

MND REGIONAL ROAD SHOW NORTH



Chair's report from the MNDA Regional Roadshow held May 2024 in York. Representatives from "The North" heard talks from a variety of people. Tanya Curry, CEO of the Association, spoke about Our Vision, Impact and Strategy, the need to build on our five promises.

Tanya spoke of the need for investment in research & innovation, faster access to treatments and interventions plus increased choice & control for people affected by MND. The investment in research nurses, who will be linked to the MND centres we fund, will ensure people get access to research to speed up diagnosis. Nick Cole, Head of Research for the Association, spoke of "an explosion of knowledge", underpinned by research funding leading to an increase in the number of publications year on year. The Association is currently funding 110 research projects with approximately 200 people working on the causes of MND, markers of the disease, a model of MND, developing treatments, & health care. Go to www.mndassociation.org/research for more information. There was time to celebrate & recognise volunteer achievements with a wonderful sideshow of what's been happening in the region. Michelle Malouf and myself were interviewed by our patron, Tanya Arnold, about "the Rob & Kev effect" on fundraising and volunteering. Colin Pearson, Area Support Co-ordinator, spoke about the York Group's project with St. Leonards Hospice to enable collaborative working. Then we had a breakout session in small groups to come up with statements we would like to be progressed. Here are some of them: -
The Association is fighting NICE about access to Tofersen. The Association is looking at an App to translate Voice Banking into other languages. The Association is looking to increase the grant ceiling. MND Connect has been reduced to office hours so staff can work towards replying to all calls & emails on the same day and the evening helpline has been paused due to very low demand. In all, it was a very informative day, bringing us up to date with what's going on both nationally & regionally. Tracy Sanderson, Branch Chair.

DATES FOR YOUR DIARIES

- Carers Groups** 1st Wed in the month, Holiday Inn, Ossett WF59BE 10am - 12 noon
- Get-Togethers** 2nd Wed in the month, 1.30 - 3.30pm.
- Nov 13th Brighouse Sports Club, Russell Way, Brighouse HD6 4LX
- Cornflower Past Carers Group** Last Wed in the month, Skelton Lake Services, M1 Junction 45, 2.00-4.00pm
- PMA PLS Support Group** on Zoom 2nd Mon in the month 5pm
- Tracheostomy Group** on Zoom 3rd Tues, either 2pm or 6.30pm
- Continuing Health Care** on Zoom every 6 weeks April 8th 11am
- Veterans Group** on Zoom 4th Wed in the month 2.30pm

TEAM 3 IN 3



On June 30th Richard Benny Shaw, Josh Mashiter & Kev Bower set off on a challenge of a lifetime. They cycled 2700km from Malaga in Spain, across France to the Coliseum in Rome, their final destination. 3 mates peddling up to 100 miles, everyday for 3 weeks across 3 countries. Each

member of the 3 in 3 team knows or has lost someone to MND and the inspiration for the challenge comes from Rob Burrow & Kevin Sinfield who, Richard says, have set an example of friendship like no other. A well-deserved £12,826 raised.

CARLTON HIGH SCHOOL



This is Ollie. He did the Colour Run at Carleton High School back in May and raised £160. He is only 4yrs old and came straight from nursery to do a full circuit of the race. His dad, Thomas, is the PE teacher at the school and he organised the event. Sue Lodge

SITraN OPEN DAY



On the 12th of July, we were lucky enough to attend the Sheffield Institute for Translational Neuroscience Open Day.

With talks from the most esteemed professionals in neuroscience and a chance to don on lab coats as part of the interactive laboratory tour, we felt very privileged to visit a world class research institute working towards better treatments and outcomes for people living with MND. SITraN houses some of the world's best clinicians and scientists who are dedicated to harnessing advances in Neuroscience and translating these into benefits for patients with neurological disorders. These include Parkinson's disease, dementia, stroke, multiple sclerosis with a strong focus on motor neurone disease.

To sum up the day, the talks covered positive developments in gene therapies, non-invasive ventilation, head-up collars and how they are working tirelessly towards improving the infuriatingly long drug trial processes. Dr Esther Hobson discussed some of the frustrations of the care and management of MND for patients and her focus on improving support available for families, helping people living with MND feel better and live longer, and ultimately finding that cure! Equality and inclusion were heavily featured in the talks along with improving pathways to treatment and support, whilst the interactive tour was an opportunity to see the latest cutting-edge technology and equipment and engage with the personable and caring scientists.

It was overall a wonderfully positive day, with a strong feeling of overwhelming gratitude from the researchers towards the MND community in how you have contributed to developments in treatment for MND and continue to bang the drum. You can find more information about SITraN and their work at Sheffield Institute for Translational Neuroscience | SITraN | The University of Sheffield Alex and Liv xxxx

FUNDRAISING DAY SUNDAY 1ST SEPTEMBER

This event was held in memory of **Janet Kenyon**, who passed away from MND 1 year ago. This was the date of her birthday. It was held at Moldgreen Con Club, Huddersfield, organised by her husband **Peter**. "He says the event went very well, raising £550 for MND. Hopefully, one day they will find a cure for MND."

GHYLL ROYD CARE HOME

On Wednesday 26th June, Ghyll Royd Care Home opened its doors to the local community, during Care Home Open Week 2024. The Community Hub was open to the anyone who wished to visit as well as residents and their relatives. They aimed to make a positive impact in Guiseley by raising awareness of MND and the support available. The Branch were invited to give a short talk and **Tracy** took up the challenge, also raising £100 in donations for people with MND. The Home went on to make West Yorkshire Branch their chosen charity and invited us to have a stall on Sept 14th at the Western Themed Summer Fair. You can see



Tracy and Colin Hey manning the tombola, raffle and merchandise stall. Tracy's choir, **All Together Now**, sang to entertain the residents and visitors. Thank you

to everyone who contributed to the £286.50 raised. Love the hats and very authentic necker!

DENBY DALE CARE HOME



Lucy Wood reports an amazing fundraiser at The Denby Care Home in Denby Dale back in June. "We raised a fabulous £326 which was sent straight to the West Yorkshire Branch. The band played all afternoon and everyone got involved. We had a sponsor who paid for all the staff to wear the T-shirts which was the local **Shelley Cricket Club**. There is no better deserving charity in my eyes." Thank you to Lucy and the care team and to all the residents.

SWIMMING CHALLENGE

Gayle Goodyear completed a 6k swim in the 1st week of May for MND. She said, "I have just had confirmation that the money raised will be passed to the West Yorkshire Branch MND, I hope this small donation will in some way help."

MND & CORONATION STREET

Article by Michelle Malouf Area Support Co-ordinator

I've had the unusual privilege of being involved in the Coronation Street storyline and scripts. At writing, this was a big week in the popular soap's heavy hitting storyline as Paul lost his battle with motor neurone disease after being diagnosed 18 months ago. A few facts; This is the first time a much-loved character on a British soap has been diagnosed with MND; First time viewers will see and understand the disease progression and the impact on day to day life and, importantly, those around them; There has been 22,000+ social media posts and engagements mentioning MND and Corrie; almost 1,000 people Googled MND on the first day MND was mentioned on Corrie; Daniel Brocklebank (Billy) was already a Patron of the MND Association prior to the script being presented to him – why – because his Grandad had MND and Daniel was his carer. The script writers weren't aware of this when they explained the upcoming storyline.

Our in-house experts, and partners, have answered hundreds of questions – speed of disease progression, equipment, benefits, support, conversations with Neurologists, impact on children to name a few. Our Speech and Language Therapist shaped the scenes where Paul was using his eyegaze equipment to communicate. Many people have resonated with aspects of Paul's journey – being accused of being drunk because their speech isn't clear, the frustration of not being able to communicate, the fight to get benefits. There have been spikes in website traffic around key storylines – at diagnosis, when Paul and Billy got married and when voice



banking was shown on screen. Daniel Brocklebank and Peter Ash engaged with us a lot, raising awareness, doing

interviews, attending events and raising money – we are very grateful to them.

WOODHALL HILLS GOLF CLUB



What a great atmosphere at Woodhall Hills Golf Club Beer and Music Festival on a beautiful day in June. The Branch held a tombola and raffle raising £740. Thanks to Captain Alan Cooper for supporting us and to the club and Music Box for donations of raffle prizes.

Thanks go to Alison Bridle, Terry Oxley, Alex Shann and Liv, Jonathan and Louise Griffiths for their help.

DARRINGTON GOLF CLUB



Thanks go to the Darrington Golf Club, Pontefract, for raising £2035 at the annual Craigo Tournament in memory of Craig, one of their members who died from MND seven years ago.

FAMILY FUN DAY



On Sunday 5th May, a Family Fun Day was held at Hillam Cricket Club, Leeds, organised by Ryan and Sarah Whalley. A fantastic £2,938.44 was

raised for the Branch and £2,700 for the Association. Nat West also contributed £500. Thank you to everyone who made this happen and for thinking of people with MND.



ROB SCOOTER RIDE OUT



On Sunday 16th June, big-hearted riders from

various clubs from the Yorkshire Scooter Alliance, took part in the **Rob Burrow** Ride Out event. They set off from Odsal Stadium at around 11.30am, bound for Headingley. It was a spectacular sight as many hundreds of riders left the ground. It was also an emotional and wonderful tribute to late, great rugby league legend Rob, who died aged 41 on June 2 after a four-and-a-half-year battle with motor neurone disease (MND). From Headingley, the riders headed to the Black Bull pub at Horsforth for a celebration of their achievements and the life of ex-rugby league star Rob. The event was organised by **Axle Foley and Neil Waudby**. Axle and Neil thanked everyone who was involved in making the Rob Burrow Ride Out such a success, paying tribute to Rob. Tracy Sanderson, was there to collect money for the Branch. She said the event made her "so proud" and said the funds would make "such a difference to so many people".



On Sunday July 14th, the Yorkshire Scooter Alliance held a Family Fun Day at The Ings, Guiseley to view the premiere of the film of the 'Ride Out For Rob' the previous month.

They also launched a fantastic raffle, first prize a Vespa! There are more events planned with the raffle being drawn at the last meet up of the season on October 26th in Bridlington. Thanks go to **Axle Foley and family** for the great organisation.

Following this event, an auction was held on Saturday 23 August, of a shirt signed by Rob Burrow and the Leeds Rhino players. **Axle Foley** tells us that the auction was held at a scooter run. He says he was amazed that one of the first bids was £200! The final bid was £250. "Absolutely blown away and so grateful for the donation of the shirt." So far this group of scooter fans have raised a huge £6,000.

MIRFIELD ORIGINALS SCOOTER CLUB



As last year and as we do every year, Mirfield Originals Scooter club held our annual multi meet, 15th June, at our base, The Shoulder of Mutton Pub in Mirfield. We and the pub wanted to raise money again for our local MND group for the support they have given one of our long-standing members Phil Long, who has ridden scooters for years and still loves the smell of 2 stroke and actually sits downwind behind the scooters when we go see him just to appreciate the aroma as we all set off. The weather was terrible as usual but didn't deter us, and us few diehards braved the weather and rode to the Yorkshire Sculpture park and back to the Shoulder for an afternoon and evening of music from the Band, Modness, and our resident DJ and of course one or two drinks were consumed. We had a great day and night. The event managed to raise £500 through donations from the scooter club members, the pub, attendees of the event and selling a few football cards.

FAMILY FUN DAY



On Bank Holiday Monday, a Pro Celebrity Crown Green Bowls Tournament

was held at Brighouse Sports Centre. **Tracy** wishes to thank **Katy Carter, Betsy and Willow, Colin Hey and June Cox** for their help with the tombola. The Branch volunteers met Coronation Street stars **Peter Ash and Daniel Brocklebank**, our Patron and raised over £300 for the West Yorkshire Branch. Tracy's grandsons enjoyed the football, cricket and archery as well as watching the bowls. Thanks go to **Lynn Pritchatt** for inviting the Branch.

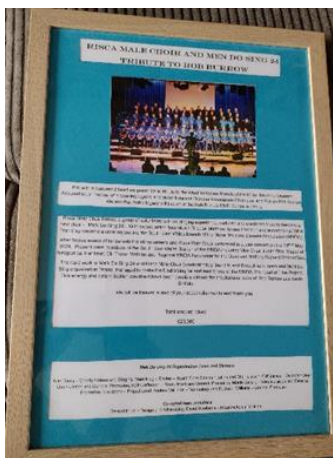


FEATHERSTONE MALE VOICE CHOIR



Thanks go to the Featherstone Male Voice Choir for their support for the West Yorkshire Branch. I attended a wonderful concert, hosted by them at St. Giles, Church of England, Pontefract. They, along with their guests, The Risca Male Voice Choir from South Wales, were wonderful. The event raised amazing £4,225! The Welsh choir is supporting MND South Wales and presented me with a picture of a roundup of what they have been doing. Thanks to **Richard Hirst**, organiser, and **Duncan Wood** (formerly of Calendar) the compere on the night. Tracy.

Picture presented to our Branch from Risca Male Voice Choir



“It is with a saddened heart we present this tribute to the West Yorkshire Branch of the Motor Neurone Disease Association, in honour of a sporting legend and Motor Neurone Disease Association Champion and Patron **Rob Burrow**. This energy and determination would not have been possible without the inspirational work of **Rob Burrow and Kevin Sinfield**. We will be forever in awe of your accomplishments and thank you.”
 Total amount raised for MND by the Risca Choir, £20,000.

MND IN INDIA

Ayushi tells us that her mother, **Mrs Sejal Zaveri**, a resident in Kandivali, Mumbai, suffered from MND for the five years. The mother of two, a housewife and a daughter in law, managed the household, even from her wheelchair. “Diagnosed in 2015, I never thought MND would be this consequential. I thought it was curable,” says Sejal. “I am already blessed with my family who has helped me overcome the storm, an amazing set of friends, my doctors and how can I forget my carer.” Sejal believed that she wasn’t A Victim but A Survivor. Now she has sadly passed away, and her daughter, **Ayushi**, a student at Leeds University, wishes to continue to help people with MND. She has already run in two recent marathons and wishes to meet people with MND in West Yorkshire and to make a donation to the Branch. She says that unlike in the UK, there is little awareness of MND in India.

ART EXHIBITION



The exhibition, organised by **Adrian Lord** was held in commemoration of his son **Jonathan**, who passed away from MND in August 2012 at the young age of 46. A selection of **Adrian’s** paintings were exhibited at the Mechanics in Marsden, to raise funds for the MND Association.

DARRINGTON GOLF CLUB



Many thanks go to **Peter Marchant**, outgoing captain of Darrington Golf Club, for choosing the West Yorkshire Branch as his charity of the year. A massive £7105.80 has been raised, which will help so many people in West Yorkshire living with MND. We are very grateful.

PONTEFRACT PARKRUN



A community of 400 people came together on June 8th, to show their respects to **Rob Burrow**. It was a very emotional event with a sea of people

wearing colours synonymous with Rob. 71 people were running for the first time in this Pontefract park run with representatives of 50 different clubs taking part. It wasn't possible to fundraise on council owned property without a licence but awareness of MND was raised considerably. Thank you to the organisers and to everyone who took part.

DRAGON RACE



Julie Bagga tells us her son-in-law, **Mike Broadbent**, a physiotherapist, has an interest in sports therapy and more recently an interest in MND. He owns his own business, the Physiotherapy Room in

Holmfirth. He took part in the 100mile Dragon Ride in Wales, on the 23rd of June, with a group of friends and personally, Mike raised £1,100 for the MND association. He said he survived it smashed it and loved every minute.

LEEDS BRADFORD INTERNATIONAL AIRPORT



On Friday August 16th, the Branch was invited to have a bucket collection at Leeds Bradford Airport. Thanks go to **Mike Bridgman**, **Sarah Marshall**, her Mum and daughter, for collecting in the morning, **Tracy Sanderson** took the afternoon shift. The total raised was

£266.21 plus a few cents and old pound coins! No buttons? Thanks for having us LBIA.

DRAGON'S BACK RACE

Hannah Jackson's Dad, **Lloyd**, was diagnosed with MND in May 2023. On Sept 2nd, his friend from work, **Andy Davies** ran in the Dragon's Back Race, a 6 day race covering 236 miles, with a total ascent of 53,800 feet, the equivalent of running up Everest twice. Andy says, "The way that **Lloyd** and his incredible family have adapted to this devastating disease is both humbling and inspirational. I am therefore very proud to say that this September **Lloyd** has given me the honour of allowing me to run the 2024 Dragon's Back Race in his name, for Motor Neurone Disease Association." Billed as 'The World's Toughest Mountain Race', the route spans the entire mountainous spine of Wales, starting at Conwy in the North and finishing at Cardiff in the South. Andy says, "Arrived at Cardiff castle after the 6 toughest days of my life. Incredible experience but the terrain is totally brutal. A huge thank you to all who have donated and supported me throughout." Andy managed to raise a fabulous £2,888.

GIANTS TWENTY20 CRICKET



Mike Bridgman tells us, "The day was very windy and wet so this limited the number of people considerably. The Giants could not have been more welcoming and would like to liaise

with the Branch for future events. We had a tombola and raffle which raised £160 and had a welcome visit from Big G"

EASTMOOR DRAGONS



Thanks to Eastmoor Dragons Amateur RLFC, Wakefield. They raised £1,410 with their St Patrick's Day event.

TIM GATES & THE GREAT NORTH RUN



Last year, Tim had to lose his place in the Great North Run due to needing an urgent operation on his eye. This year, despite his poor eyesight, he was determined to take part with his Guide, Adam. He was

delighted to finish in a new best time. Tim was raising money for the West Yorkshire Branch in memory of his dear wife Angie, who passed away 5 years ago at just 49. Both keen supporters of the Branch. Well done Tim and thank you for your continued support. Tanya Arnold, a Branch Patron, was at the Headingley meeting, where Tim was given a certificate of appreciation.



Get-Togethers 2nd Wed in the month, 1.30 - 3.30pm.
Nov 13th Brighthouse Sports Club, Russell Way, Brighthouse HD6 4LX
Dec 11th to be announced.

WETHERBY BULLDOGS



Thanks to Jordan and Ash at Wetherby Bulldogs ARLFC for raising £600 for the MND Association at a recent fundraiser. A rugby tournament was organised and

funds raised were split between the Branch and Cancer Research.

NORMANTON GOLF CLUB

Tracy was invited to the Annual Dinner of the Yorkshire Rabbit Association where the raffle raised £510. Thank you to Richard Poynton for the invitation, Eorl Crabtree, ex Huddersfield Giants and England Rugby League, for a highly entertaining after dinner speech.



MND Carers Group

Current carer for a person with MND?

If so, you're welcome to join us on the 1st Wednesday of the month. Meet others in the same situation in a friendly, supportive and gentle environment.

Where: The Holiday Inn, Queens Drive, Ossett WF5 9BE
Time: 10-12noon

For more information contact:
michelle.malouf@mndassociation.org 07876 575032
Sam: samanthaoakes@nhs.net 07717 701229

www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
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IN MEMORY OF STEVEN MERREY



No chains, no bars, no prison cell
Yet deep within his outer shell
My brother's heart and soul did dwell
His spirit danced, he looked so well.

His love shone out
Without a doubt
His eyes were bright
With inner light.

He didn't suffer MND
He lived with it for all to see
This dread disease did not define
His humour kept it down the line.

His love shone out
Without a doubt
His eyes were bright
With inner light.

And now he's fought his last campaign
No more struggle, no more pain
Our lives will never be the same
Only memories remain.

Laura De-Lucchi

GET WELL SOON MICHAEL



Michael Jeffrey, who chaired the Branch a few years ago, recently had a nasty fall and was admitted to hospital. Now he is in a rehabilitation unit working hard to get back home. Best wishes Michael from all your MND friends.

TOMBOLAS & RAFFLES

Any donations of items for future raffles and tombolas gratefully accepted!



WANT TO GO PAPERLESS?

To save postage we are happy to send out the newsletter to anyone with an email address unless you prefer to receive a paper copy. Please let Sue Starkey know if you wish to change from paper to email.

BRANCH CONTACTS

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West Yorkshire Branch Motor Neurone
Disease Association



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