

NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

SPRING 2025



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motor neurone disease
association

Registered Charity No 294354
Branch Patron: Suzanne Maguire

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Welcome to the Spring Edition of the South Yorkshire Branch Newsletter

Welcome to the Spring Edition Newsletter of the South Yorkshire Branch of the MND Association and to those of you reading it for the first time, I hope you will find it interesting. We are always happy to receive articles for inclusion so please don't hold back but send anything you think will be of interest to our readers. These can be about the fund-raising you have done or places you have visited, or been on holiday and found the accommodation user-friendly for people with a range of disabilities. And if you would like a member of the Committee to help support your fundraising, please contact our Vice Chair, Julie Ward.

We are always looking to welcome other volunteers. In this edition you will see a couple of articles seeking people to join us. The first is seeking membership of the "70 Club" and the second is for someone to help me in my role as Newsletter Editor. If you have some time to spare, please do consider volunteering with the Branch.

AGM

The Annual General Meeting of the Branch usually takes place in February, and as in the past couple of years the Branch will be producing a written report instead of a face-to-face meeting. The Report from the South Yorkshire Branch will be published on the Branch Website, so please do log on and read the Report; it gives, amongst other things, an insight into the work of the Branch over the last twelve months, including the way in which funding raised has been used to help people living with MND in our area. A hard copy can be obtained by contacting me directly.

Finally, please do let us know of any changes of address that we should be aware of to ensure that you receive your copy of the newsletter. We hope to see many of you at some of the forthcoming events, which we hope you will support whenever possible.

Christine

Chairman's Report

Dear All

Welcome to another newsletter and with it the prospect of Spring and all that it entails.

There's a lot happening in our world currently and I for one sometimes find it difficult to know who or what to believe. However, one thing for certain is the continuing efforts of all the SY Branch in continuing to support local people who are affected by MND.

So that, as you will read elsewhere, our finances are in great shape, and we will once again use these to the best of our ability in ensuring support locally.

This allows us to repeat the successes of 2024 as well as looking to create new events. A special mention goes to "Bare Legs Brian" (Jackson) for his latest cycle adventure to raise both funds for and awareness of MND. This will involve him cycling from his home in South Yorkshire to all the four nations capitals in the later Spring. I hope you will join me in supporting in yet another epic bike ride!

Once again, I would like you to think about supporting our work by considering a volunteer role within the region. The tireless effort of all our volunteers is special to be part of, so do think about it. All the contact details are later in the newsletter. All the very best and see you at our events in 2025.

Andrew

Treasurer's Report

I report on the quarter ended 31st December 2024 and also the year to that date, our financial year end.

The income for the final quarter was £16,354 which included £1,504 from the Lloyds Foundation, £1,800 from the Unite band concert and £2,250 from the Royal Order of Buffaloes in Doncaster. I previously reported on the October receipts. This brought our total income for the year to £95,733, a record by some margin. When I started the role of Treasurer 18 years ago, our annual income was around £20,000. We have come a long way as a branch in that time due to the fantastic team we have built and the raising of awareness.

In the early years, I generally had to tell people what MND was. That rarely happens now and the raised awareness has benefitted the branch, and consequently, those who need our help. I doubt that 2025 will be as successful, but as receipts for January were £6,261, we have made a good start.

What we spend is just as important as our income. In the final quarter of the year, we spent £20,366 on care making the total for the year £63,090, another record. In November, we paid out £15,000 to a research project being conducted at SITraN in Sheffield, where progress is being made into the causes of MND.

Research is so important and we are lucky to have such a highly regarded centre in Sheffield. We ended the year with available reserves of £8,000 to carry forward, which leaves us in a comfortable position to start 2025. Demands on our resources are ever increasing though, so we must strive to maintain our income at this higher level.

Paul

Chesterfield Royal Hospital Fund Raising on behalf of the South Yorkshire Branch

On Wednesday 22nd January Brian Jackson and Christine Naylor were invited along to Chesterfield Royal Hospital to receive a cheque for £1,800 raised by staff and community at the hospital.

The fundraising was the idea of Elaine Waddington who works at the hospital and has a friend who is living with MND. Raffles were run over the year and this very generous amount was raised to help the Branch. The staff we met were very interested in the Branch and it was a prime opportunity to raise awareness of MND and how the Branch supports the MND community in South Yorkshire. Thanks to Angela Innes, Staff Nurse at the hospital and to Elaine Waddington for their warm welcome and a huge thank you to all concerned in raising the £1,800.

Neil's 70th Birthday Fundraiser

Neil Morris, a retired Community Worker and Charity Volunteer from Barnsley, was diagnosed with MND in September 2024. He has already received support from the MNDA, who provided a laptop to enable Neil to bank his voice.

Neil wanted to help spread the word and raise funds for the MND community in South Yorkshire. With his 70th birthday coming up in January 2025, Neil decided to have a big party, but instead of gifts, everyone at the party was invited to make a donation.

With the help of Jenn Scribbens, MNDA Regional Fundraiser, Neil set up a Just Giving page and ordered an MNDA publicity pack. The online donations soon came flooding in raising £712 + £146 Gift Aid. In addition, there was also a bucket collection at the party, which raised £310. If you wish to contribute to Neil's fundraising, you can do so by accessing his just giving page at

<https://www.justgiving.com/page/neil-morris>

The Branch wished Neil a Happy Birthday and sent a huge thank you to Janet and Neil Morris for raising £1,168, which will be used in the South Yorkshire Branch to support local people living with MND.



Can you spare a few hours to help the branch?

We're looking for a volunteer to edit our Branch Newsletter

Chris Naylor has been our newsletter editor for some time now. Chris inherited this task as part of her duties as Branch Secretary. However, she also answers branch queries, helps with fundraising, acknowledges donations, books venues and does the agendas and minutes of all Branch meetings. So, Chris does need more help, but our small group of committee members and branch volunteers have also got a lot of other tasks to do.

The Branch Newsletter is printed four times a year. The job of editor entails collating relevant news articles and reports each quarter. We try to feature stories from the MND community, research news, fundraising and of course dates

of regular meetings and events in each edition.

The editor then forwards everything to the printers and examines the proofs.

That's it basically. Are you a good communicator (we're a friendly bunch), a good proof-reader and willing to give a bit of time to help the local MND branch?

If so, please get in touch with Chris or Ann for more details. Chris Naylor 01142653774, ann.quinn@mndassociation.org.

It's a worthwhile task and there will be support if needed.

If this task is not for you but you feel you could help in others ways, we'd love to hear from you too.



70 Club

Would you consider supporting the 70 Club?

To become a member, we ask for a yearly donation of £32 per person. A £50 first prize and £25 second prize is drawn each month and where possible, a special draw is also held. Half of the subscription goes in prizes and half to Branch funds, helping us to provide support and equipment to people locally living with this devastating disease. In the last year, the 70 Club was able to support the Branch by funding £1,000 towards care.

Last year South Yorkshire Branch paid out more grants to people living with MND than ever before, so if you can make a donation, it really would be appreciated, as this helps ensure that we can continue to support all people in our area, at a time when they need help more than ever.

To contribute to the 70 Club this can be done in the following ways.

You can send a cheque made out to '70 Club' MND Association SY Branch and sent to me at 55 Newfield Lane, Sheffield S17 3DD

Or if preferred by BACS payment '70 Club' MND Association SY Branch –

Sort code 30-97-51
Account 00090683.

For those choosing to donate please contact me for a gift aid form.

It would be helpful if you could send me an e-mail or letter to confirm your payment, stating your name and address and if you are paying for more than one person, please mention in your letter or e-mail the names of the people you are paying for. My address is as above, and the e-mail is:

Paul.Hebblethwaite@mndassociation.org

or by telephoning me on 01142 363222.

Brownhill Vickers Supporting MND Association in South Yorkshire

Brownhill Vickers, is a Sheffield and Barnsley-based commercial property company, which was established 140 years ago.

Robin Curtis, Director at Brownhill Vickers, contacted the South Yorkshire Branch. He explained that a former colleague had lived with MND and another staff member had lost her mother-in-law to the disease, so as part of their celebrations they decided to raise funds for the MND Association.

We are delighted to say that Brownhill Vickers raised £3,000 and we say a big thank you to you all for raising funds to support the MND community in South Yorkshire.

Pictured here are Robin Curtis (back row) with members of Brownhill Vickers Team, handing over the funds to Julie Ward, our Vice Chair (centre) and Paul Hebblethwaite (right hand side).



Simply Swing Dinnington Fundraiser

Simply Swing is a U3a Swing Band playing music from the hey day of jazz bands in the 1930's and 40's. Annette Barker, their co ordinator, contacted us late last year to let us know that they were playing their next seasonal concert in Dinnington.

Sadly, as the partner of one of the band's players had been diagnosed with MND, they decided that the money raised would be coming to the local MND Association.

Some committee and branch members attended what was a fabulous evening of music and singing by a group of people who were obviously having fun themselves too. Dinnington Resource Centre proved to be an excellent venue, and the performances, along with the pie and peas, were top class.

A successful raffle and a full house on the night raised just under £900. Many thanks to Annette and all the band.



Readable Research at SITraN Sheffield Helping you to understand

Are you aware of this scheme?

www.readableresearch.com

There is a team of people at Sheffield SITraN, Sheffield Institute for Translational Neuroscience, who work together to produce clear, simple summaries of the work in Neuroscience, and particularly Motor Neurone Disease research, hot off the press.



- The aim is to let people know what is going on with simple summaries of the scientific papers in MND research.
- If people understand the work going on they can be more involved.
- They do this by partnering with a lay panel made up of the public who provide feedback on the summaries.
- Anyone who has been affected by Motor Neurone **Disease** can help by providing feedback on the summaries before they are published to make them as 'readable' as possible.

This team recently produced a lay summary from an important study "**Exploring a new drug to protect motor neurons and treat ALS/MND**". Its scientific title is Neuroprotective effects of Elloraxine in neuronal model of degeneration. There is a link to the full study published last year on the Readable Research RR site.

The team felt this was an important study to look at because "we may be able to slow the progression of ALS with the potential neuroprotective effects of a new drug called Elloraxine, a synthetic version of vitamin A."

They explain what the authors of the study did, how they went about it and what the results were. Finally, whilst acknowledging that such research was still in the early stages, they explain what the findings mean going forward for people with MND.

They would like to **recruit** more MND panel members to the scheme. You can do this from home. It normally consists of 1-2, two-page summaries every month and you'll be given specific guidance on the type of feedback that they need.

If you are interested and would like to help, then please contact Dr Scott Allen s.p.allen@sheffield.ac.uk

If you have any research questions having looked at this study or having browsed the site, you can contact email@readableresearch.com

Bare Legs Brian's Next Challenge

5 Capitals Challenge



April 7th is not far away now and I am almost ready for the first part of my 2025 challenge. I have accommodation for three of the five nights I need and have to find somewhere for Market Harborough and Luton. AirBNB, Premier Inn or Travelodge might suffice for those unless anyone can come up with some hospitality for those places in the next few days. Cardiff comes along in June, then Edinburgh in July, with Dublin and Belfast in September. Watch out for my posts on Facebook, the South Yorkshire Facebook and on my website.

BareLegsBrian on a Bike

Stitch and Sew

Stitch and Sew are a welcoming community group based at Draycott Walk Community Hall in Skellow. Throughout the year they make items to sell at Christmas Fairs, the proceeds of which they donate to charity. South Yorkshire Branch is pleased that this year they chose to support us and presented us with a cheque for £392. Many thanks to everyone at Stitch and Sew for your support.



Teen Day

Unfortunately, we have had no interest shown for the Teen Event. As we need to inform the venues by the 25th of March, it has been decided not to go ahead.

Hopefully, we can try again in 2026.

Family Fun Day

As the Teen Event is no longer taking place, the South Yorkshire Branch will hold another Family Fun Day at Gulliver's Valley on Saturday 21st June. Registrations can begin from the beginning of March. Contact Ann Quin, Chris Naylor or Brian Jackson.



Fundraising Event at the Royal Oak, Ulley

Pete and Lesley, of the Royal Oak in Ulley near Rotherham are kindly organising a number of events this year in support of the South Yorkshire Branch of the MND Association. On Bank Holiday Monday 5th May, they are holding a Fun Day complete with Morris Men, Clog Dancers and various other activities. All are welcome. Please make a note in your diary and come along and help to raise funds for the Branch.

Many thanks to Pete, Lesley and staff for their support.

Sterling Meat Company

In January John Viggars, Managing Director of Sterling Meat Company presented a cheque for £1,000 to the South Yorkshire Branch of the MND Association at the Royal Oak in Ulley.

The money was raised from the 10p surcharge which is payable on plastic carrier bags. South Yorkshire Branch would like to thank Sterling Meat and their branches in Hellaby, Barnsley and Doncaster for this amount and what an innovative way of raising money!



Frecheville Carnival

Frecheville Carnival Committee have chosen MNDA South Yorkshire as their charity for 2025. The Carnival will be held on Saturday 28th June at and around the Community Centre on Churchdale Road, Sheffield S12 4XT commencing with the Grand Opening at 11 00 am and events run all day until 5 30 pm.

Entry is free and the day is planned to have Craft Stalls, Cake Stall, Food Stall, Games, Music and more. There will also be a Bar area.

The Branch will be contributing to the day by having a Branch presence with the opportunity to raise awareness of MND.

All proceeds will be going to the MNDA South Yorkshire Branch so please put this date in your diary and come along for a day out and help to support us.

SUPPORT GROUP MEETINGS

- 1 In Sheffield – Peer Support Cafe meetings are held on the last Wednesday of the month from 2.15 pm until 3.45 pm at Clifford House, Ecclesall Road South, S11 9PX.
Meeting dates are 26th March, 30th April and 28th May 2025.
- 2 In Barnsley – Peer Support Group meetings are held on the first Friday of the month from 1.30 pm until 3.00 pm at Emmanuel Church, Huddersfield Road, Barnsley S75 1DT.
Meeting dates are 7th March, 4th April, 2nd May and 6th June 2025.

All people across South Yorkshire who are affected by MND are welcome at any of our support meetings. Please contact Jayne.Thompson@mndassociation.org for further details about Support Group Meetings.

PAST CARERS' MEETING DATES

Meetings will take place between 10.30 am-12.00 pm on the first Thursday of alternate months in the Holiday Inn, West Bawtry Road, Rotherham S60 4NA

(2 mins off M1 Junction 33) on the following dates - 3rd April 2025 and 5th June 2025

FORTHCOMING EVENTS in 2025

Saturday 10 th May	Spring Quiz at Rotherham Titans Rugby Club, Clifton Lane Rotherham S60 2SN
Tuesday 3 rd June	Doncaster Golf Day at Wheatley Golf Club, Armthorpe Road Doncaster DN2 5QB
Saturday 21 st June	Family Fun Day at Gulliver's Valley, Mansfield Road, Sheffield S6 5QW
Wednesday 25 th June	Golf Day at Dore & Totley Golf Club, Bradway, Sheffield S17 4QR
August 2025 Date to be confirmed	Walk to D'Feet at Lakeside Village Shopping Centre, White Rose Way, Doncaster DN4 5PH
Friday 1 st August	Golf Day at Hallowes Golf Club, Hallowes Lane, Dronfield S18 1UR
Friday 29 th August	SMH Golf Day Chesterfield Golf Club, Matlock Road, Walton Chesterfield S42 7LA
Date to be confirmed	Soak a Scientist, Endcliffe Park Rustlings Road, Sheffield S11 7A
Saturday 20 th September	Dreamboats & Petticoats Concert, Beighton Miners' Welfare Recreation Ground, High Street Beighton Sheffield S20 1ED
Friday 10 th October	MND Quiz Tpton Hall, Shore Lane, Sheffield S10 3BU
Further Events Dates yet to be confirmed	Band Concert, Jazz Concert and Christmas Concert – all at Niagara Conference Centre S6 1L

The Motor Neurone Disease Association

Website: 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

South Yorkshire Branch

Website: www.mndassociation.org/southyorkshire

Committee Members 2025

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Vacancy

Website Administrator: Vacancy

Social Media Administrator

Vacancy

Area Support Co-ordinator:

Jayne Thompson

jayne.thompson@mndassociation.org

Relationship Fundraiser:

Jenn Scribbins

jenn.scribbins@mndassociation.org



MND Coffee Club at Clifford House

Last Wednesday of each month,
2.15pm until 3.45pm

Do you have MND? Are you affected by or care for someone with MND?

Join us at our tea & coffee club, this is a safe space to meet others from the MND community for peer support, chat or just listen.

Clifford House (part of St Lukes Hospice), Ecclesall Road South,
Sheffield S11 9PX

Free parking & complimentary tea & coffee

Contact Jayne Thompson at
jayne.thompson@mndassociation.org
or call 07811 280893

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www.mndassociation.org

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