

NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

AUTUMN 2022



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SMH Sutton McGrath Hartley.

Welcome to the Autumn Edition of the South Yorkshire Branch Newsletter

I'd like to commence this newsletter with a personal word of thanks to the Branch Committee and some of our readers who contacted me by telephone, card or e-mail to wish me well during my recent ill-health.

Particular thanks must go to Ann Quinn, who stepped in and took over the newsletter, fitting it in with all the other volunteering she does for the Branch.

Volunteering

The Branch is always looking for more people to help with all the tasks it undertakes supporting people living with MND in our area. Help would be appreciated in lots of ways, such as baking cakes for or selling tickets at some of our fundraising events, through to general administrative tasks such as assisting with this newsletter.

Please see the Volunteering opportunities elsewhere in this newsletter so if you have some time available, please do contact me.

Now for some exciting news. Many of you will have watched Britain's Got Talent and seen the success of Sheffield's **Maxwell Thorpe**. Max has agreed to do a fundraising concert for the Branch on **Sunday 13th November**. Max has supported the Branch previously, singing at the band concerts, so please come along, help to raise some funds for the Branch and wish Max good luck as he launches his professional career. Please see the flyer for how to obtain tickets, which are available from www.eventbrite.co.uk/e/an-evening-with-maxwell-thorpe-for-south-yorkshire-branch-mnd-association-tickets-406797090047.

Please let us know if you have anything to pass on or share with others. Families affected by MND often find that information about the experiences of others is really helpful. If you would like to share a story of living with MND, a holiday you enjoyed, or any fund-raising you have done or plan to do, we would love to hear from you so do get in touch with us. All our contact details can be found inside the back cover.

Christine

Chairman's Report

As I write this, we are in the midst of political change with a new PM to be announced in the very near future. Indeed, by the time you read this newsletter that will be old news.

However, this exemplifies that things don't ever stand still and this is a theme that has been all too visible over the last two very turbulent years. I have been reflecting on this with the branch committee and we have come to the conclusion that we are not immune to change. We have therefore written a three-year action plan to ensure that the South Yorkshire Branch remains strong and sustainable in all aspects of our endeavours in delivering what is needed to continue to provide high quality support to Plwmnd. If anyone wishes to read the plan it will be available shortly on the Branch website at www.mndassociation.org/southyorkshire.

Our Primary aim in the next 12 months is to ensure that we have enough people resource to perform our function. To that end we are actively looking for people of all ages and backgrounds which reflect our community demographic to join us in any capacity. This includes AV work

but also committee work and indeed deputy support for me and key committee members. You will find further details in the Volunteering article within this newsletter. We are likely to see considerable challenges ahead in the charity sector as the country has to corporately "tighten its belt" to manage economic pressures and hardships of many. This will include Plwmnd. With a strong and sustainable branch and with more people involved we will try and make light work of these challenges.

If you feel that you can help or if you know someone that can help, or would like to discuss helping, then let us know. You can do that by using any of the branch member's emails or simply by the old-fashioned word of mouth. We look forward to hearing from you soon.

I hope to meet some of you at the planned events we have scheduled over the autumn months and in the meantime, stay safe.

Andrew

Treasurer's Report

Our income for the second quarter of the year was £7,728, and as in the previous quarter, lower than usual. We do, however, have a few events occurring over the next few months which will boost our income. The amount spent on care and equipment in the quarter was £5,818. We are seeing a substantial increase in grants that we give out, no doubt as a consequence of the current economic climate. As of 23rd August, we had funds available of £6,039. This is lower than I would like and somewhat below what we would normally have at this time, but sufficient, at present, to meet all grant requests. We do, however, need to bear in mind that there are likely to be higher demands on our resources as winter approaches, so may I ask that those who are able, support our fundraising events and consider making either a donation to us, or set up a direct debit to give us a regular income. If you can Gift Aid this, even better, as it adds 25% to the value of your donation. Cheques should be made payable to MND Association South Yorkshire and sent to Mr P Hebblethwaite at 55 Newfield Lane, Sheffield S17 3DD or you can pay 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 or email me - treasurer.mndasy@gmail.com. **Paul**

Current information about the Specialist Nursing Team and the Nurse led Clinics at the Royal Hallamshire Hospital.

The MND Specialist Nursing Service is there to support you and your family. MND specialist nurses are general nurses who have been trained to provide specialist support and advice for people who are affected by Motor Neurone Disease. They are part of the nursing team at the Sheffield Motor Neurone Disorders Care and Research Centre, and they have a local case load of between 150 -165 patients. Specialist Nurses can also be a link between other health professionals, helping you get the support you need in the community. There are 3 MND Specialist nurses at present, Jo Brookes, Tara Bradford and Jenny Booth, but only two support the MND patients at a time.

Jo and Tara have oncology and palliative care backgrounds, Jenny has a Neurology background and all 3 nurses have over 10 years' nursing experience each.

Nurse Led Clinics

The Nurse led clinics are currently held at the Royal Hallamshire Hospital in Sheffield.

The MND nursing team aim to offer you an initial 60-minute appointment in clinic within 4 weeks of your initial diagnosis, with the option for further follow up appointments in addition to your consultant appointments. They also have over 50 booklets and leaflets to help support patients and their loved ones, covering diagnosis information, dietary advice/ information, disabled access information, psychological and emotional support, information for children and teenagers, information for carers as well as information about planning for the future.

Important update on Research Funding

In the Summer newsletter we reported on the ongoing discussions to get the £50 million pledged for MND research last year into the labs of the researchers so that work can be accelerated. There have been several meetings between patients, researchers, charity representatives and government ministers to try and simplify the method of grant distribution and reduce the time and bureaucracy involved. The change of Prime Minister and other department personnel was a

concern for the next stage of the process.

However, on September 5th a **statement** was made in Parliament by the outgoing Secretary of State for Health and Social Care, Steve Barclay, about the discussions.

“In November 2021, the Government announced it would make £50 million of funding available for research into motor neurone disease over five years. Following work over the summer between my Department and the Department for Business, Energy and Industrial Strategy, through the National Institute for Health and Care Research and UK Research and Innovation, to support researchers to access funding in a streamlined and coordinated way, we are pleased to confirm that this funding has now been ring-fenced. The Departments welcome the opportunity to support the MND scientific community of researchers as they come together through a network and linked through a virtual institute.”

The confirmation that the money will be ring fenced for MND is good news and the delivery of the money will continue to be monitored by the Association and other parties.

Two great opportunities to join our team

The South Yorkshire Branch was founded nearly 25 years ago and is run entirely by volunteers and aims to give the best possible support to local people with Motor Neurone Disease, their families and Carers. We now need more people to achieve this, and two new posts have been developed.

We are looking for an **Administration Volunteer** to provide admin support to the Branch Committee, which includes communication tasks within the local volunteer-led Branch.

As admin support, you will assist the Branch Secretary with the following:

- prepare, in liaison with the Chair, agendas for committee and other meetings and provide admin support at meetings, including taking minutes/notes
- take notes of members' ideas as they arise and make sure they are brought forward onto the next agenda
- book venues, speakers and entertainment for meetings
- respond and deal with all Branch correspondence

- circulate the minutes of meetings and appropriate information to committee members, regional staff and our national office
- ensure the effective and accurate communication and updating of group information including Branch membership list
- keep and file appropriate documentation
- take part in Branch or Association training and attend meetings as required.

We are hoping you will commit to approximately 2-3 hours a week, including willingness to attend meetings at various locations across South Yorkshire and by zoom. This role would suit someone who has good IT and organisational skills.



Grants Volunteer

Would you like to gain experience in applying for grant & trust funding for a local volunteer led group? We need you, apply today!

We are looking for a grants volunteer to help increase the branches income by identifying and applying for local awards that the South Yorkshire branch qualify for.

As a Grants Volunteer, you will:

- Research grants available through websites such as Turn 2Us
- Build networks with stakeholders that have grant programmes
- Make applications for grants on behalf of the South Yorkshire branch

You don't need personal experience of MND but this role will suit someone with good written communication skills, good IT and research skills but

most of all a willingness to learn

This is an excellent opportunity to develop your skills, gain experience in grant applications and contribute to raising funds for local people with MND across South Yorkshire

This role is flexible and you can give as much time as you want and are able to give.

Induction will be provided and travel expenses will be reimbursed for both of these positions.

Contact Chris Naylor for more information Chris222@sky.com

Upper Denby Family Folk Day



Sunday July 24th saw the coming together of the Upper Denby Family Folk Day, following months of detailed planning and organisation. The whole village became involved, with The George Pub being the main venue for the music and dancing and the village church hosting a craft fair throughout the day.

All proceeds from the event were in support of the South Yorkshire Branch of the Motor Neurone Disease Association and as is the case with the November Folk Concerts, now an annual event, many leading folk artists from the north of England volunteered their services free of charge. The day's proceedings included two live folk

concerts, musical sessions in the pub, Morris Dancing, craft fair, sing along in the pub and a Samba Band processing through the village.

The planning of the event made one large assumption, being well into the British summer, the weather should behave itself – wrong! The heavens opened around lunchtime and failed to stop before major operative and logistical decisions were required. As water had severely affected the main PA system, the evening concert which was to include the folk-rock band – Gaelforce and well-known local singer/songwriter Ray Hearn had, unfortunately, to be cancelled.

A huge message of thanks has to go to Dean and the staff of The George Pub, Ailsa Gardner for organising the craft fare, Chris Dyson from Roisin Ban who recruited all the artists – Duncan McFarlane Trio, Roisin Ban, Gaelforce, Ray Hearn, Rum Doodle, all the Morris Teams, The Samba Band and not forgetting the fantastic members of the South Yorkshire Branch who turned out to man the car park, direct traffic, sell raffle tickets and many more tasks. The event raised £773 for the Branch.

According to local gossip it looks like the event was such a success that it will become an annual occasion and could even grow to challenge Glastonbury! **Me!**

Stannington Band Concert



Sunday 26th June saw the Branch hold a fundraising event at the Niagara Centre of “Movie Music, Musicals and More” performed by the superb Stannington Brass Band. The band never cease to provide a musical treat for all tastes and once again did not disappoint those who attended. Stannington Band are to be congratulated on being the current Yorkshire Area First Section Champion Band and will be representing Yorkshire at the National Brass Band Championships of Great Britain later this year – and it was not hard to see why. The event was well attended and raised £1,365 for the Branch.

Golf Day

On 5th August, Dronfield 41 Club held a charity golf day at Hallowes Golf Club. I entered a team and we had a very enjoyable day, though my golf was somewhat disappointing! We held a tombola and £491 was raised from this. Dronfield 41 Club will also give us a share of the overall proceeds in due course, which will be a welcome boost to our funds. My thanks to all at Hallowes who made us so welcome, to the helpers on the day and to those who gifted items for the tombola. **Paul**



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An evening with MAXWELL THORPE

Niagara Conference & Events Centre, Sheffield
Sunday 13th November 2022

Sensational singer & Britain's Got Talent finalist Maxwell Thorpe will be performing live to raise funds for the South Yorkshire Branch. The doors and bar will be open from 6.15 pm with the concert starting at 7.30 pm. The venue is accessible with a lift and has free secure parking (Niagara Rd, Sheffield, S6 1LU)

Tickets available on Eventbrite by scanning the QR code or visiting www.eventbrite.co.uk/e/an-evening-with-maxwell-thorpe-for-south-yorkshire-branch-mnd-association-tickets-406797090047

Tickets cost £21

For more information contact trevorpeacock56@gmail.com



MND Assoc South Yorkshire



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www.mndassociation.org

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Are you interested in supporting someone who is caring for someone living with MND?

By taking part in this study, you could make a huge difference to people living with MND and their carers.

The Study:

This research study aims to find out the usefulness of a 12-week virtual support programme for people caring for someone with MND. We will look at the impact caring has on wellbeing and try to understand how user friendly and acceptable the online peer support programme is to family carers in the study.

This is an exciting opportunity to become a peer supporter.

What's involved?

You must have lived experience as a carer for someone with MND. As a peer supporter, the research team will link you via an app with a family carer of someone with MND. This app is a bit like WhatsApp but more secure and can be used on your smartphone, tablet, or computer. These family carers are part of the research study and you'll be helping them.

The role is a 12-week commitment. During this time, you will need to check-in (contact) with your allocated family carer a minimum of once a week for each of the 12 weeks. This can be done through text or audio/video call (or both) via the app called aTouchAway. You will also need to reply to texts or calls from your allocated family carer.

In your role, you can share your personal experiences and your knowledge of resources or tips on useful carer strategies you have learnt. However, you are not expected to provide specific advice related to medical treatment or medical technologies.

The role will suit you if:

- you are a good communicator
- You are happy to use the app (like WhatsApp) for communication and have access to your own device suitable for this
- you can develop and maintain supportive relationships
- you are non-judgmental and respectful of diverse lifestyles
- you understand the need for confidentiality and the importance of data protection
- You can assess when extra support is needed

You will also join in a weekly discussion forum via a Zoom link through sharing your carer experiences and knowledge. Here is the list of topics for discussion each week.

Promoting self-care and how you look after yourself as a carer	Caring for your loved one	Setting boundaries as a carer	Navigating the health and social care system	Caregiving and other relationships	Ask the Expert
Managing stress	Social Activities	Finding joy in caregiving	Navigating technology	Ask the Expert	Experiences with peer support programme

The research team will give you with one-on-one training (via Zoom) on how to use the app to send text messages and make audio or video calls, at a time that suits you. You will also receive three one-hour group training sessions (via Zoom) on peer support. The research team will be there to support you throughout the 12 weeks including check in/debrief sessions at 6 and 12 weeks.

How can I take part? - For further information, please contact Rebecca Rogers at: peersupport@kcl.ac.uk



SMH Group raises £2,000 for MNDA in Annual Charity Golf Day

SMH Group, the Yorkshire and Derbyshire based firm of chartered accountants and business advisers, have raised £2,000 for their charity of the year, the South Yorkshire Branch of the Motor Neurone Disease Association (MNDA), at their annual charity golf day, which took place at Chesterfield Golf Club on 2nd September 2022.

The Texas Scramble format tournament included 19 teams of four competing for a range of prizes on the day, with the team from Principal Mortgages being crowned the overall winner.

Organised by James Furniss, Head of SMH Commercial Finance, the day gave close contacts of the firm a great opportunity to take up some in-person networking, as well as being the catalyst to raise funds for a very deserving local charity.

James Furniss, Head of SMH Commercial Finance comments:

“After the success of our first event last year, we’re delighted to roll out our charity golf day again in 2022. The event provides a great opportunity for us to connect with clients and contacts of the firm in a relaxed and informal setting.

“We have a lot of keen (and competitive) golfers in our network,



Principle Mortgages, the winning team from the SMH Group charity golf day 2022

which made for a very entertaining day with on course competitions, such as closest to the pin, and longest drive, taking place.

“SMH Group have been supporting our local branch of MNDA for a number of years, so it’s a pleasure to be able to hold this event again and raise a great sum of money for the charity. We’d like to extend our thanks to the MNDA charity team who helped out on the day with the raffle, as well as some fantastic local organisations who donated raffle prizes, who we have publicly thanked via our social media channels.

“A big well done to the team from Principle Mortgages who finished in first place, along with Joe Daniels from the SMH Commercial Finance team who won the longest drive, and Carl Finlayson of Praetura Finance and Phil Nunney of Begbies Traynor who won the closest to the pin competitions. We’re looking forward to making next year’s event bigger and better already.”

Fundraising and Personal Challenges

We are featuring and following the fundraising challenges of three brilliant local women. They have all managed to find time in their busy lives to train and plan running events in aid of the Motor Neurone Disease Association. All have their own reasons and personal motivation for supporting people affected by MND, and reading their own stories is inspirational.

Bridget Hemstock will be running the Great North Run. Bridget has been running a long time and has done lots of fundraising, “born from her lovely Mum being diagnosed” but Bridget is currently working and doing a full-time degree course to become an Occupational Therapist so training time is not easy to find. Her total fundraising is nearing £8,000. Amazing!

<https://www.justgiving.com/fundraising/bridget-hemstock>

Sarah Harmon is student at SITraN researching nutrition in MND. She has entered the 2022 Dragon’s Back Race. This is an incredibly tough, multi stage mountain race the length of Wales from Conwy Castle to Cardiff. Completed over 6 days the route

is 380K and the total height gain is 17,400m. Unbelievable!

<https://www.justgiving.com/fundraising/sarahaharmon>

Rachel Sinclair has never run a marathon but next year will be the 5th Anniversary of losing her Mum to MND and says she will never forget the help and support she got from the MND Association. Rachel therefore thought that the Leeds Marathon would be a suitable challenge, and although finding it quite daunting she has a good training plan. As a warm up race Rachel will be joining other MND runners for the 2023 Sheffield Half Marathon on Sunday 26th March and she will be starting her fundraising page shortly. Fantastic!

A massive thank you, and good luck to you all.

Please let us know if you are doing any fundraising of your own, it doesn’t have to be an arduous running challenge. If anyone is going to enter any local races though, it’s great to get an MND team together.

**Coming up: Sheffield 10k
Sunday 25th September.
Doncaster 10K Sunday 27th
November**



Thursday Carers' Meeting South Yorkshire

September 29th 2.00pm Wickersley Rd
Rotherham S60 4JN

Are you supporting someone with Motor Neurone Disease and would like an opportunity to talk to others in a similar situation? If so, come and join a group at the United Reform Church. This will be the 3rd meeting of our small group and we're planning them every couple of months. It's informal and the support comes from others who have an understanding of your situation. Tea & coffee provided. Stay as long as you like. Meeting ends at 4.00pm
Can't make this one? Then join us on November 24th 2022.

For more information contact Ann Quinn mndvisitor@gmail.com

 MND Association SouthYorkshire

www.mndassociation.org

MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
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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

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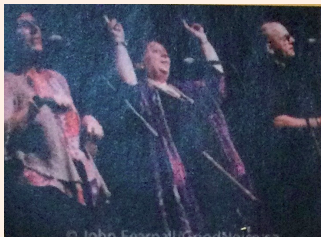
Charity Folk Concert

Crookes Social Club
Mulehouse Road
Sheffield
S10 1TD

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Registered Charity No. 294354
Patron: Suzanne Maguire



Artisan



Union Jill



Roisin Ban



**Sheffield Steel
Rappers**



**Keith Kendrick &
Sylvia Needham**

Sunday 6th November 2022

Admission – £10.00 advance/£12 on the door

More information and advance tickets from

Mel White – symnda@yahoo.com

SOUTH YORKSHIRE MOTOR NEURONE DISEASE ASSOCIATION

www.mndassociation.org/southyorkshire