise funds for supporting those living with MND in the South Yorkshire area. Each year employees from Lloyds Bank spend thousands of hours volunteering in their local communities.

The South Yorkshire Branch of the MNDA will benefit through matched-funding, so for every pound raised by our fundraising events, Lloyds will match this, effectively doubling the funds we generate. Lloyds Bank also has their *Day to Make a Difference Scheme*, so we will receive £500 for each employee who chooses to help with one of our fundraising events.

We held our first joint event in April, which raised £488 from the Awareness Day & Cake Sale. A huge thank you to Fiona Kilner and Julie Chant at Lloyds Bank for making the day such a success, also to bank staff for bringing in their impressive home bakes!



# mnda

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## South Yorkshire Branch Memory Walk

Scan here →



## Doncaster Lakeside Walk Sunday 13th August 2023

Join the South Yorkshire branch & Walk To D'feet MND on this year's Memory Walk. The route is an easy route around the lake which is accessible for wheelchairs and pushchairs and also dog friendly. Walk with us to remember all the loved ones, friends and colleagues lost to Motor Neurone Disease (MND), and help us fight back to raise funds for local people with MND, their families and carers. Scan the QR code to set up your fundraising page for the walk for the branch (please include 'All funds raised for the South Yorksire Branch on your page')

**Walkers need to register at 10.30 am at the Outlet Tower at Lakeside Village Outlet, White Rose Way, Doncaster DN4 5PJ**  
**For more information contact Dave**  
**davebooker1712@gmail.com 07803167978**

 MND Assoc South Yorkshire  @SYMNDA

[www.mndassociation.org](http://www.mndassociation.org)

MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ  
| Registered charity no. 294354 | Created in RightMarket - 13/4/2023 - 16:00:23



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## Support Group Meeting Dates

- 1 In Sheffield** – Peer Support Cafe meetings are held on the **last Wednesday of the month** from **2 00 pm until 3 30 pm** at Greenhill Methodist Church, School Lane, Greenhill, Sheffield S8 7RL
- 2 In Barnsley** – Peer Support Group meetings are held on the **last Monday of the month** from **2 00 pm until 3 30 pm** at Emmanuel Church, Huddersfield Road, Barnsley S75 1DT
- 3 In Doncaster** – Peer Support Group meetings are held on the **first Tuesday of the month** from **11 00 am – 12 30 pm** at Aurora Centre, Montague Hospital, Adwick Road, Doncaster S64 OAZ
- 4 Rotherham** – Herringthorpe Reform Church, Wickersley Road, S60 4JN -held **every six weeks** on **Thursdays** at **2 00 pm until 4 00pm**.  
Next meeting dates are **1<sup>st</sup> June and 3<sup>rd</sup> August 2003**

All people across South Yorkshire who are affected by MND are welcome at any of our support meetings.

### Can you Spare some Time Please?

The branch would benefit from more people to help with all the tasks it undertakes supporting people affected by MND in our area. Let us know if you would like to volunteer in any way. You do not need to be on the committee. We're informal and friendly but we're a dedicated team of people. Help might include..

- Baking cakes or selling tickets at fundraising events
- Assistance at events, meet & greet or set up & take down stalls or photography
- Fundraising
- General administrative tasks

## Events for 2023

Gulliver's Valley Family Fun Day	Saturday 17th June 2023
Woodhouse Band Concert	2nd July 2023 @ Niagara Conference & Events Centre (see flyer for more details)
Folk Event, Upper Denby Village	23rd July 2023 (details from Mel at <a href="mailto:Chalks50@yahoo.com">Chalks50@yahoo.com</a> or telephone 07870 298985)
Walk to D'Feet & Memory Walk	13th August 2023
Yorkshire Outlet, White Rose Way, Doncaster	(see flyer for more details)
Dore & Totley Golf Day	23rd August 2023
Julian Jones & Simply Strings in Concert	8th October 2023 @ Niagara Conference/Events Centre (details from <a href="mailto:trevorpeacock56@gmail.com">trevorpeacock56@gmail.com</a> )
Quiz Night	20th October 2023 @ Tapton Hall
Stannington Band Concert Movie Music	Sunday 12th November 2023 – Remembrance Day Niagara Conference & Events Centre (details from <a href="mailto:trevorpeacock56@gmail.com">trevorpeacock56@gmail.com</a> )
Ceilidh The Hoolimen & Friends This is a joint event with West and South Yorkshire MNDA	Saturday 25th November 2023 Featherstone Community Hall, Victoria Street Featherstone, WF7 5BB (details from Mel at <a href="mailto:Chalks50@yahoo.com">Chalks50@yahoo.com</a> or telephone 07870 298985)
Murder Mystery Night	date to be confirmed
Cannon Hall Treasure Hunt	date to be confirmed

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# The Motor Neurone Disease Association

Website: [www.mndassociation.org](http://www.mndassociation.org) Tel: 01604 250505

Registered office: MNDA, Francis Crick House,  
6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ  
MNDA Connect Helpline 0808 802 6262

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## South Yorkshire Branch

Website: [www.mndassociation.org/southyorkshire](http://www.mndassociation.org/southyorkshire)

### Committee Members 2023/24

Chair: Dr Andrew Gibson  
[andrew.gibson7@nhs.net](mailto:andrew.gibson7@nhs.net)

Vice Chair: Julie Ward  
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Social Media:  
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Area Support Co-ordinator:  
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Regional Fundraiser:  
Jenn Scribbins  
[jenn.scribbins@mndassociation.org](mailto:jenn.scribbins@mndassociation.org)

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South Yorkshire  
Branch presents

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## Woodhouse Prize Band Playing Movie Music, Musicals & More

Sunday 2nd July 2023 at 7.30 pm

Doors, bar and sales table open from 6.15 pm

Niagara Conference & Leisure, Niagara Road, Sheffield, S6 1LU

The venue is accessible with a lift and has free parking.

**Tickets are £5 reserved in advance or £7 on the door available  
from Trevor Peacock on 0114 242 2956 or  
trevorpeacock56@gmail.com**



MND Association South Yorkshire



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| Registered charity no. 294354 | Created in RightMarket - 4/4/2023 - 21:05:11



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