

RUGBY LEAGUE COMMUNITY & LEEDS RHINOS



We were honoured to welcome **HRH The Princess Royal**, Patron of the MND Association, to AMT Headingley. The Association held a special reception to thank the Rugby League community and **Leeds Rhinos** for their support of people impacted by MND. The Princess Royal was guest of honour at an afternoon tea with 80 invited guests. Princess Anne met **Rob Burrow and family**, as well as some of the rugby league fans who have supported the MND Association since Rob's diagnosis. Together, they have raised around £8.2m. **Tanya Currie**, chief executive of



the Association greeted The Princess Royal and later gave a speech thanking everyone for their support and helping to raise awareness of MND. Princess Anne also

spoke thanking everyone for their efforts. **Tanya Arnold**, our West Yorkshire Patron also attended along with **Tracy Sanderson**, Branch Chair, plus **Angus O'Donnell**, our Regional Fundraising Advisor. **Richard Benny Shaw** said, "It was an absolute honour to be invited for afternoon tea with HRH Princess Anne and rubbing shoulders with the legend Rob Burrow and his family and all the other MND warriors and Leeds Rhinos players. Princess Anne showed her appreciation for everything everyone in that room has done for the MND Association, I even got a nice well done and a smile."

ROCK THE LOFT



Following the success of the inaugural 'Rock the Loft' festival that was held in Cleckheaton in 2023, the festival was held for the second time

on the 24th of February, with all proceeds going to the MND Association. Organised by **Steve Hodge** and hosted by **The Loft** on Northgate in Cleckheaton, this year's festival featured 9 West Yorkshire based bands. Headliners, **The Hijacked** were joined by **Friday Night Lights**, **Motor City Murder**, **MC16**, **Gevaudan Dogs**, **Mammoth Tank**, **Shambolic**, **Dead Reckless** and **Wolfora**. It was a fantastic night, music fans from Cleckheaton and the surrounding area came out in force to support both live music and the MND association, and in tough times, a fabulous £941 was raised. The festival has now raised £2400 for the association over the past 12 months. Keep your eyes peeled for the 3rd 'Rock the Loft' in early 2025!



NORMANTON GOLF CLUB



On Fri 8th March, David Ryley held his final fundraiser for the West Yorkshire Branch. Tanya Arnold was the guest speaker and she spoke about her career and links to MND and took questions from the very appreciative audience. David presented a cheque for a whopping £10,109 to Michelle, Tracy, Sue and Colin. Thank you to all.

LONDON MARATHON



Harry Spracklen ran in the London Marathon on April 22nd this year, in memory of his father, **Christopher Spracklen**. On April 26th 2023 his father passed away from MND, just 20 months after his diagnosis. Up until that time he had been a funny, fit and healthy man who

loved nothing more than taking long hikes and travelling the world.

Saatchi Spracklen, Christopher's wife says, "Harry felt exhausted and in pain around the 14mile mark, he stopped and thought he couldn't carry on. However, a kind lady fed him salt & vinegar crisps and gave words of support and he was able to continue. Our family had salt tablets and protein gels as well as pain meds. Harry is amazing, raising over £10,000 for the MNDA. His feet have suffered but he says it's worth it to complete the

Marathon in memory of his dad. Christopher, father to **Harry**, **Yasmin**



and **Niamh**, Grandad to **Arlo**. Congratulations Harry. I wonder which brand of crisps he ate? Might have discovered a magic food.

NICK KITCHEN



Once again, our thanks go to **Nick Kitchen**, who completed the MND Association Challenge of walking 15,000 steps each day in January. **Tracy Sanderson** met Nick at his

favourite place, Bradford City Football Club, for the cheque presentation. Nick was inspired by MND warriors **Stephen Darby** and **Rob Burrow**. You see Nick beside the football pitch. Thanks go to Bradford City for allowing them both into the dugout. Nick raised £1664. Well done!

CHALLENGE 3 IN 3



Richard Benny Shaw writes, "We are team 3 in 3 - On June 30th I will be joined by team mates **Josh Mashiter** & **Kevin Bower** on a unique challenge of a lifetime. The plan is to cycle a massive 2700km from Malaga, Spain across the width of France to the

Coliseum in Rome, Italy, our final destination! 3 mates peddling up to 100 miles every day for 3 weeks across 3 countries. That's it. Oh, apart from none of us are renowned cyclists nor will we have a support team!

Why? That's the easy bit... Our hope is to raise awareness for the Motor Neurone Disease association and maybe a few quid too. The mental and physical challenge facing us is huge but it's also temporary, Motor neurone disease is permanent there is no cure.

Each member of our 3 in 3 team knows or has lost someone to MND and we've become inspired by **Rob Burrow** & **Kevin Sinfield**, who above all else have set an example of friendship like no other.

https://www.justgiving.com/page/richardbenny15?utm_medium=fundraising&utm_content=page%2Frichardbenny15&utm_source=copyLink&utm_campaign=pfp-share

ST PATRICK'S DAY



Once again, the Leeds St. Patrick's Day event did not disappoint. Very well organised with fabulous music all day and some spectacular Irish dancing. Thanks go to The Leeds Irish Centre for inviting us. Our tombola made

£417.50. **Feargal Sharkey**, lead singer of the punk band **Undertones** - A Good Heart these Days is Hard to Find - came to say hello and pose for a photo. Thanks go to **Rachel Brooke** and **Angelina Michelle James** and the girls, **Michelle Forbes** and my amazing friend, **Alison Bridle**. **Tracy Sanderson**.



BRITISH INSURANCE BROKERS ASSOCIATION



Thanks go to BIBA, British Insurance Brokers Association, for inviting us to their charity dinner at The Queen's Hotel, Leeds, on Friday 26th April. Outgoing chair, **Alexa Owen**, chose

the West Yorkshire Branch to support during her year of tenancy. Thanks go to our patron, **Tanya Arnold**, for agreeing to be the after-dinner speaker. £2,535 was raised on the night thanks to the generosity of the guests. **Tracy Sanderson**



ERIC 90 IS WELCOMED TO HEADINGLY BY LEEDS RHINOS



Jean Horsman, one of our long-time Branch supporters, mother of **Glenn** who passed away from MND Oct 2020, was at Headingley rugby

ground with her family. Glenn's father **Eric**, recently celebrated his 90th birthday. He played for the Rhinos between 1958 and 1962 and is the oldest surviving player. To mark his special birthday, the Rhinos invited him and the family onto the pitch at Headingley and as a memorial to Glenn, the family all wore their MND Association shirts.



KARL JORDAN ARTIST



Karl says, "For the next two years, funds raised from the sale of paintings of Leeds United Football Club and

Leeds Rhinos, will be split between Leeds United Supporters Trust, the Rob Burrow Centre and the Motor Neurone Disease Association. The first painting, Dynasty of the Grays, is expected to sell for £600."

CARLETON HIGH SCHOOL



On Saturday 11th of May, Carleton High School in Pontefract, held a colour run to raise money for the MND Association. So

far this year, they have raised 5K. **Rob and Lyndsey Burrows** were there to cheer on their daughter. A HUGE thank



you to **Thomas Wandless** who started this event. Thanks also to the headteacher who made us feel very welcome. Your pupils are a credit to you 🙌. **Sue Lodge**.



SANDMOOR GOLF CLUB

Thank you very much to out-going Captain, **Andrew Wright**, at Sand Moor Golf Club, Alwoodly, Leeds for choosing us as his charity for the past year. The club raised £5,600 for the branch.



ROB BURROW MARATHON



HOLLY EYRES



Thank you for taking the time to read my story. As some of you may be aware I took on the challenge of running my first marathon at the inaugural Rob Burrows Leeds Marathon last year and raised money for the Motor

Neurone Disease Association (MNDA). This year I have decided to take on the half marathon distance and these are my reasons why. Last year, my mum, **Barbara**, as always, was there to support and cheer me on, watching from the streets of Headingley. I fortunately got to see her twice on the route and as I crossed the finishing line. I could hear her screaming and shouting above the crowds, waving a handmade banner. For those who know my mum, she exuberates life and will support her loved ones in anything they want to do. Little did we know at the time, that the MNDA charity would become close to our families' hearts. Shortly after the marathon she was referred to the Neurology department at Seacroft Hospital. Mum's health had been deteriorating for 2 years after suffering from two strokes, sadly her voice and speech were not improving and required further investigations. On the 7th of September 2023, mum was diagnosed with Motor Neurone Disease. A mere 4 weeks later, whilst on holiday with friends, playing her much-loved Bridge card game, she suffered multiple strokes. She was hospitalised and has never returned home. This has changed our lives forever. She now resides at a lovely care home in Adel (which happens to be on the Leeds half marathon route). The past 6 months has taught me time is precious and family and friends are the most important things in our lives. Therefore, this year, I have chosen to run the half marathon to raise money for this wonderful charity. The MNDA has already provided my

family with a lot of support during this difficult time and will continue to do so. We do not know how long we have with my determined, kind, thoughtful, amazing, and fierce mum. Therefore, I would like to raise awareness and money for this wonderful charity to support families like our own in the future. Last year I raised over £700 and I would love to exceed this. Therefore as 7 is such an integral number to this charity, my aim for the year is to raise £777 over two half marathon events – Leeds Half Marathon in May and the Great North Run in September. I appreciate your support, however big or small, to raise money for this fantastic charity. Thank you, **Holly Eyres** xxx

Update. A Cake Bake has raised nearly £1,200! "After a successful bake sale at my running club I got £400 in one night. Thankfully 🍰 they love cake as much as running" 🏃‍♀️

JENN SCRIBBINS



The majority of my training has been running with **Jakob** in his running buggy. Runs have required much more planning around feeding and nap time but we've had fun too, finishing in parks or stopping to see lambs or ducks on the way. My long runs I have done on my own, setting off early whilst Jakob is still sleeping and trying to get back earlier to make the most of some family time at the weekend. This again has meant planning carefully as I am breastfeeding so have to pump and make sure everything is ready for Jakob to have milk when he wakes up. Sometimes this has been after a disturbed night's sleep when I have been up in the night. A big thank you to **Dale, my parents and my running club Team Caterpillar** for helping me get these runs done. It hasn't been easy but it's nothing compared to the challenges that MND can throw at people which is why I may still be on maternity leave but I am asking for your help in raising much needed funds in the fight against this cruel disease.

The funds raised will be split 50:50 between my local group the Hambleton & Richmondshire Group and MND research. The support offered by local branches and groups is incredible and they are made up of so many selfless and inspiring individuals who I am lucky to know and work with.





2nd Wed in the month, 1.30 - 3.30pm

June 12th Skelton Lakes Services

M1 J45, Leeds, LS9 0AS. Located at J45 of the M1 approximately 2 miles east of Leeds city centre.

July 10th Normanton Golf Club

Hatfield Hall, Aberford Road, Stanley, Wakefield, WF3 4JP

All welcome for a chat and a cuppa.



Past Carer Group

Have you been a carer for someone with MND? You are welcome to come along to this friendly peer support group and be among others who are also bereaved. We will share a cup of coffee and an opportunity to have a short walk, if you want.

This is not counselling but emotional support in a friendly and supportive environment.

Contact: Michelle Malouf, ASC, MND Association 07876 575032 or Sam Oakes, Family Support Worker, Leeds Care Centre 0113 392 6755

**Where: Skelton Lake Services, M1 Junc 45, Leeds (above Pizza Express)
When: Last Wednesday of the month. Time: 2-4pm**

f West Yorkshire Branch **@** @MND_WestYorks

www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
[Registered charity no. 294354] Created in RightMarket - 28/2/2023 - 13:23:08



MND Carers Group

mnda
motor neurone disease
association

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: samantha.oakes@nhs.net 07717 701229

f mndassociation **@** @mndassoc or MND_WestYorks

www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
[Registered charity no. 294354] Created in RightMarket - 8/6/2023 - 15:56:56

FR Registered with FUNDRAISING REGULATOR

PENNINE BARRIER ULTRA 50



This year, **Leanda Cox** challenged herself to do this tough 50mile race. Starting in the beautiful village of Malham, taking in Malham cove, the Dry Valley of Watlowes, Malham tarn, Fountains Fell, Janet's Foss and the Yorkshire 3 peaks of Pen-y-Ghent, Whernside and Ingleborough.

"From my first challenge in 2020, when I started running for MND, I have raised a total of £2,795. I would like to get that up to £3,000 by the end of the year 😊 I have a few more 50 + miles booked this year and next year I think I would like to make a push to try a 100 miler and maybe raise even more 😊😊" WOW Leanda, that's a lot of running and a lot of funds raised for MND. Thank you.





2024 Britain's MND Veterans Group Needs You

Please join us on the 4th Wednesday of each month
2:30 - 3:30 pm

We would like to welcome all veterans to join us for a different type of support. Not just about MND but about you and your background and some common interests. A safe place to talk with like-minded people. Please let me know if you would like to join us and I will send you a Zoom link to join.

Please contact:
Dawn.pond@mndassociation.org

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN4 6BJ
Registered charity no. 294354 | Created in RightMarket - 4/12/2014 - 144452

[mndassociation](https://www.facebook.com/mndassociation) [@mndassoc](https://www.instagram.com/mndassoc)

FR Registered with FUNDRAISING REGULATOR



PMA-PLS Support Group

Zoom Support Group

The meeting is held on the second Monday of the month at 5pm – 6pm. You are welcome to join but access to the link is only via MND Connect by telephone or email. The remaining 2024 meetings are: Jun 10th, Jul 8th, Aug 12th, Sept 9th, Oct 14th, Nov 11th, Dec 9th
mndconnect@mndassociation.org
0808 802 6262



Let's talk CHC

Peer Support CHC Group

Next meeting Monday 13th May 11am via Zoom

Join our peer support group for people with and affected by MND. Volunteers with the MND Association and Health and Social Care Professionals wanting to understand more about the process of obtaining Continuing Health Care (CHC) funding, or who are facing problems with an existing care package. The group is facilitated by our CHC Peer Support volunteers, and is open to people with MND and their family members across England. Meetings take place via Zoom, every 6 weeks starting at 11am. The next meeting date is 13/05 and following dates are 24/06, 05/08, 16/09, 28/10, 09/12

For more information and joining details please email chc@mndassociation.org

[mndassociation](https://www.facebook.com/mndassociation) [@mndassoc](https://www.instagram.com/mndassoc)

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN4 6BJ
Registered charity no. 294354 | Created in RightMarket - 17/02/2014 - 181037

FR Registered with FUNDRAISING REGULATOR



MND Tracheostomy Carers group

"Are you caring for someone living with MND and a tracheostomy"

We alternate monthly daytime and evening groups to ensure those with work or childcare commitments are able to join.

You are welcome to join either or both groups on daytime - Tuesday 16th January & March 19th @ 2pm, with our bi-monthly evening group on Tuesday 20th February and 23rd April @ 6.30 pm to share ideas, experiences and peer to peer support from other Carers.

For more information please contact Lisa.burnard@mndassociation.org or Alli.anthony@mndassociation.org

[mndassociation](https://www.facebook.com/mndassociation) [@mndassoc](https://www.instagram.com/mndassoc)

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN4 6BJ
Registered charity no. 294354 | Created in RightMarket - 17/02/2014 - 181037

FR Registered with FUNDRAISING REGULATOR

See poster for new dates

Please contact for new dates and times.

BREAKING NEWS

The incoming Captain of Woodhall Hills Golf Club has picked the West Yorkshire Branch as his chosen charity for the year. We've been invited to have a stall at this event. So I'll be there both days with a tombola. If anyone has any tombola or raffle prizes they would like to donate I'd be happy to take them off your hands. Looks like it will be a great event. If you decide to come do come for a chat. Thank you. **Tracy Sanderson**



THIS IS WHAT OUR SUPPORT GROUPS LOOK LIKE



BRANCH CONTACTS

Chair: Tracy Sanderson

tracy.sanderson@mndassociation.org

07837485436

Secretary & Treasurer: Sue Starkey

<mailto:sue.starkey@mndassociation.org>

07704245632

Branch Contact & Newsletter: Jackie Johnson

jacqueline.johnson@mndassociation.org

07889523793

Carers Group: Michelle Malouf

michelle.malouf@mndassociation.org

07876 575032

PRINTED BY ACTIVE PRINT SOLUTIONS

<https://www.activeprintsolutions.com>

Tel 0113 203 6030

Email info@activeprintsolutions.co



West Yorkshire Branch Motor Neurone Disease Association



@mnd_west_yorkshire



https://twitter.com/mnda_westyorks