

NEWSLETTER

Motor Neurone Disease Association South Yorkshire Branch

WINTER 2020



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Welcome to the Winter Edition of the South Yorkshire Branch Newsletter

As we draw to the end of 2020 it is difficult not to be tempted to reflect on what an unprecedented year this has been. However, whilst not being able to meet up with you in the normal way and fundraising has not been possible in its usual forms, thanks to the generosity and efforts of so many of you we have been able to continue to support as many people living with MND, their carers and families as we have had requests for that support. Until we can resume face-to-face contact and resume Open Meetings, we will continue to keep in touch with as many of you as possible offering help and advice, so please do contact your Association Visitor, or any Branch Committee member if there is anything we can assist you with.

Quiz Night

Geoff is continuing to hold Virtual Quiz nights on Tuesday evenings, commencing at 8 00 pm, so if you feel like joining in, download and install free Zoom onto your laptop/ computer and log in with the details 854 0224 5350 password SYMNDA.

It would be helpful if you could let Geoff know prior to joining, so that as host he can "allow" you in - his details can be found on the next to back page of this newsletter.

AGM 2021

The Branch intends to hold its Annual General Meeting on Tuesday 16th February 2021 at

6 00 pm and will be by Virtual meeting. Please make a note of the date and time and visit the website for details of how to log in to attend.

We hope you find something helpful and of interest in this edition of the newsletter. Thanks must go to Mensa Printers for their very professional production of the Newsletter and to Sutton McGrath Hartley for their ongoing funding of it.

A huge thank you to all those of you who support the Branch throughout the year by regular donations or via fundraising and a special word of thanks to all the Health & Social Care professionals who have gone the extra mile this year to support people living with MND.

On behalf of the Branch Committee, we send each and every one of you our greetings for the forthcoming festive season and good wishes for 2021.

Chairman's Report

Ironically, as I sit down to write my report for Winter 2020 I have just been informed that it looks like a vaccine for COVID 19 has been developed and final tests are taking place. Good news indeed for everyone but probably more so for those who are vulnerable and it is with some hope that we will be able to get back to some form of normality as the New Year breaks.

Regardless of the constraints created by COVID we have continued to provide the much-needed support required by people living with MND in South Yorkshire. So far this financial year we have been successful in meeting a total of 55 requests for support including 12 Quality of Life grants and 20 general support grants. Our care lead – Brian Jackson - or “Bare Legs Brian” as known by many - continues to provide an exceptional service for those needing support and whose commitment to helping those in need should not be underestimated, particularly within the current climate.

I am extremely happy to welcome and introduce two new young members to the Branch. We have for some time been using Social Media platforms to enhance the

way we do business and we have been extremely thankful for the help provided by Chloe Allen from SITraN. Chloe has now finished her studies and will be moving on. We have, however, been extremely fortunate to be able to recruit two replacements who, like Chloe, will be working from SITraN. Bridget Benson and Natalie Pye will be sharing responsibilities for Facebook and Twitter and will in due course be establishing a Social Media Strategy to enable the Branch to take forward and make best use of these valuable media platforms. I am sure you will all be meeting Bridget and Natalie at some stage in the future when we are once again able to stage our Open Meetings.

In my Autumn report I reported that we were in the process of recruiting a Branch Contact. This need remains and we are still to find a suitable replacement for Marlene Bryan who has now left for pastures new.

I also feel it is appropriate at this stage to take this opportunity to announce that I have decided to step down as Branch Chair. I therefore hope to be able to introduce and welcome my successor at the AGM next year. I find to my astonishment that it is now 8 years since being

appointed as the Chair of the Branch. I can without reservation record that it has been an honour to serve alongside such a group of dedicated and committed Branch members who continually strive to support people living with MND in the South Yorkshire area and be able to share with them many notable achievements and successes. The support they have given me, especially during the early days, has without doubt enhanced the experience and I shall be forever in their debt.

It goes without saying that we all look forward to getting back to “normal business” as early as possible but in the meantime please stay safe – where possible have a Merry Xmas and Happy New Year to you all. **Mel**

Treasurer's Report

Despite the current crisis, and cancellation of our fundraising events, our Branch is doing reasonably well financially. It helped that we started the year with a good level of reserves, so we continue to be able to support all those people living with MND and their families. 2021 will undoubtedly be a difficult year, but I am confident that the level of support we offer will not be affected.

Our supporters have been most generous, and I send our grateful thanks to all.

Our income for the 3 months to 30th September 2020 totalled £20,238 which was a good result in view of everything that has been going on. In the quarter, we spent £4,925 in supporting those living with MND in our area. In addition, we were able to contribute £5,000 to the national Emergency Appeal to help ensure that research continues at the current level. At the quarter-end we still had £18,904 in unrestricted funds. In conclusion, our funds are more than enough to help everyone who needs assistance, at what must be a difficult time for all, so do let us know how we can help.

Cheques in support of fund raising 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**

Want to make a difference and become part of a friendly dedicated team?

The South Yorkshire Branch is looking to recruit a new **Branch Contact** and more Association Visitors.

Branch Contacts act as the first point of contact with the Branch for people with MND, their families and carers in the South Yorkshire area. They respond to calls and emails informing people of the work of the Branch and the Association and signpost people to appropriate alternative sources of help, advice and information.

Association Visitors – Do you enjoy listening to and helping people? Are you looking for a volunteering role where you can do just that? By becoming an Association Visitor and donating your time, energy and skills, you can make a real difference to the lives of people affected by MND.

If you are interested in any of the above roles or can help in any way, please do contact us. The more volunteers we have, the more support we can provide for people affected by MND. Whatever your skills, background and age, we can find a role for you.

Express your interest or just make an enquiry by emailing **Mel White symnda@yahoo.com** More details available on our website **www.mndsouthyorkshire.org**

Information Update about Support Grants

Following on from the information included in the last newsletter we'd like to let you know a little more about the grants we can consider. The Association is able to offer some financial support to help with emergency funding while staying at home during the coronavirus outbreak and these might include funding equipment and services that people with MND have been assessed as needing; funding for children and young people living with someone with MND; non-paid carers supporting someone living with MND; improving quality of life for someone living with MND. A form can be downloaded from the Association website under Emergency Grants or for further details please contact **Brian Jackson at associationvisitor.bj@gmail.com**

Photographic Calendar

The planned production of the MNDA Calendar for 2021 has had to be deferred for publication until 2022. This is in order for us to allow for more people to send in their entries.

To register, please **e-mail Contact@calcomp.co.uk** and do consider sending us your photographs over the next year so that we can compile a first-class calendar and help to raise funds for the Branch.



Afternoon Carers' Meeting

South Yorkshire Branch zoom session.

Are you supporting someone with MND and would welcome the opportunity to talk to others in a similar situation?

If so, you may be interested in joining us. We are currently running two local meetings, but we're looking to set up more. The groups are small, the chat is informal and the support comes from others who have an understanding of your situation.

For more information contact Ann Quinn
mndvisitor@gmail.com

www.mndassociation.org

MND Association Francis Crick House, 6 Summerhouse Road, Northampton,
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Supporting Children and Young People

The Branch has received a generous donation from a supporter in South Yorkshire who wishes it to be used to support children and young people with someone in their families affected by MND.

We would initially like to arrange an event for 5 to 12 year olds, with plans for further events for older children under consideration. We need information from you about children and grandchildren in your families for us to proceed any further.

If you are interested and give permission to be contacted please contact **Ann Quinn at mndvisitor@gmail.com**,

Andy Jaffray at andyjsymnda@yahoo.com or **Brian Jackson at associationvisitor.bj@gmail.com** giving the names and ages of your children/grandchildren.

Counselling Service for Young People affected by MND

Children and young people affected by MND can now access professional counselling thanks to a new service developed by the Association in collaboration with Barnado's.

The service is based on the Barnardo's 2020 Family Support Service which has supported families dealing with the challenge of the Covid 19 pandemic and has been specifically adapted for families affected by MND.

Young people can access the counselling at any stage they need support and therapists will also support and empower parents, giving them the tools, knowledge and access to resources.

If you are interested in the service, please contact Laura Wilix, Children and Young Person's Development Manager at the Association at **cyp@mndassociation.org**

Provision at the Cavendish Care Centre and Aurora Centre

A reminder that the Cavendish Care Centre is continuing to provide telephone and online services including counselling and body-based therapies. Although the actual centre is temporarily closed, anyone in Rotherham, Barnsley or Sheffield with MND can receive support at this time whether you are newly diagnosed, or have been living with MND for some time and finding it particularly difficult to cope at present. You can refer yourself, and services are also provided for the main Carer and your children.

The Doncaster Aurora Wellbeing centres are not open to people with MND at present but there is an Emotional Support Service offering help to anyone in the Doncaster area living with MND. Their telephone no is **07517 835028**

More information about both centres is available on the Local Services section of our website **www.mndsouthyorkshire.org**

31st International MND virtual Symposium

Each year, the Symposium, organised by the MND Association, attracts over 1,000 delegates, representing the energy and dynamism of the global MND research community. It is the largest medical and scientific conference specific to MND/ALS and is the premier event in the MND Research Calendar.

The Symposium should have been taking place this year in Canada between Wednesday 9th to Friday 11th December. However, due to the pandemic the event will now take place virtually.

If you are interested in what is happening in the world of research, you can follow some of the work in this year's symposium as well as watching videos from last year's symposium in Perth through the research section on the Association website.

<https://symposium.mndassociation.org>

MND in the news

It is important to keep raising awareness of MND and in last month's Sheffield Telegraph there were two articles of interest.

Firstly, they published an article written by Professor Dame Pamela Shaw celebrating 10 years of research at SITraN (Sheffield Institute for Translational Neuroscience). In it, Professor Shaw talks about the development of the research centre and how the world class team is driving experimental science into international clinical trials- meaning that people in Sheffield and South Yorkshire have access to novel treatments before patients in other parts of the country. She praises the dedicated staff and students who have worked so tirelessly to achieve so much in the last 10 years.

Many of us in the Branch will remember our previous Chairman Gordon Harrison and Branch Contact Olga Bannister who donned hard hats for the cutting of the first turf for SITraN and were there a couple of years later for the Queen's visit and the opening ceremony.

The second article reports on the new App developed with clinicians and scientists at Sheffield which

helps to improve quality of life for people with MND. Professor McDermott explains that it is not only the physical difficulties that present a challenge, but that the emotional and psychological effects of MND can also be extremely difficult to deal with.

He adds that in addition to improving quality of life, it helps people to stay connected with the specialist MND care team without having to travel long distances.

This remote health monitoring has been particularly useful during the pandemic. For more information on Telehealth in Motor Neurone Disease visit the Care Centre website <https://sheffieldmndcarecentre.group.shef.ac.uk> There is also a link on the Local Services page of our branch website.

HeadUp Collar

HeadUp Collar manufactured by TalarMade. This collar which was designed for people living with MND here in Sheffield now comes in a large size. TalarMade is a company in Chesterfield and the collar can be purchased direct from them or through your Health and Social care professional. The instruction manual for the collar has been updated giving useful information.

2020 70 Club Winners

R. Hall G. Wright
D. Street P. Heath
A. Payne T. Carroll
J. James P. Heath

Congratulations to our first prize winners so far this year. Helen will be contacting everyone early in the New Year for the next annual £30 fee, due in **April 2021**.

Each Club member's number goes into a monthly draw to win a **£50, £30 or £10 prize**. Half of the membership money goes directly to branch funds.

Would you like to contribute to the branch in this way and become a 70 Club member? If so, please email **Ann Quinn, mndvisitor@gmail.com** or contact any committee member for details. Thank you everyone for your continued support.

The Motor Neurone Disease Association

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Branch Publicity: Vacancy

Open Meeting Venues Overleaf



Branch Meeting Venues

We are sorry we are not able to hold any Open Meetings at the moment. As soon as we can resume face to face meetings we will publish dates on our website and via our newsletter.

For new members reading this newsletter for the first time, these are the venues and times where Open Meetings are held:-

Sheffield	Tuesday from 2 00 pm - 4 00 pm Salvation Army Citadel, Psalter Lane, Sheffield S11 8YN
Rotherham	Monday from 2 00 pm - 4 00 pm United Reform Church, Stag Roundabout Wickersley, Rotherham, S60 4JN
Doncaster	Thursday from 2 00 pm - 4 00 pm Linney Centre, Weston Road Doncaster DN4 8NF
Barnsley	Wednesday from 1 00 pm - 3 00 pm The Potting Shed, Pot House Hamlet Barnsley Road, Silkstone, S75 4JU

Please note:- No meetings are taking place at the moment due to Covid 19 guidance.