

NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

SUMMER 2022



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Welcome to the Summer Edition of the South Yorkshire Branch Newsletter

To anyone reading the newsletter for the first time I hope you'll find it interesting and informative.

We're pleased to have our secretary Chris Naylor back with us again, although she is still rehabilitating, so I've stepped in to help with another edition.

We're hoping for sunny days for most of the upcoming events in the branch diary for 2022. Sunshine would be most welcome for the Folk Day on the 24th July and also for the first ever Family Fun Day at Gulliver's Valley on 17th September. The Local Meetings and our Contacts pages are worth particular attention in this edition. The necessary updates on support and communication with the branch committee are really important.

Nationally, raising awareness of MND and campaigning continues. The second reading of the change to Special Rules to fast track benefits is going through the House of Lords so finally "Scrap six Months" will come into place. On a less positive note, the Association and others are still battling to get any of the the £50 million that has been pledged by the government for MND research into the hands of the researchers.

Professor Chris McDermott from the Sheffield MND Care Centre appeared on BBC Breakfast time recently. He explained how the over bureaucratic and slow distribution of these vital funds will set back the mission to find effective treatments and a cure for the disease. A straightforward and simpler system is needed. We'll try and follow developments with this issue.

Lastly the announcement that the MND Association was named as a partner for the inaugural Rob Burrow Leeds Marathon in 2023 has sparked new enthusiasm amongst the MND running community. People are rising to the challenge for this one, so some training, new shoes and perhaps a 10K race in Sheffield should help.

As ever do get in touch if you have some relevant news of your own or information to share either here in the newsletter, or on our website or social media platforms. If you would prefer to receive the newsletter electronically, please let me know.

Ann

Treasurer's Report

Our income for the first quarter of 2022 was £10,800, which is quite good bearing in mind that this is the quietest time of year.

The amount spent on care and equipment was £8,659. We have seen an increase in grants in April and for the first 4 months of the year, income and expenditure were roughly in balance, which is how it should be. The Branch remains in a strong financial position and has sufficient to meet all grant requests.

If you want to support us, you can do so in several ways. Cheques in support of fundraising or donations should be made payable to MND Association South Yorkshire and sent to Mr P Hebblethwaite at 55 Newfield Lane, Sheffield S17 3DD or can be paid directly to our account 02972378, sort code 30-96-09. If you would like to set up a monthly direct debit, then I would be delighted to hear from you. You can call me on 07729 118 590.

Paul

Complementary Therapies & Professional Support

If you think that this is what you need. Please make a call.

For some years now people affected by an MND diagnosis have been using the services of Cavendish Care in Sheffield and Aurora in Doncaster.

Thankfully face to face services have been safely resumed, and all treatments for people with an MND diagnosis and their main carer are funded by the South Yorkshire branch MND Association.

A new service offering Emotional Support at home, is being offered by Aurora to people affected by MND in Doncaster and Mexborough. This service is in addition to the various therapies offered at the Aurora Well Being Centre at Doncaster hospital.

The Cavendish offers counselling and a range of therapies including massage and reflexology at their centre in Wilkinson St. Sheffield. They can also offer some home services if you live within 10 miles of the centre.

For more information and to arrange an appointment call:

Aurora. Lynne Rothwell
07889 988037

Cavendish Cancer Care
0114 2784600

New Volunteers

The lack of meetings and face to face events over the past couple of years has meant that branch members and other volunteers have missed out on the chance to introduce themselves. We hope that's going to change.

In the meantime, we're asking our new volunteers to tell us a bit about themselves in the newsletters



Hi, I'm Fran! I came on board with the MNDA at the start of this year as an Association Visitor.

I currently visit two people with MND in Sheffield and Rotherham. From 2012-2014 I was a member of the South Yorkshire Branch committee, editing the newsletter, sending out press releases and looking after social media.

Having previously lived in

Uganda I moved back there for a few years in 2014. I ran a project in collaboration with existing NGOs to provide tailoring classes to women who had disabled children. Now back in the UK, as well as being an AV, I currently do some care work, make and sell bags, facilitate "Writing For Wellbeing" workshops and edit non-fiction books.

I'm so pleased to be back with the Association which does such a great work for and with people who have MND and their families.

Thanks Fran. Your first newsletter introduction was nine years ago, when you told us about your Mum's MND diagnosis in 2008 and the support you had received from her Association Visitor Olga at the time. It's great to have you back.

Local Meetings. Can we have your views please?



It is now time to decide if we're going to return to face to face meetings, as other local branches have done. Support meetings, Carer meetings and the South Yorkshire branch AGM have all been held on zoom in the past couple of years, but as we have seen in the Jubilee weekend of celebrations, events are returning to pre pandemic formats.

There have been a lot of changes since our last face to face open meeting in March 2020 and the branch committee need to know what people would like to see happening in the future.

Your choices and opinions will help form their plan for the months ahead.

Options may include:

- Retaining virtual meetings on zoom
- Resume Open/Support meetings in Barnsley
Doncaster Rotherham
Sheffield
- Whole South Yorkshire branch meetings
- Support meetings without a speaker
- Open meetings with Speakers. MND related or general
- Other options

To let us know what you think, you can:

- Email Chris Naylor chris222@sky.com
- Phone or text Branch Contact Ann Quinn 07776 191333
- Talk to your Association Visitor
- Make contact with anyone listed inside the back page of the newsletter

Musky Mutineers raise over £15,000 for MND Research



We're not entirely sure where their title comes from, but this enthusiastic group of gentlemen raised an amazing amount in one year of fundraising and challenges. Dave Booker asked them how the money was raised?

"In Jan 2021 Christian MacKay, Adrian yates, Carl Wyatt, Robbie Atkinson, Kelvin Smith, Chris Neil and Guy Appleton decided to run/walk the Jan 100km challenge. We all succeeded in this and raised approx £4,500

Then in August we had our annual football match, run out of the Flying Childers pub in Bessacarr- the match is played between the regulars- raising approx £1500- we have had this

match for 5 years now.- We also donated £500 to a local based Doncaster homeless charity.

Then in November Christian Mackay, Adi Yates and Carl Wyatt hosted a black tie ball at Doncaster golf club - raising approx 9K

Throughout the year we have had collecting tins in the Punchs Hotel, the Flying Childers and Zuvu fishmongers in Tickhill.

Our grand total for the year was £15,257.91."

Many thanks to all concerned.

Interested in Research & Design?

There are many opportunities to become involved in Motor Neurone Disease research, and online activity now means that there are easier ways for people affected by MND to play their part. SITraN in Sheffield is one of the world leaders for MND research and the number of projects they are working with is increasing all the time. It's not only drug trials, and this work is both diverse and inclusive.

We've been asked to share two new posters..

Firstly there is a design project to create an aid to assist people with hand and arm weakness. See poster p8.

Secondly they are recruiting for a new dedicated Research Advisory Group looking at Better Outcomes in MND. See poster p8.

Contact details for both are on the posters or get in touch for more information.

Finally we mentioned last year that the original Research Advisory Group set up over 10 years ago is also recruiting new members.

The group helps to identify and

prioritise research topics from the patient's perspective. It is currently meeting remotely, using zoom. If you would like to know more or you're interested in becoming a member please contact

Annette Taylor 0114 2222289
smndrag@sheffield.ac.uk or visit
www.smndrag.group.shef.ac.uk

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
- Assistance at events, meet & greet or set up & take down stalls or photography
- Editing the newsletter
- Fundraising
- General administrative tasks



Novel upper limb orthosis project for people living with MND: **Co-Design participants wanted!**

Paid

Project Overview

Participants wanted for co-design project to develop novel upper limb and hand orthoses using state of the art soft robotics as Part of 6-month phase of 3.5 year project.

Co-designers will input on:

- Key movements, and features
- Review of design specification
- Direct feedback on designs and prototypes

We are are looking for

- ✓ People living with MND
- ✓ Carers of people living with MND

Ideally...

- ✓ MND presentation as arm/ hand weakness
- ✓ User/ potential future user of orthoses

Partnership project between:



- Fully virtual study
- Group and individual online video consultations
- 5 hours over 6 months

Interested?

Please contact **Edith-Clare Hall (lead researcher)** by any of the following:

- Scan: the QR code
- Email: edithclare.hall@bristol.ac.uk
- Go to the link: <http://tiny.cc/MNDorthosis>



The University Of Sheffield.

We are looking for people living with Motor Neuron Disease and family carers in the UK to join the Research Advisory Group for the new research programme 'Better outcomes in MND'.

Meetings will be held online. The group will help to shape the research over the next five years.

For more information and to apply, contact Dr Lizzie Coates e.coates@sheffield.ac.uk

Better outcomes in MND

Join the Research Advisory Group for our new NIHR funded research programme led by Professor Chris McDermott

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NIHR

National Institute for Health Research

Branch Events: Diary Dates 2022

For more information about any of these events please get in touch.
Our details are all inside the back page.

Sunday 26th June.

Stannington Brass Band Concert
See poster. Contact Trevor
trevorpeacock56@gmail.com
0114 2422956

Sunday 24th July

Folk Day @ Denby.
Contact Mel
chalks50@yahoo.com
07870298985

Thursday 14th/28th July
Date to be confirmed.

Carers' Meeting. Contact Ann
mndvisitor@gmail.com
07776191333

Saturday 20th August

Soak a Scientist.

Saturday 17th September

Children and Family day @
Gulliver's Valley Theme Park
Rotherham. See poster.
Contact Brian
associationvisitor.bj@gmail.com
0114 2376814

Sunday 25th September

Sheffield 10K
Contact Bridget or Ann
bridget.a.ashford@gmail.com
mndvisitor@gmail.com

In aid of

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association

Stannington Brass Band

Performing...

Movie Music, Musicals and More

Sunday June 26th, 7:30pm

Doors, Bar, and Sales Tables open at 6:15pm

The Niagara Conference and Events Centre, Sheffield, S6 1LU
Disabled facilities available

Tickets are £6 reserved in advance, or £8 on the door
Children go free

Available from Mr T Peacock:
trevorpeacock56@gmail.com
01142422956

Tickets include free programme and prize draw

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www.mndassociation.org

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The Motor Neurone Disease Association

Website: www.mndassociation.org Tel: 01604 250505

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MNDA Connect Helpline 0808 802 6262

South Yorkshire Branch

Website: www.mndassociation.org/southyorkshire

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Regional Fundraiser: Jenn Dodd
jenn.dodd@mndassociation.org

The logo for the Motor Neuron Disease Association (MND Association) features the lowercase letters 'mnd' in blue and 'a' in orange, with a stylized 'd'.

motor neurone disease
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Family Fun September 17th

Register now. Free Admission

Families are invited to meet up & enjoy the outdoor/ indoor activities of Gulliver's Valley. Fully accessible and suitable for children 2yrs + height restrictions apply to rides. Bring your own lunch or food outlets available. Dedicated lunch space to meet up Register ASAP closing date. 31st August

**Contact Brian Jackson associationvisitor.bj@gmail.com
07467242232 Ann Quinn mndvisitor@gmail.com 0777619133
Chris Naylor chris222@sky.com**



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