NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

AUTUMN 2024



Inside: Tough Mudder Paul's Challenge Crosspool Open Garden

www.mndassociation.org/southyorkshire Facebook: southyorkmnd

Twitter: SYMNDA



Registered Charity No 294354 Branch Patron: Suzanne Maguire

Newsletter Sponsors



Welcome to the Autumn Edition of the South Yorkshire Branch Newsletter

Welcome to all those new readers of the Branch Newsletter. It's an opportunity to share with you some of the events we have held since our last publication and to let you know important news about the Branch, forthcoming events and latest information into research. We are always willing to share any articles that you feel would be of interest, your experiences of places to visit that are accessible to all, so if you have something you would like to contribute, please do contact me.

This year has been very successful in fund-raising and thanks must go to the fund-raising committee for organising these events and of course, to all those of you who have supported these events over the past months. The aim of the Branch is to help and support as many people living with MND, and their carers, throughout the South Yorkshire area. If there is any way in which we can be of help, please do get in contact via your Association Visitor, the Branch Contacts. Brian Jackson who handles Grants on behalf of the Branch, or Jayne Thompson, the

Area Support Co-ordinator.

Please note that one of our fundraising events (Unite the Union Band Concert) scheduled for 13th October has had to be postponed, but a new date has been arranged for Sunday 17th November, same band, same venue. We look forward to seeing some of you there.

Raffle and Tombola Prizes

Do you have any unwanted gifts that could be donated to the Branch as raffle or tombola prizes?

We are always in need of contributions towards the many events we hold where a raffle or tombola is held. Trevor and Doreen Peacock do a sterling job in collecting and collating items so anything that you think may be suitable for a raffle or tombola prize, please contact them directly. Trevor's contact details are Trevor. Contact details are Trevor. Peacock56@gmail.com

MNDA South Yorkshire Branch Calendar

Following the first print of a Branch Calendar last year, we are delighted to announce that the MNDA South Yorkshire Branch Calendar for 2025 will be available in early October and will be on sale at the Quiz at Tapton Hall on 11th October and the Band Concert on 17th November. Photographs have been taken by our Chairman, Andrew Gibson. The Calendar costs £8 at events, or £9 if you wish to receive it via post and can also be obtained by contacting me on Christine.naylor@mndassociation.org Please consider purchasing a calendar and help to fund-raise at the same time.

Finally, some exciting news!

Joe Linsky, our new Communications Lead is planning to take the South Yorkshire Branch of the Motor Neurone Disease Association up a notch with the launch of our brandnew, bi-monthly email newsletter! You won't want to miss this—get all the latest updates, heartwarming stories, inspiring volunteer showcases, exclusive videos, and insider news on our fundraising events, delivered right to your inbox every two months.

Stay connected, stay inspired, and be part of our incredible community. To make sure you're in the loop, sign up now https://forms.office.com/e/Bygm59YA1z.

Happy reading!

Chairman's Report

Dear All

We are closing in on Autumn fast and the year has flown by for me!! It has been a good summer for the Branch, and you will see our Treasurer's Report detailing our successes and events so that our financial position is very positive at the moment.

We have been able to continue to support PLWMND at 100% since earlier in the year and that is all due to the fantastic generosity of you and the people of South Yorkshire. In addition, our funding planning continues to develop, and we are very proud of the initiatives that we have supported. In view of the success of the Family Fun Day at Gulliver's Valley we are exploring a new venture aimed at giving a fun day out for teenagers whose lives are touched by plwmnd. Once we have sorted out the detail, we will be asking for expressions of interest from 13-18 year olds. So be sure to look out for that exciting prospect which is likely to be in the Spring of 2025.

Look after yourselves and we hope to see you at one of our events in the near future.

Andrew

Christine

Treasurer's Report

I report on the second quarter of the financial year to 30th June 2024, which has been our most successful ever. First of all, we received a legacy of £10,000 from a will. Then, as previously reported, we received the proceeds of the Rotherham Titan's quiz, and from a ladies' event at Doncaster Golf Club. We also received £3,000 from The Inner Wheel of Doncaster. We must also send our grateful thanks to the Lloyds Bank Foundation who through matched funding and funding of our volunteer hours, gave £7,980 this quarter.

Our thanks go to Fran, the charity officer, who made this application successful.

The total income for the quarter was £40,343 and the running total for the year is £53,388. It should also be mentioned that we received a cheque for £2,500 from the Dronfield 41 Club as a result of the Hallowes golf day on 2nd August. We are most grateful to them for organising this excellent annual charity golf day.

Expenditure on care, equipment and support for the quarter totalled £20,619, which is also a record for any quarter. In addition, there are a large number of grants in process.

We are helping more people than ever before, so it's good news all round.

The continued success of the Branch reflects the hard work that all our volunteers do. Well done everyone.

If you wish to donate to the Branch, cheques should be made payable to "MND Association South Yorkshire" and sent to me at my address, Mr P Hebblethwaite, 55 Newfield Lane, Sheffield S17 3DD. You can also pay directly to the Branch, account number 02972378, sort code 30-96-09 You can call me on 07729 118590, e-mail me at paul.hebblethwaite@mndassociation.org or contact the Assistant Treasurer, Kirsteen Booy on 07749 111 570 or contact her on kirsteen.booy@mndassociation.org

Paul

Pub Holds Pirate Day in aid of MND

On Sunday 4th August the Dragons Tap in Rotherham held a Pirate Day. With the micropub decorated with pirate related items various events took place to raise funds for the MND Association South Yorkshire Branch. These included Fancy Dress, a pirate related Murder Mystery, Find the Missing Treasure Chest on the Treasure Island Map, a Pirate-related Quiz, Tombola and Guess the Number of Sweets in the Treasure Chest. Good fun was had by all and with matched funding from an anonymous donor a total of £1,374.60 was raised. Thanks must go to Greg Heap and Dragons Tap who made this event happen and such a big success. Enormous thanks to the anonymous donor, whoever you are.

Do you have Motor Neurone Disease (MND) or know someone who does?

Researchers from the University of Sheffield are developing technology to help support people living with MND.

We are inviting people with experience of living with MND to share their feedback on a new digital tool which we hope could help identify memory or cognitive difficulties and enable better access to support for this.

Can you help?

If you would like more information, please contact: Lise Sproson

Email:<u>Lise.Sproson@nihr.ac.uk</u> Telephone: 0775 3827428

We can offer reimbursement as a thank you for your time







The following is the Press Release issued by Sutton McGrath Hartley (SMH Group) which the South Yorkshire Branch is proud to include in this edition of the Newsletter

SMH Group raises over £12,000 for MNDA in Fourth Annual Charity Golf Day

SMH Group, a Yorkshire and Derbyshire-based firm of chartered accountants and business advisers, raised over £12,000 for their chosen charity of the year—the South Yorkshire branch of the Motor Neurone Disease Association (MNDA)—at their annual charity golf day on 23rd August 2024 at Chesterfield Golf Club.

The day kicked off with bacon sandwiches for all the players. Despite initial concerns about strong winds, which threatened to disrupt the day's events, the sun eventually broke through. The event saw 104 players across 26 teams from local businesses, all competing for various prizes, with the Sickleholme Bandits emerging as the winners. The day was wrapped up with fish and chips, and an auction in the clubhouse, adding a perfect ending to a successful day.

The day was organised by raffle and auction prizes were Ross Jordan, a Partner at SMH invaluable. We are also deeply

BullockWoodburn, part of the SMH Group. Ross noted that the event not only provided clients and close contacts of the firm with a valuable networking opportunity but also served as a crucial fundraiser for a deserving local charity.

The MNDA holds a special place in the hearts of many at SMH Group, as it supports those affected by the life-altering impact of Motor Neurone Disease (MND). With no known cure, the MNDA is vital in offering essential care, support, and funding for research to improve the lives of those battling MND.

Ross Jordan commented: "As a forward-thinking company, we set out to make this year's charity golf day our most successful yet. Building on the success of previous events, we set a high fundraising target and are thrilled to have surpassed it, raising nearly twice as much as last year. "This achievement is thanks to all our sponsors, whose generous donations for tee sponsorship, competition sponsorship, and raffle and auction prizes were invaluable. We are also deeply

grateful to all 26 teams who participated and donated—we couldn't have done it without you! "We had a fantastic turnout with enthusiastic and competitive golfers, making for an exciting day filled with individual and team competitions for first, second, and third place.

"Congratulations to the Sickleholme Bandits for securing first place, as well as Matt Civil of Connected Search Group for winning the longest drive competition, Wes Price and John Pointon for their closest to the pin victories, and Josh Butterworth for winning the simulator closest to the pin competition."

Paul Hebblethwaite, Treasurer of the MNDA South Yorkshire Branch added: "The raffle, combined with the various fundraising activities that took place throughout the day, raised an impressive sum of over £12,000, all made possible by the remarkable generosity of the SMH Group, the sponsors of the event and the golfers who participated.

This significant contribution will have a meaningful impact, helping us to continue our vital work in supporting individuals and families living with Motor Neurone Disease (MND) in the South Yorkshire area. The choice

of the SMH Group to support the MNDA charity means so much to the Branch, as it ensures that we can carry on providing essential care, services, and research funding to those affected by this devastating disease. The support from events like this makes all the difference, and we are proud to have partners like the SMH Group and such a generous community standing with us in this cause."



The South Yorkshire Branch of the Motor Neurone Disease Association can be contacted via its Branch Secretary on 0114 265 3774 or by visiting: https://www.mndassociation.org/support-and-information/local-support/branches/south-yorkshire-branch/

Going above and beyond: Making a Difference & Making Memories

Lucy Richardson recently received a certificate for "Individual of the Year" 2024 at The Rotherham NHS Foundation Trust's Annual Proud Awards in June. The awards celebrate the achievements of the Trust's staff and the impact they have on the people of Rotherham.

Wayne Cooper applied to attend the South Yorkshire Branch Family Fun Day in 2023. He was living with MND and wanted to attend with his young daughter to watch her have fun and make memories. Unfortunately, Wayne was wheelchair based and living in a first-floor flat awaiting rehousing. There was no lift, and it wasn't suitable for a stairlift, so Wavne was confined to his flat. Lucy is a Health Support Worker for the Trust who visited Wayne and his family at home offering support with many aspects of his day to day living with MND. She knew how much it would mean for them all to have a family day out at Gulliver's Valley. The only safe way to get Wayne down the stairs was with help from professionals so Lucy called on the fire brigade. She rustled up

some volunteers to carry Wayne and his wheelchair downstairs and organised transport to the theme park. When the family had enjoyed a lovely day on the rides in the sunshine, Lucy organised the volunteers to get him home again safely.



Lucy (in green) with Proud award winners.

Sadly, Wayne died some months later so the exercise couldn't be repeated, but his daughter and her Mum wanted to relive that happy day and applied again for the Family Fun Day this year. Lucy was recognised for going above and beyond in 2023 and was rightly recommended for an award from her Health Trust.

Lucy has a lot of experience with families affected by MND and has been volunteering with the Branch for a while. In addition to making memory boxes Lucy helps people to sell equipment when it is no longer needed. She is internet savvy and recently helped the family of the late Joan Morris to sell goods on line raising more money for the local branch. If you'd like Lucy's IT help you can contact her at Lucyrichardson243@yahoo.co.uk.

Many thanks Lucy

Crosspool Open Gardens June 2024

Mavis Roadhouse has been opening up her lovely garden to the public for this annual event for many years. This year, supported by her friend Jill Hill, the South Yorkshire Branch of the MND Association was her chosen charity. Thank you, Mavis, for raising awareness of the disease locally and for the funds raised too.

Jill Hill's volunteering for the Association goes back a very long way and the hugely successful Annual Quiz that she and her husband John organise has raised thousands of pounds for branch funds. We asked Jill how she first became involved. Jill said "I first became aware of Motor Neurone Disease when my father was diagnosed way back

in 1975. Fortunately, he lived another 11 years and since then we have, as a family, supported fund raising for MND. Originally, we supported the National Association but since 2012 we have supported the local branch as well.

My main area of raising money is through the Annual Quiz Night and Pea & Pie supper we hold at Tapton Hall. This started with a modest 50 people attending and has grown to over 140.

Recently I helped at one of the open gardens in Crosspool where £350.00 was raised to support the local branch.

Now I am busy making up my questions for the coming quiz night - Friday October 11th this year - do contact me via E mail if you would like to come Jillandjohnhill@aol.com "



Paul's Challenge 2024

I have done numerous challenges over the years, but it's been a few years since my last. I therefore decided to sign up for a 52k walking challenge from Bakewell as advertised in the MND magazine.

Over 3,000 people were raising funds for their own charity, and there were different other challenges over the weekend; 100k, 75k, 25k and 10 miles.

It was an early 7 a.m. start and the weather was ideal for walking. There were 3 stops on the way with food and drink and medical support. The organisation was brilliant. I talked to numerous people on the way round, each with their own stories of why they were raising money for their charity. Some had lost loved ones and some were living with someone affected by a disease.

It was both informative and inspirational to listen to them.

Being a regular walker, I was confident of completing the challenge, having done the necessary training as advised by

the organising company.

I completed the full distance in 11 hours 20 minutes, tired but in good spirits and free of injury. I raised £1,300 on my Just Giving page, which is still open should anyone like to contribute.

Go to www.justgiving.com and search for 'Paul's 50k challenge for MND'.

Do consider raising funds for MND by doing a fundraising event. There are many options if you look on the MND Association website.



Dore & Totley Golf Day

This was the second golf day that I organised. The event was originally set for May but had to be cancelled due to heavy rain. Thankfully, 17th July was a fine day and 56 players competed. I had some brilliant support from the members and staff at Dore & Totley and I wish to send them all my thanks. In total, we raised £1,890, slightly down on last year, but not bad considering the cancellation of the original event.

Gulliver's Valley Fun Day 2024

There was another successful day enjoyed by families at Gulliver's Valley in June when we saw 20 families enjoy a day of fun and meeting others. There were 75 adults and 50 children who attended – three more children than last year. The weather was reasonably kind to us, although there were one or two showers which didn't particularly spoil the enjoyment. There were many photographs taken which are in the process of being matched with families. It was good to see so many families and youngsters enjoying a day out with parents and grandparents and also gave members of the Branch Committee great pleasure in meeting you all face to face.



An Upcoming Event for Teenagers

The South Yorkshire Branch is working on holding an event for teenagers aged 13-18 years of age who live with or are related to families affected by MND. We hope to hold this in April 2025 and aims to offer a range of experiences. Families interested will need to register their interest in the same way as with Gulliver's Valley so keep an eye open for further details.

Soak a Scientist

This year's "Soak a Scientist" in Endcliffe Park was once again a great success. The crowds were not deterred by the changeable weather and the enthusiasm of the SiTraN scientists helped create a memorable day in which we collected almost £650. The event also helped to promote awareness of MND as well as an opportunity to teach the visitors to our stalls about neuroscience and research into the neurological diseases like MND.

As you can see from the photographs taken by Sophia Sutherland, they did get a soaking but all in a great cause.



The cakes and savouries were all kindly baked or donated by

the scientists and went down very well with the park runners and park visitors. It would not have been as successful without the support and generosity of the people of Sheffield.



I would also like to thank the local businesses that supported the day with generous gifts for the tombola especially Tiara, Saypoloma, Porter Brook Deli, The Famous Sheffield Shop, Hollinsend Fire Safety, SUFC, Pom Kitchen, Naked Ape, Petal accessories and Sheffield Sharks.

We will be back every year until a cure for MND is found.

Andrew & Tobias

Tough Mudder

For 2024 I wanted to do something different as a fund raiser, after all it's not every year you have a significant birthday. An email dropped into my Inbox about doing a Tough Mudder and that became the inspiration for



this year's event.

Tough Mudder, to quote from the website "creates hardcore obstacle courses designed to test your all-round strength, stamina, and mental grit". They take place all over the world but Skipton in summer seemed a good choice. I discussed it with my grandkids to see if they thought I could do it and that was it, settled. When I say settled, there were family members who thought I was crazy but who am I to argue.

So, on the 28th July at Broughton Hall Estate near Skipton myself plus Lindsay one of my daughters and two of my grandsons, Luke and Zak, together with Luke's girlfriend Keelin, we assembled at the start to get ready to cover 15Km and 23 obstacles of varying types. This isn't a race but a challenge where everyone helps each other at the obstacles.

Looking around the crowd waiting to start I was clearly in the minority with regards to my age, but too late to worry about that as we started the warm-up. The first two thirds of the event was more about the distance than the physical obstacles. However, the estate is not flat, so we spent a lot of time going up and down hills in that first 10k.

The obstacles varied from getting over or under things. The under tended to involve water as well. It didn't take too long before I understood why it was called a tough mudder. The last third of the challenge was flatter and had a lot more obstacles but from here spectators could see you and cheer you on and take embarrassing photographs.

Would I do it again, no. Having said that I'm glad that I have done it with family - it was definitely a challenge, but I will try to pick something a little more sensible next year.

Paul Green - MNDA Visior

Research: Ways to get involved

In the Summer newsletter we highlighted the Readable Research scheme www.readableresearch.com at SITraN and their request for lay panel members.

Below is the latest paper to be reviewed by them with the opening paragraph. To read the whole review, log on to the site where you can also find a link to the full published study.

Trial indicates psychological therapy can improve quality of life for people living with MND

Lay summary by David O'Brien, reviewed by Ian Coldicott and an MND lay panel 29/07/24
Background

Motor neurone disease (MND) causes damage to the nerves controlling muscles involved in movement, speech, swallowing and breathing. There is currently no cure, so the main focus is on treating the symptoms of MND and maintaining quality of life. MND affects both physical and mental wellbeing, and we know that depression, anxiety and fear are common in those who have MND. We also know that people with MND might benefit from psychological support to cope with such a devastating diagnosis and adapt to their condition as it progresses over time....

Research updates at the MND Association.

People affected by MND attended many of the Association's Roadshows this year. At the Association's North Regional Roadshow in May the Executive leadership team held a Research Q&A session. They provided answers to people's questions such as:

"Physical exercise as a risk factor in MND is it on our genes?" The full questions and answers from this event can be found on the Association website www.mdnassociatio.org/ research and signing up to receive the MND Research Blog is a really useful way to keep in touch with what is happening. They have recently introduced a Back-to-Basics Series. The Back-to-Basics series aims to provide members of the MND community with a knowledge base of scientific topics that are relevant to MND research.

Using videos and graphics, the blogs will break down complex science so that you can better understand and easily follow the latest updates in MND research.

Each blog will have buttons at the bottom of the posts to click through to the next blog or go back to the previous blog in the series. You can also access all the blogs in the series via the menu at the top of the blog. As more posts are added to this series, these will be linked to the others and appear on the Back-to-Basics page. These blogs have been reviewed by

a small number of people with and affected by MND to provide us with feedback and ensure that the content is clear and easy to follow. We really appreciate the time that these people gave to help us with this and would like to say a huge thank you to them for their involvement in this project.

SUPPORT GROUP MEETINGS

- In Sheffield Peer Support Cafe meetings are held on the last Wednesday of the month from 2 00 pm until 3 30 pm at Clifford House, Ecclesall Road South, S11 9PX
- 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.
- In Doncaster Peer Support Group meetings are held on the first Friday of the month from 11 00 am – 12 30 pm at the Linney Community Care Centre, Weston Road, Balby, Doncaster DN4 8NF.
- 4 Rotherham for Carers. Herringthorpe Reform Church, Wickersley Road, S60 4JN held every eight weeks on Thursdays 2:00pm until 4:00pm, next meeting is 26th September

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

Please contact <u>Jayne.Thompson@mndassociation.org</u> 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: - Thursday 5th September Thursday 7th November

DATES FOR YOUR DIARY

Quiz Night

11th October 2024 @ Tapton Hall (with Pie & Peas) To take part and order supper, plus any dietary needs please contact Jillandjohnhill@aol.com

Unite the Union Band Concert

13th October 2024 - postponed Niagara Conference & Events Centre

Unite the Union Band Concert

17th November 2024
Niagara Conference & Events
Centre



Our Patient & Family Support service is coming to your area

Are you living with a palliative condition such as cancer, COPD, Parkinson's, or MND? Do you care for friend or a family member with a palliative condition?

Join us to explore the support available to you. You'll have the opportunity to connect with others who share similar experiences and enjoy some fun social activities. Our staff will be on hand to offer practical support, and complimentary drinks and cakes will be provided.



Secure your spot for our upcoming sessions by registering online at www.stlukeshospice.org.uk/pafs-outreach or contact us using the details below.

Q 0114 235 7650

pafss@hospicesheffield.co.uk



Registered Charity No. 254402

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 2024

Chair: Dr Andrew Gibson andrew.gibson@rcp.ac.uk

Vice Chair: Julie Ward julie.ward@mndassociation.org

Branch Contacts:

Ann Quinn
ann.quinn@mndassociation.org
Christine.naylor@mndassociation.org
Christine Naylor (0114 265 3774)
Christine.naylor@mndassociation.org

Treasurer: Paul Hebblethwaite (Home) (01142 363222) Mobile (07729 118590) paul.hebblethwaite@mndassociation.org

Assistant Treasurer: Kirsteen Booy Mobile (07749 111570)

kirsteen.booy@mndassociation.org

Secretary: Christine Naylor (01142 653774) christine.naylor@mndassociation.org

Grants: Brian Jackson (01142 376814)

(01142 376814) brian.jackson@mndassociation.org

Fundraising:

Temporary Lead: Julie Ward julie.ward@mndassociation.org Trevor Peacock trevorpeacock56@gmail.com

Quarterly Newsletter Editor: Christine Naylor (0114 2653774)

Communications Lead:

Joe Linsky Joe.Linsky@mndassociation.org

Website Administrator: Vacancy

Social Media Administrator

Wynter Yeomans wynter.yeomans@mndassociation.org

Area Support Co-ordinator:

Jayne Thompson jayne.thompson@mndassociation.org

Regional Fundraiser:

Jenn Scribbins jenn.scribbins@mndassociation.org

Jill and John's

Quiz Night with Pea and Pie Supper

In aid of Motor Neurone Disease Association - South Yorkshire Branch

Friday 11th October

7 for a 7.30pm prompt start

Bar from 6.45

Venue - Tapton Hall, Shore Lane, Sheffield S10 3BU

ONLY £17.50 EACH
Maximum number in a team 7

Prizes for the **RAFFLE** would be appreciate

BRING YOUR FRIENDS and ENJOY a GREAT NIGHT

There are pre- ordered Vegetarian and Gluten Free options available.

And please Email us with your name, number of places and any dietary requests

jillandjohnhill@aol.com mob. 07971235678 Tel. 01142301882

South Yorkshire Branch presents





Performing Movie Music, Musicals & More

Sunday 17th November 2024 at 7.30pm.

Doors, bar and sales table open from 6.15pm.

Niagara Conference & Leisure, Niagara Road, Sheffield, S6 1LU The venue is accessible with a lift and has FREE secure parking.

Tickets are £6 ordered in advance or £8 on the door available from Trevor Peacock on 0114 2422956 or trevorpeacock56@gmail.com





www.mndassociation.org

Francis Crick House, 6 Summerhouse Road, Northampton, NN3 68J Registered charity no. 294354 | Created in RightMarket - 19/1/2024 - 14:48:20

