

NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

WINTER 2024



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Welcome to the Winter Edition of the South Yorkshire Branch Newsletter

As we approach the end of 2024 it gives the Branch Committee an opportunity to reflect on our efforts to organise as many fund-raising events as possible throughout the year to support as many people living with MND in the South Yorkshire area as possible. As you will see from the Treasurer's Report, this year has been a successful one for the Branch in terms of the money raised. Enormous thanks must go to 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. Despite the current financial situation so many are facing, people have dug deep. Thank you to all of you who have supported us. Please remember, we are here to help in any way we can, so please do speak with your Association Visitor or contact Brian Jackson if you need help.

The Branch Newsletter cannot, unfortunately, include every

event in its issues, but if you do wish to contribute an item that you feel would be of interest to our readers, please do send them to me, along with photos if possible. If your article has missed the deadline for the current edition, it can always be included in a future one. The fund-raising committee are always interested in your views on the kind of fund-raising events you would like to see take place, so again, please get in touch with us with your ideas.

Once again, a huge thank you to everyone who has supported the Branch. Amongst those thanks are John & Jill Hill, Mensa Printers for the professional production of the newsletter and to Sutton McGrath Hartley for their ongoing funding of it. Lastly, but not least, thanks to all 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, have a very Merry Christmas and every good wish for 2025.

Chairman's Report

Dear All,

I hope you are all well in the run up to the Festive season as we inevitably reflect on the year that's gone. It's been another tumultuous time with some astonishing and almost unbelievable events unfolding here and abroad. As I write this, the phenomenal Kevin Sinfield is once again performing a marathon feat to raise both money and awareness of MND. The SY branch has also had a fantastic year in terms of both raising funds and supporting PLWMND as you will have read in Paul's report. We have also been extremely fortunate to have our income matched by the very generous policy of the local Lloyds branch and our thanks, and your thanks, goes to them for that.

We have had some very successful events this year and it will be a challenge to repeat this in 2025 but that won't stop us trying! Our tireless teams are already planning events for next year and these include repeats of previous successes as well as new events. Brian is once again getting on the road in a brand

new challenge to cycle from his home to the capitals of our four nations, whilst sporting events and music events will be worth watching out for.

I hope you enjoy the newsletter, and I would like to wish you a happy and peaceful festive period and look forward to seeing you all at one of our events in the New Year.

Finally, I would like to thank all of the committee and all the local volunteers for their tireless efforts, without which, the branch simply would not function.

All the best.

Andrew

Treasurer's Report

I report on the third quarter of the financial year which ended on 30th September, which has been another brilliant period. Our receipts for the quarter totalled £25,991, making total income for the first 9 months £79,380.

We've never had a year so good and we cannot expect income to continue at this sort of level.

Special thanks should go to SMH whose golf day made a massive contribution this quarter, as reported in the last newsletter. Also, to those at the Dragon's Tap in Rotherham who raised £1,385 and Lloyds Bank who again gave us some matched funding. In October, Jill and John Hill organised another successful quiz at Tapton Hall raising £1,523, and St Vincent's GAA raised over £1,500 at their event. Total income of the branch to the end of October was £86,216.

We were also successful in providing grants to those with MND who needed support. Total grants made for the above quarter were £18,649 making the total this year £45,391, with a further £6,216 in October. Demand has never been so great. Winter is always a quiet period for income, and although grants required are likely to continue at a high level, we have sufficient reserves to be able to fund these. Our balance of unrestricted funds at 31st October stood at £35,333. It is the intention of the committee to use some of these funds to support local research projects.

Paul

Donations

If you wish to donate to the Branch, cheques should be made payable to "MND Association South Yorkshire" and sent to me. You can call me on 07729 118590 or e-mail me at paul.hebblethwaite@mndassociation.org and I can advise you how to donate.

Alternatively, you can contact the Assistant Treasurer, Kirsteen Booy on 07749 111 570 or email her at kirsteen.booy@mndassociation.org

To donate to the South Yorkshire branch via Just Giving, go to the website home page www.mndassociation.org/southyorkshire and use the "Give now via JustGiving" tab.

St Vincent's Round Sheffield Walk

St Vincent's GAA (Gaelic Athletic Association) was established in Sheffield in 2017. St. Vincent's GAA provides opportunities for people in Sheffield and the surrounding region to play Gaelic sports here in the heart of South Yorkshire.

This year, the club chose to fundraise for the MNDA South Yorkshire branch to support the amazing work that the charity does to support people with MND and their families in our local community.

On Saturday 28th September 2024, we undertook the popular 'Round Sheffield Walk.' This is a 15 mile walk which starts and ends at Endcliffe Park.

The walk takes you around the city through scenic parks and beautiful woodland trails.

A total of 22 people, including players past and present and friends of St Vincent's GAA completed the walk. The sun shone all day making it a very enjoyable experience for all.

We fundraised a total of £1504.21 for the MNDA South Yorkshire branch.

A sincere thank you to everyone who participated and donated to our event!

Thank you also to the MNDA South Yorkshire committee for their support in organising our event.

Written by Helen Hynes, on behalf of St. Vincent's GAA



Cinq Mille Accroupissements pour MND

Tracy Woodward has been fundraising for the branch for many years. Marathons, Half Marathons and Tough Mudders are her usual challenges. Tracy also runs a Saturday morning bootcamp at various locations in Barnsley and Sheffield, and I attend regularly.

Last month, as a team, we took up the Association's challenge of 5000 squats in November for MND. So, in addition to running and interval training, we did sets of 30 squats along the way. However, to ease the pain and drown out the noise of creaking knees we counted down the sets in different languages.



French, German and Spanish. Exercising mind and body and smiling throughout, the girls also generously donated to the branch for the pleasure of this Saturday morning ritual.

Thank you, Tracy, and everyone for the strong legs, smiles and support.

Ann



New Changing Places Pods

Four new Changing Places pods have been built around the city to help make Sheffield accessible for more residents. Changing Places pods include an adjustable adult-sized changing bench, an electric hoist system, electric adjustable sink, a privacy screen and a non-slip floor. Providing these toilets in public places makes a dramatic difference to the lives of thousands of people who desperately need these facilities. Many people with profound and multiple learning disabilities, as well other disabilities that severely limit mobility, cannot use standard accessible toilets. People may be limited in their own mobility so need equipment to help them or may need support from one or two carers.

The new facilities can be found at Hillsborough Park, Millhouses Park, Crystal Peaks Shopping Centre and Weston Park Museum. Residents can also find more of these accessible toilets across the city and in parks including the Moor Market, Rivelin Valley Park, Cambridge Street Collective, the Town Hall and more.

Cllr Kurtis Crossland, Chair of the Community, Parks and Leisure Committee at Sheffield City Council, said:

“The addition of these Changing Places toilets are a vital part of making Sheffield a city that is accessible to all residents.”

Between 2022 and 2023, Sheffield City Council applied for two rounds of funding from the Changing Places Fund at the Department of Levelling Up, Housing and Communities. The Council were successful in both applications, which covered the four sites.

The Council are now pleased to announce that all four Changing Places toilets are built and open to the public at all four sites, improving the accessibility of all four of these locations and adding four new fully accessible toilets to the city.

September 2024

Camino de Santiago Walking Challenge

The Camino de Santiago is a pilgrimage to what is believed to be the final resting place of St James the Apostle, which is located in the cathedral of Santiago de Compostela, Spain. Our Vice-chair, Julie Ward, decided that she wanted to take on the challenge of walking 125 kilometres over 5 days, starting from Portugal and concluding at the cathedral in Santiago de Compostela.

Julie was motivated to take on the challenge in order to remember her husband, Roy, who was diagnosed with MND 10 years ago, as well as raising funds for the South Yorkshire Branch of the MND Association.

Accompanied by four close friends, Julie set off on 1st September to walk the Camino Portugues or Portugese Way. They covered around 25 kilometres per day for the next five days and literally limped into Santiago de Compestela in the pouring rain!

The Branch extends thanks to Julie and friends for taking on the challenge, raising £1000 which will be used to support those living with and affected by MND in South Yorkshire.



Grants Update

As of the 11th November, there has been £53,808.85 paid out in grants this year.

The South Yorkshire Branch has contributed £51,708.85 of that amount. This has been made up of 37 Quality of Life grants, 27 Support grants, 20 Carers' grants and 8 Children and Young People grants. There were 58 individuals supported by these grants.

Further news on the grants front: the Cost of Living grant has now been raised to £500. Anyone who has received £350 (the former amount) this year can request the additional £150 before 31st December. If you need any more information about grants, contact Brian Jackson. His details plus the new flyer on grants can be found in the Newsletter.

35th International Symposium on MND

Early December is a very important time for research at the MND Association as it hosts the annual International Symposium on ALS/MND. This year marked the 35th Symposium, the largest scientific and medical conference specific to ALS/MND. This global event gives the MND research community the chance to share their work, exchange knowledge and foster new collaborations.

In 2023 the Basel symposium was attended by over 1300 delegates from 44 different countries, including researchers, healthcare professionals and people from the wider MND community.

This year, the Symposium was held in Montreal, Canada from the 6th– 8th December but

there was also a virtual option for attendance. The virtual attendance allowed delegates to watch select sessions live, with on demand access for all sessions available after the event too.

There were 20 plenary speakers talking about ALS/MND covering a wide range of topics from understanding more about the biology of MND to improving care and support for people with and affected by the disease.

For a full account of the symposium go to the Association website <https://symposium.mndassociation.org> If you are interested in research signing up to the Association MND Research Blog is a really good way to find out more.

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35th international
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Bare Legs Brian's 2025 Challenge

It's back on his cycle for Bare Legs Brian in 2025. He will be cycling from Sheffield to each of the nation's capitals and including Dublin. These journeys will take place in different months throughout the year. The mileage covered by the rides is likely to be close to 1000 miles in total.

Brian is looking for overnight accommodation in various places on his journeys. At present, out of the 23 overnight stays, he has nine definite offers. If you feel you are able to help in any way, please, get in touch with him using the contact details at the back of the newsletter. Keep an eye on social media for further news.



Movie Music, Musicals & More



There was a packed house for the final, branch fundraiser band concert of the year, at the Niagara in Sheffield on Sunday 17th November. Unite the Union band delighted the audience with some, well loved Movie and Musical numbers from many eras and it was a wonderful evening. The band thanked Doreen and Trevor Peacock for their excellent planning again. In addition to the fabulous music, there is always a delicious selection of cakes and other stalls as well as the usual fundraising entertainment. Thanks to all the branch volunteers.

November's concert raised over £2,000 to add to the magnificent total raised by all the brass band concerts playing in aid of MND, in South Yorkshire in 2024.

Thank you to Kath Groom

At the last branch committee meeting on 13th November, we said goodbye and thank you to Kath Groom who has stepped down from the committee after 25 plus years. Kath's husband John died of MND in 1997 and she was one of the first members of the newly formed South Yorkshire branch at that time. This group of people, affected by MND, began to meet together on a regular basis for support, and Kath helped to organise the first meeting and refreshments at Wickersley in Rotherham. Kath continued to organise

refreshments and volunteer at all the Open Meetings in South Yorkshire throughout the years, as well as joining the branch committee and fundraising in many ways.

Kath explained that back in 1996 they were fighting to get riluzole on prescription and Kath as an early campaigner appeared on local television to promote the cause. Kath will undoubtedly be missed but she intends to keep in touch as a general branch volunteer. On behalf of the MND community in South Yorkshire we wish her all the best and send heartfelt thanks for all she's done.



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
- 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. No January meeting. Next Meeting Friday 7th February 2025
- 3 **In Doncaster** – The Doncaster Group meeting is cancelled until further notice.
- 4 **Rotherham** – The Rotherham Carers Group meeting is cancelled until further notice.

All people across South Yorkshire who are affected by MND are welcome at the Sheffield and Barnsley 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 Conservatory Restaurant, Holiday Inn, West Bawtry Road, Rotherham S60 4NA (2 mins off M1 Junction 33) on the following dates: -
Next meeting Thursday 6th February 2025

DATES FOR YOUR DIARY

Our next Newsletter due in March will have confirmation of the 2025 events.

If you would like to share information about fundraising or events relevant to people in South Yorkshire affected by MND please contact our Secretary Chris Naylor christine.naylor@mndassociation.org



Children, Young People and Families **Counselling and Support**

providing one to one counselling to children and young people under the age of 25 affected by MND; in partnership with Barnardo's.

Improving mental health and emotional wellbeing.
Exploring fears, anxieties and difficulties.
Reducing feelings of isolation.
Supporting family stability and resilience.
Focusing on strategies and practical solutions to challenges.
Empowering parents to support their children.

**To refer please contact your local
Area Support Coordinator or
Laura Willix: 01604 800633
laura.willix@mndassociation.org**

www.mndassociation.org

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The Motor Neurone Disease Association

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MNDA Connect Helpline 0808 802 6262

South Yorkshire Branch

Website: www.mndassociation.org/southyorkshire

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MND Grants - what's available for those living with or affected by Motor Neurone Disease.

MND Support (care) Grant

Up to a maximum of £1500 per application. Predominantly equipment or adaptations requiring a professional assessment.

An MND Support (care) Grant must be accompanied by an assessment from the relevant Health or Social Care Professional. Examples of funding would be contributions towards: -

- Adaptations to property
- Stairlift rental/purchase
- Washer dryer toilet
- Respite care costs
- Riser recliner armchair

Included in support grant limit of up to £3000 in a rolling 12-month period.

Quality of Life (QOL) Grant

Up to a maximum of £500 per application. Serves to support both the person with MND and the family.

Our Quality of Life grant can help towards services or facilities which help maintain a person with MND's independence, dignity, comfort, and social connections. It can also be used to contribute to the cost of things which promote the well-being of the person with MND and immediate family. Examples of funding would be contributions towards: -

- Support with essential garden and home maintenance
- Daily living aids
- Holidays / Days out
- Keeping connected
- Hobbies and interests
- Special transport
- Complementary therapy

Included in the support grant limit of up to £3000 in a rolling 12-month period.



Cost of Living Support Fund

From November 2024, our Cost of Living Support Fund is available for people with MND facing financial hardship with a one-off payment of up to a maximum of £500 towards household bills and food shopping costs.

Outside the support grant limit of up to £3000 in a rolling 12-month period



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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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