NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

SUMMER 2024

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Living with MND and still loving life

Titans Support MND

Crosspool Festival

www.mndassociation.org/southyorkshire
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mnda
motor neurone disease association

Registered Charity No. 294354
Branch Patron: Suzanne Maguire

Newsletter Sponsors SMH Group

Welcome to the Summer Edition of the South Yorkshire Branch Newsletter

It seems hardly possible that we are half way through 2024 already. Throughout the next few months, the Branch Committee will continue to hold as many fund-raising events as possible to be able to meet all requests for support that we receive. Without the support of all our fundraisers and volunteers we would not be in a position to do this, so thank you to all our supporters in whatever capacity you contribute.

We welcome your ideas for new fund-raising events, so please do let us know your thoughts. If you plan to hold any of your own and would like someone from the Committee to come along do get in touch with us. Julie Ward our Vice-Chair is the Lead person to contact, or Trevor Peacock; their contact details are contained elsewhere in this newsletter and we will always endeavour to have a volunteer to attend to support your events.

The Branch is happy to welcome a new member to our committee, Joe Linsky, who will become Lead of Communications within the Branch – read more about him in this newsletter.

We are also happy that Wynter Yeomans has taken on the role of Social Media Administrator and will be handling Facebook and our social media platforms on our behalf.

The Branch is always looking for more volunteers, so if you have any time to spare and feel you can help in any way either by baking cakes for sale on our famous cake stall at band concerts, selling raffle tickets, or generally helping out at fundraising events, please do contact me for an informal chat – my contact details are Christine.naylor@mndassociation.org or chris222@sky.com

Branch Calendar

Last year the Branch published its first South Yorkshire MNDA Calendar, and it proved to be popular. Thanks to the photographic talents of our Chairman, Dr Andrew Gibson, we are planning to publish another one for 2025. Last year's calendar was snapped up (pardon the pun) quickly and we hope to have calendars available in early September. For those who purchased one last year I'm sure you will agree that the photos were excellent; the calendar would make an ideal Christmas gift as well as raising funds for the Branch at the same time. The price of calendars will be announced in the next newsletter and should be available at our events from September onwards or can be obtained by contacting one of the Branch Committee.

Request from the MND Association – MND Guarantee

Ensure your next MP champions people with MND by urging them to sign the MND Guarantee.

This month, the Association's Campaigns Team launched the new **MND Guarantee campaign,** ahead of the General Election. We're joining them in calling for everyone to write to their local MP candidates, urging them to sign the MND Guarantee, a commitment that will champion constituents living with and affected by MND. It's vital we get as many candidates as possible to sign the MND Guarantee to ensure we have local support from MPs, as well as a solid support base in the new Parliament, enabling us to keep making progress for the MND community.

Discover more about the campaign and find suggested wording to help you draft your email at www.mndassociation.org/MNDGuarantee

The lead up to the General Election is a pivotal time to engage potential future MPs and make sure MND is a key part of the next government's agenda.

Finally, let's hope that the next few months bring some much-needed sunny weather to enjoy.

Christine

Chairman's Report

Hello again and I hope that you are all as well as you can be as we wade through the waters of Spring into the sunshine of Summer. The gardeners out there will no doubt be, as I am, trying to recall a wetter start to the year. Indeed, such were the downpours this last week that we had, reluctantly, to cancel our golf day at Dore and Totley golf club which was, coincidently, the same day that our PM gave us news of the July 4th snap election. Things must have been pretty bad at number 10 as there wasn't an umbrella to be had anywhere.

However, our tireless Treasurer has managed to reschedule the event for the 17th of July, and I am confident it will be an enormous success.

The branch has already had a busy year and moving forwards we have a packed itinerary. Thanks to Julie, Paul and Kirsteen we held a highly successful quiz night at the Rotherham Titans RUFC which is possibly the most hospitable and generous rugby club in the UK. The quiz is sure to be repeated and its success was mirrored on the following day by the Titans winning their league. Well-done Rotherham Titans and thanks from us for supporting people living with MND. It means a lot to a lot of people in our local community.

In other news we have been joined by a new committee member Joe Linsky who is now our Communications lead. He will be a great asset to the branch and has already made significant improvements to our processes. In addition, he helps to reduce the average age of the committee by a decade or two!! Watch out for his work and communications as he gets to grips with his new role.

By the time this newsletter lands on your welcome mat we will be well into the process of choosing a new government with potentially great change in the offing. Whatever happens nationally there will still be the need for huge efforts locally to support people living with MND. Don't forget that we are always looking for help and if you think you would like to give it a try then get in touch.

Finally, I would like to wish you all the very best for the summer and look forward to seeing you at one of our events which will be fantastic whatever the British weather decides to throw at us.

Andrew

TREASURER'S REPORT

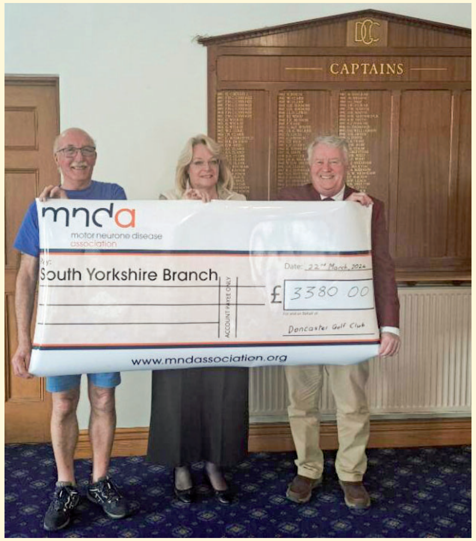
My last report related the positive news about the improvement in our finances in 2023, and I am pleased to report an excellent start to 2024. Our income for the first quarter to March 2024 was £13,045 (2023 £9,433), with a further £11,235 being received in April, including £3,380 from the ladies of Doncaster Golf Club who deserve special thanks. Reluctantly, our golf event on 22nd May was cancelled due to heavy rain, but we plan to rearrange that.

Expenditure on care, equipment and support totalled £6,122 (2023 £8,218) for the first quarter and a further £4,402 in April. There are a large number of grants currently in progress reflecting the demand for our services.

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

Paul

Donation from Doncaster Golf Club



On Friday, 22nd March I was invited to the Doncaster Golf Club for the handing over of a cheque for £3,300.00. This wonderful amount had been raised throughout the year by the past Lady Chair and Past Chair of the golf club with numerous fund- raising events after they had chosen the MNDA as one of their two charities. I was made very welcome and shared a meal with them. It is thanks to groups like this who provide the funds that allow us to continue helping people affected by MND in South Yorkshire. Thank you very much Doncaster Golf Club.

Bare Legs Brian

Meet a new member of the Branch Committee

Hi, I'm Joe a student at the University of Bath and I'm currently between Sheffield, Reading, Illinois, and Bath.

In September 2022, my close friend Richard was diagnosed with MND. Richard, once a vibrant sports enthusiast and the CEO of Kings Camps, a children's charity, has been massively affected by MND. However, his Christian faith has been his strength during this challenging period.

I'm very entrepreneurial, and wanting to do something to support Richard and help raise awareness, in May 2023 I set up a clothing brand called EndMND which donates all profits to the MND Association. All our products are designed to raise awareness.

I've recently joined the South Yorkshire Branch of the MND Association as the Communications Lead. This is a great opportunity to not only utilize my skillset, but also to enhance it. I work with a great team who are all very skilled in their areas and passionate about helping in this fight against MND, so I'd encourage anyone, whatever your profession is, to consider joining the team.

Working on these numerous roles takes time, but time is something that I have being a student (and unmarried), and volunteering is such a great opportunity to make a difference. I've got lots of exciting plans of how we can enhance our communication strategies. My aim is to provide care for those living with MND, but also to increase awareness and donations, all in the aim of ultimately finding a cure.

Joe Linsky

Living with MND and Still Loving life

(For all the weakening of my muscles and the consequent failings of my body, I am still me.")

Martin Kelly was diagnosed with MND in April 2017. Understandably a great shock for everyone. He was 59, fit, healthy and looking forward to a long retirement doing interesting things. Seven years later he has reflected on his situation many times. He recorded his learnings on the free app Record Me Now. This app allows you to make a lasting video legacy for yourself, your family and loved ones. It uses prompts.

Martin shared what he called "his ramblings" with us. "Maybe for the interest of some and hopefully the benefit of others with MND" he said. He's also shared it with his consultant for the benefit of medical students. We are very pleased to print his honest and courageous article.

The full four-page account of Martin's reflections are in the Useful Information section of the Branch Website but we've printed some paragraph headings with subsequent quotes below.

Acceptance. "I have achieved my peace of mind by getting to the acceptance stage very quickly."

Don't acknowledge the occasions that you may be doing something for the last time.

"I think this has helped me come to terms with losses and not spend unnecessary time lamenting."

Don't look back "My attempt (is) to always look forward. To celebrate what I am still able to do and enjoy -there is always much."

Seek knowledge when you are ready but before you need it. "I have concluded that the right time for me to have all the information is when I realise a change is coming and that I need to make the best decision I can to be ready for it.

The MND Association is a good source of information. "They have many useful fact sheets on various symptoms" The Benefits Helpline was very useful" The local MNDA contacts introduced us to others and the Association Visitor still comes to see us.

Get a good healthcare team around you and develop relationships with key people.

"No doubt because of the expertise they have built up over the years, they have been an invaluable source of knowledge and support."

Prepare for the inevitable changes. "Do the things you can do whilst you are able and the things that are important to you like travel with the family" – it's easy to bury your head in the sand. Our direct MND team guided us on issues like voice banking…My Enteral Dietician helped me understand when the right time might be to have a PEG feeding tube fitted"

As each step change happens, understand that it takes time to effectively adjust. "Expect that and don't worry about getting it all right instantly" - often through trial and error there is indeed a way"

MND gives you time to sort your life out "How much time varies from person to person of course" This has allowed me the opportunity to prepare my family…"

Consider getting involved with MND research "I have participated and given feedback on many UK and international MND research projects" All of this has helped me tofeel more connected with, and to understand the big picture better."

A positive mindset can conquer most things "If you believe that you can cope with something, you will cope with it"

"Martin and Carol Kelly with Martin's fabulous carer Rachel Edmondson. Rachel raised over £7k in May for the Motor Neurone Disease Association with a 268 mile walk of the Pennine Way"

A Huge “Thank You” to Rotherham Titan’s Rugby Club

The Branch would like to extend a massive thank you to the Rotherham Titans Rugby Club for their assistance in mounting our first ever MND Spring Quiz on Friday 26th April. In particular, we would like to thank John Whaling and Diane Thurman from the club who cheerfully and patiently guided us through the process. It would be impossible to overstate the role they played in making the evening such a success.

£2,270 was raised on the evening, which included a quiz, bingo, raffle and auctions and we were fed a hearty Pie & Pea supper by Sam, the club’s chef.

The club also invited us to hold a bucket collection on the day of the final home match, when a further £578 was raised for the Branch.

Crosspool Festival – Open Gardens

As part of the Crosspool Festival there are several gardens open on Saturday 29th June from 10 00 am until 4 00 pm. £4.00 gives entry to all the gardens.

The garden at 55 Selborne Road, Crosspool, S10 5ND is open in aid of the Motor Neurone Association, so please visit and help raise funds.

On Sunday 30th June there is a Street Market taking place, also on Selborne Road between 12 noon and 4.00 pm and the garden at Number 55 will again be open in aid of MND .

Drinks will be available both days.

Another Successful Night of Fund Raising

Stannington Band once again gave a superb performance on Sunday 24th March at the Niagara Centre. The band members showcased the many talents of the players, as individual soloists as well as when all playing together and it was plainly obvious why they are so respected in the brass band community. Their repertoire included a wide range of music for all tastes including a selection of James Bond themes, Disney Musicals, An American Trilogy and Pater Nosta. The cake stall was as popular as ever and thanks go to everyone who baked cakes for us enabling us to have a wide choice of goodies to sell. Thanks warmly go to Stannington Band for their continued support of the South Yorkshire Branch over many years and for all those who attended and helped to raise £1,072.57.

Readable Research

Are you aware of this scheme? (www.readableresearch.com) Would you like to become involved?

There is a team of people at SITraN in Sheffield 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.

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

SITraN

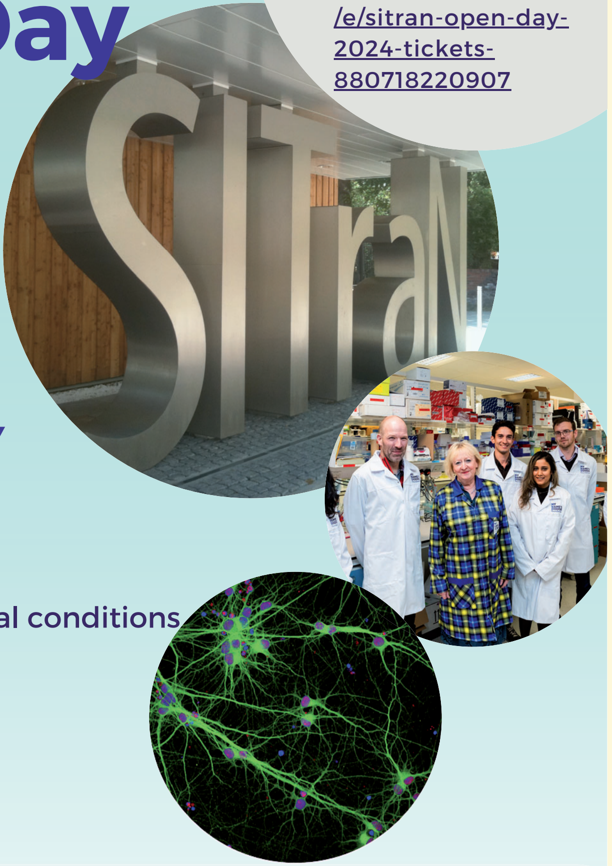
Sheffield Institute for Translational Neuroscience

SITraN Open Day

Find the Programme & Register here!

www.eventbrite.co.uk/e/sitran-open-day-2024-tickets-880718220907

- Meet the Researchers
- Watch Presentations
- Explore the Labs
- Access Interactive Demonstrations



FRIDAY 12TH JULY 2024
10.30AM-5PM

Learn about neurological conditions including :

Motor Neurone Disease
Parkinson's
Dementia
Stroke

University of Sheffield

Sheffield Institute for Translational
Neuroscience, 385a Glossop Road,
Sheffield, S102HQ

@neuroshef

University of Sheffield

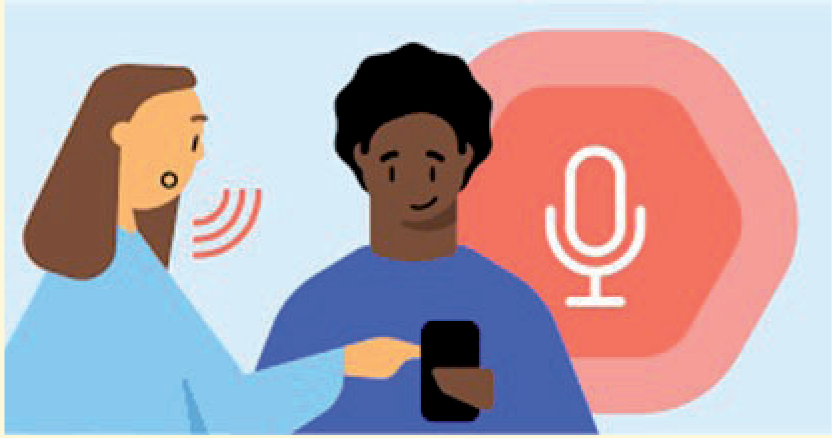
Volunteers needed for research study into voice changes in people with bulbar onset MND

Research has shown that people with bulbar onset MND have subtle changes in their voice that can be detected through recordings in a laboratory.

This study looks at whether short recordings can be done weekly, over 8 weeks, at home. The recordings will be analysed to see if there are changes to key aspects of your voice and if the recording is as reliable as those done in a laboratory.

Recordings are completed on an app on your smart phone and uploaded for us to analyse.

If you would like further information, please email kgraham1@sheffield.ac.uk



Past Carers Group

Are you a former carer?

Join us for a cuppa and peer support on the first Thursday of alternate months
10.30-12.00

Thursday 4th April
Thursday 6th June
Thursday 5th September
Thursday 7th November

Conservatory Restaurant
Holiday Inn
West Bawtry Road
Rotherham S60 4NA
2 minutes off M1 Junction 33

jayne.thompson@mndassociation.org

07811280893

f mndassociation @mndassoc

www.mndassociation.org

Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
Registered charity no. 294354
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South Yorkshire Branch Presents

THE CASTLEFORD SALVATION ARMY BAND including MUSIC FROM STRICTLY COME DANCING

Sunday 23rd June at 7.30pm.

Doors, bar and sales table open from 6.30pm.

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

Tickets ordered in advance are **£5** from Trevor Peacock 01142422956 or trevorpeacock56@gmail.com
Tickets bought on the night are **£7**
Children up to 16 yrs FREE
Tickets include a FREE programme and a FREE prize draw.

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www.mndassociation.org

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Events

Support Group Meetings

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 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.

3 **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 00 pm until 4 00pm.,** next meeting is **1st August.**

All people across South Yorkshire who are affected by MND are welcome at any of our Support meetings.
For further information please contact Jayne.Thompson@mndassociation.org

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 For Planned Events 2024

Gulliver's Valley Family Fun Day	15th June 2024 from 10 00 am
Castleford Salvation Army Band	23rd June 2024 Niagara Conference & Events Centre
Dore & Totley Golf Day	17th July (event rearranged from 22nd May
Walk to D'Feet	21st July 2024 @ Doncaster Lakeside Village from 10 30 am
Hallowes Golf Day	Friday 2nd August 2024
Soak a Scientist Event	10th August 2024 in Endcliffe Park
SMH Golf Day	23rd August 2024
Quiz Night	11th October 2024 @ Tapton Hall
Unite the Union Band Concert	13th October 2024 Niagara Conference & Events Centre

Other events will be published once they are confirmed

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

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

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Area Support Co-ordinator:
Jayne Thompson Jayne.Thompson@mndassociation.org

Regional Fundraiser:
Jenn Scribbins
jenn.scribbins@mndassociation.org

Walk to dfeet

South Yorkshire Support Group

Join us on the 21st July at the Lakeside Village, in our "Walk to d'feet" Motor Neuron Disease.
Registration from 10,30 am , walk round the lake from 11 am. Start point by the Soft Play Area.
Fancy dress optional, Dogs welcome .
Join us for a Day of Action.

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