

MESSAGE FROM YOUR CHAIRMAN



Welcome to this bumper edition of Chatter, which contains details of some of the many recent activities involving the Branch. Thank you to our secretary Ruth for putting it all together. There are more left over for the next edition.

What goes unseen is the amount of forward planning and the time commitment involved. We have acquired a much-needed new awning, and a proximity reader reflecting increasing numbers paying or donating with cards. Our stock of items for sale needs regular replenishing to reflect current demand, and attractive affordable items for children. Our store of tombola prizes needs replenishing from donations.

Support for the MND Association is still on the crest of a wave, but it will not last forever. Kevin Sinfield acknowledges there is a limit to the number of times people will continue to support his challenges in the way they have done to date. In her first welcome piece for Thumb Print our new Chief Executive Tanya Curry explained our task is to drive everything we do during 2023 and beyond. We must, for example, embrace our big opportunity to build on our work, drive forward research, collaborate to ensure the MND community has the care and support it needs, and inspire more people to fundraise for us.

At Branch level our commitment to help provide care and support for our MND community is a given, and our small team of qualified visitors is always busy. Currently we can also respond positively to requests for financial support for grants approved by the MND Association which in whatever way improve the lives of our MND community.

As a Branch we need to inspire more people to volunteer: to help us to maintain and build on the provision of care and support, and to fundraise for us. We know that two of our neighbours: West Yorkshire Branch and York Group, appear to have many more active volunteers than we do. Volunteers do not need to be members of the Branch committee. Please do consider us if you are interested in volunteering, and contact us. It is true that the more you put into the fight against MND, the more you get out of it.

A special mention to the community of Ripon for their great support of our work through several fundraising activities since the pandemic. We are very grateful and long may it continue.

Finally, many congratulations to Jenn Scribbins, our brilliant Regional Fundraiser and her husband on the birth of their first child, Jakob. He arrived on his due date too!

John Pike.

ROB BURROW MARATHON, LEEDS - 14 MAY 2023

Our Chairman John Pike reports - Last Sunday I joined Libby (who has provided some of the photos) and Robert, and Ruth Paynter and Tom, at Stephen Smith's garden centre cheer point, Otley. We were also joined by Kirsty Hudson from York Group (who has kindly provided the other photos) and Paul Fowler from West Yorkshire Branch with Angus, Tracey and Sally from the MND Association..

It was a long day, starting with setting up from 8.30am, until the road reopened at 2.30pm. I can't thank everyone enough: it was a really memorable experience. Despite the fact only a few people walked out to Stephen Smith's to watch, we had some visitors to the gazebo and significant donations (thanks to our contactless proximity reader).



We also had collecting buckets and a team willing to 'go the extra mile' along the road to look for contributions. The result was an amazing total on the day of just over £1123 .

We were at mile 16 and at that stage it was clear the runners really valued our support. Three ladies next to us from MNDA Scotland had driven from Glasgow to cheer some of their members who were running.

Approaching three hours after the start time numbers of runners started to decrease, as did the number of spectators, and many still taking part were mainly walking. There was a notable increase in the range of ages, shapes and sizes, and degrees of fitness. Some clearly were not going to finish. It was very hot. It was then that our cheer point really came into its own. It was humbling to see what people were putting themselves through, particularly when they thanked us for that support.



Two things in particular stand out for me. Two ladies were among the walkers and Tracey as ever encouraged them with 'well done, keep going, you look amazing' They smiled, called back their thanks and said 'looking amazing, feeling shit!' They would not have been alone.

A young woman came to put a donation in our bucket near the gazebo, simply said she had lost her father and brother to MND, and went off again.

Finally, a special mention to Stephen Smith. Their staff were in MNDA tee shirts, the cafe was open and all drinks were donated to us. They must have had dire takings due to the road closure, as they closed at 4pm. One would assume it would normally be one of their busiest days of the year. They made us very welcome.

I hope I have included everyone, and again, many thanks on behalf of the Branch.

John

Here are photos of Rob himself with Kevin Sinfield and the team



And the indefatigable Ian Flatt who has during the summer been climbing mountains and raising thousands of £££ for the MND Association - you can read more by following the link after the photo

<https://donate.giveasyoulive.com/fundraising/ian-flatt-whats-your-mountain>

A BIT OF FISHING ANNE WALKER MEMORIAL SHIELD FISHING

ANGLERS WANTED! Learn to fish and help fight MND



Anne Walker Memorial Shield Fishing
Match 2023
Saturday 15th July from 10 am



The partner of one of our BMC members loves to go fishing so was delighted that the Anne Walker event was going to take place again.

It took place on 16th July in 100 Oaks Caravan Park, Sutton in Derwent, York.

The event included pegs for serious anglers, pegs for kids and also for non anglers to have a go under the supervision of qualified angling coaches.

Tom had hoped for fine weather but a typical summer day with thunderstorms was what he got!

They enjoyed (?) two thunderstorms – this rather dark photo was taken from underneath an umbrella



Lovely cloud formations!

We are so grateful for Tom sitting it out as his fundraising will give us in the region of £800 for our Branch when gift aid is taken into account

There is still time to donate and you can do so by following the link below

<https://www.justgiving.com/page/thomas-raper-1688219548069>

(another photo on the next page!)

On the right of Tom in this one (as you look at him) is JJB (Jamie Jones- Buchanan ex Leeds Rhino player now a Rugby League coach) standing behind his son.



FUNDRAISING UPDATE

Once again we say thank you to anyone who has raised funds for the Branch. Some of the donations are detailed elsewhere but we also need to mention £72.10 received from Barlby and Osgodby Town Council for a splendid and totally unexpected donation of £516.69 as a result of their Jubilee Fun Day. Follifoot Village Hall also donated £30 from their fundraising.



We have received £569 from Ikley Golf Club as their Ladies captain has made our Branch their charity of the year. We are very grateful for this and she has promised us more money to come!

Some more gardening by one of our Branch committee members brought in a donation of £200 and some friends of hers sent us £100 from their sponsorship when taking part in the Rob Burrow Marathon back in May and we also made a considerable profit selling MNDA themed merchandise at the Cheer Station.

Back in November 2022 Ripon Rowells organised a bonfire and from the funds raised donated £200 to our Branch. Here is a photo of one of our Avs Libby receiving the cheque from John McGrath



We must also say thank you to those who have sent such generous donations in memorium. Finally, not forgetting the monies from the Local Lotto, on average we receive at least £30 every month. If you would like to join in and boost our monies then please have a look at the website and buy some tickets!

<https://www.thelocalotto.co.uk/support/motor-neurone-disease-association>

A FEW OF SNIPPETS FROM THE NATIONAL WEBSITE

MND Association invests in MND and traumatic brain injury research – The Association has collaborated with charities MND Scotland and My Name's Doddie Foundation to fund new research looking into whether traumatic brain injuries (TBIs) can lead to an increase in the risk of developing MND. Recent studies have reported an increased risk of elite football and rugby players developing neurodegenerative diseases, including MND. One theory is that brain injuries experienced during such sport may contribute to the risk of developing the disease. The new project - Traumatic brain injury and motor neuron disease (T-MND) - is led by Professor William Stewart and his team at the University of Glasgow. They have been awarded £45,000 to use an existing electronic health records database to investigate whether there is a relationship between TBI and MND. The database, which contains over 61 million health records, has already been used for studies into conditions like dementia. The hope is that by identifying and understanding the risk factors for MND, clinicians and researchers may be able to find strategies for lowering the risk of developing MND and ways to detect it. In addition to investing in this project, the MND Association has joined an MND and Sport Expert Working Group, which is led by MND Scotland and seeks to better understand the potential link between sport and the disease

Royal Patron HRH The Princess Royal attends Think Tank technology summit - The positive impact of technology on people living with MND has been showcased at a special summit attended by the MND Association's Royal Patron, Her Royal Highness, The Princess Royal. The technology summit, organised by the MND Association and held at Rolls-Royce headquarters in Derby, highlighted the work of the NextGen Think Tank – a collaborative project, launched by Rolls-Royce and the Association four years ago, which has brought together some of the world's biggest companies to create groundbreaking technology to improve quality of life for people living with MND. The focus of the event was the multi award-winning e-book I Will Always Be Me, developed by Rolls-Royce, Intel, Dell Technologies and the MND Association. When read out loud, the short e-book can electronically 'bank' the voice of someone living with MND, allowing them to use this synthesised voice in the future if they experience communication difficulties as their disease progresses. Previous voice banking options could take days, weeks or even months to complete. To date, more than 1000 people have banked their voice using I Will Always Be Me. During the event, Her Royal Highness met Think Tank members and people living with MND who had volunteered their time to trial the technology ahead of its launch in 2022.

The Rob Burrow MND Rose - Garden enthusiasts can now combine their passion for flowers and support for Rob Burrow MBE with a new rose which launched on 3rd July nad which made its debut at Hampton Court Flower Show on the same day. Rob and his family were given a sneak preview of the stunning rose last week when Philip Harkness, Chairman of the Harkness Rose Company, visited them at their home. Rob's children Macy, Maya and Jackson donned their gardening gloves and got stuck in, helping to plant the first Rob Burrow MND Rose in a UK garden. The Rob Burrow rose is a bushy upright plant with glossy toothed foliage. As the buds form, they are tinged with a delightful light green before they burst into a stunning saffron yellow colour. The floribunda blooms will brighten up any corner of the garden and coupled with its lovely myrrh scent, it is a stunning variety. Perfect for growing in a large pot or in a border. It has a height and spread of 90x60cm and will bloom from June to October. The rose can be ordered online at <https://www.roses.co.uk/product/540250/rose-rob-burrows-mnd-bare-root> (it will be despatched bare root in November). The Harkness Rose Company, creators of the rose and renowned British rose breeders since 1879, will donate £2.50 to the Motor Neurone Disease (MND) Association for every rose sold.

TIME FOR A BIT OF SOCIALISING



The date is set – 20th September we hope you can join us

For more information please contact Libby by phone 07803 208139 or by email libbywade22@outlook.com

We also have monthly get togethers for a coffee (or tea) and a chat in the café at Crimple Garden centre on the first Tuesday of each month at 2pm

ANOTHER DATE FOR YOUR DIARY

We are planning a fun evening

Beetle, Bingo and Buffet
On 11th November 2023 at 7pm
In Pannal Village Hall

Tickets on sale from Ticket Source

[https://www.ticketsource.co.uk/yorkshire-
dales-branch-of-the-motor-neurone-
disease-association](https://www.ticketsource.co.uk/yorkshire-dales-branch-of-the-motor-neurone-disease-association)



or in person
at Crimple Fresh / the Post Office in
Pannal

in aid of
mda
motor neurone disease
association
YORKSHIRE DALES BRANCH

BEETLE, BINGO AND A BUFFET (there will be a bar too!)



Saturday 11 November 2023 at 7 pm
Pannal Village Hall

Tickets £15 from
[https://www.ticketsource.co.uk/yorkshire-
dales-branch-of-the-motor-
neurone-disease-association/t-xmzzezTicketsource](https://www.ticketsource.co.uk/yorkshire-dales-branch-of-the-motor-neurone-disease-association/t-xmzzezTicketsource)
or in person at Crimple Fresh/Pannal Post Office



CHATTER

We aim to publish Chatter three times a year – apologies once again that this edition is a little later than planned – if you have anything to contribute the next one is planned for publication in late October so do get in touch!

WINNERS OF RECENT 100 CLUB DRAWS

We allowed plenty of time for people to sign up for the new year and fully intended to announce the first winners sooner but due to Chatter being late we are delighted to announce five winners – the draws having been made at our most recent committee meeting.



April – Jessica Ann White May – Libby Wade June – John Larder
July – Elizabeth Meyrick August – Simon Benyon

BRANCH WEBSITE AND OTHER INFORMATION

Please let us know if you would like to publish something on either our facebook page <https://www.facebook.com/MNDYorkshiredales> or our website www.mndyorkshiredales.co.uk

Or perhaps you might like to contribute to Chatter? It would be lovely to publish something from one of our members - just send your article to Ruth Pridmore

Can you help us save money by sending you paperwork by email instead of the Royal Mail? If you have an email address just let Ruth know.

Branch Contacts

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