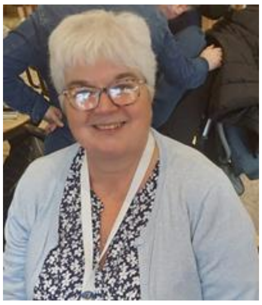
motor neurone disease
association

West Yorkshire Branch
May 2023

WELCOME TO THE WEST YORKSHIRE BRANCH NEWSLETTER



You will see as you read on, the tremendous amount of fundraising that has been going on in West Yorkshire. What happens to the money raised? I would like to tell you about some of the grant applications we have received recently.

The MND Support Grant (Care), up to a maximum of £1,500 per application, is offered to anyone living with MND; the application must be completed by a qualified Health or Social Care professional. This is what one of our members told us about their grant.

"The Care Grant towards the cost of a stair lift was gratefully received and has proved invaluable. My husband can stay up well past 6pm now, before this he would be too tired to climb the stairs. The adaptations we were considering for downstairs living have been put on hold. It's given me peace of mind as watching him on the stairs was stressful as he'd had a few falls."

The Quality of Life Grant, up to a maximum of £500 per application, is there to support both the person with MND and their family.

"The Quality of Life Grant means I can continue to go to watch football with my son & grandson as it paid for my season ticket. It also gives my wife a break from caring for me."

The Carers and Young Carers Grant, up to a maximum of £500 per application, supports the main Carer for someone with MND to allow them to take a break from caring duties and/or promote the well-being of the carer or young carer.

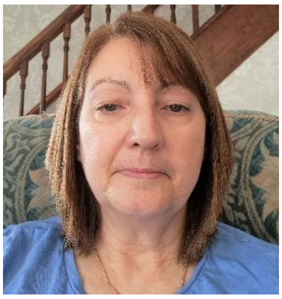
The Children &Young Person's Grant, up to a maximum of £250 per person, is for those aged 18 or under residing with a person living with MND or having a parent or guardian with MND. It could help towards hobbies, school trips, technology, or even driving lessons.

If you feel you may qualify for any of these grants, checkout the information on Financial Support Grants at http://www.mndassociation.org or contact one of the branch officers, telephone numbers etc are at the end of this newsletter.

I hope you enjoy reading this newsletter.

Best Wishes, Tracy Sanderson, Vice Branch Chair

SUE LODGE INVITED TO SPEAK TO MEMBERS OF THE HOUSE OF LORDS.

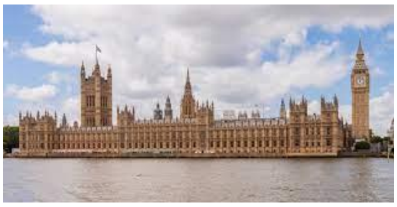


An awareness event was held for Peers at the end of January and Sue, from Wakefield, was invited to speak as a person with MND.

"I explained what it's like going through the process of being diagnosed with Motor Neurone Disease and then how it took years for me to be diagnosed with PLS. It takes most people a year or more to be diagnosed. I explained how hard it is to live day to day with MND, from something as simple as getting a shower or going shopping, how just going out is like a military exercise. I must make sure I have everything I may need to get through the day. Thanks to Kevin Sinfield and Rob Burrows, more people now know about MND, the MND warriors now have hope. The Government have pledged £50 million to MND for research and £29.2 million has already been released. I told them about the fundraising for the proposed new Rob Burrow MND Care Centre in Leeds. West Yorkshire is the biggest county in the country and yet we don't have the infrastructure to house any specialist MND services.

I said that I didn't want the Peers and MPs to leave the room feeling sorry for people with MND. Instead, I wanted each of them to go away and tell 10 people about MND and ask those 10 people to tell 10 more. I wanted them to know that MND is not a rare disease, that 1 in 300 people will receive this diagnosis. Next time when the House of Lords chamber is full with 600+ people, look around and at least 2 of those 600+ could be diagnosed with MND!

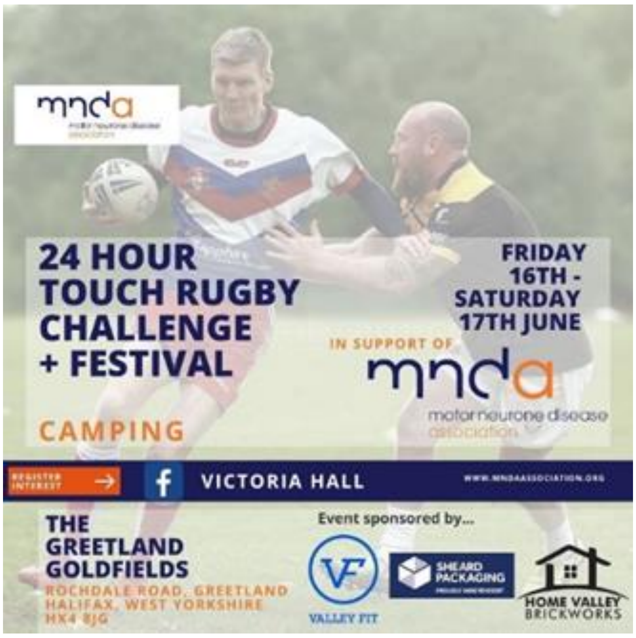
Finally, I asked the Peers and MPs when they next hear MND, not to think, 'Oh that poor person has got MND' but to think instead, MND is a horrible terminal disease and I will do everything I can to spread the word. so that hopefully, one day we will have a WORLD FREE FROM MND."

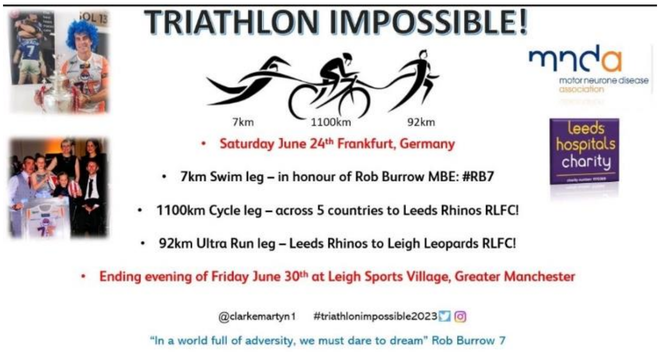


A WARM WELCOME TO SAM OAKES FAMILY SUPPORT WORKER

Hello, I am the Family Support Worker for Leeds MND Care Centre, funded, initially for a year, by the MND Association. I have a nursing background and planned to retire last year but this role was too special not to apply for and I certainly haven't been disappointed – working as part of a great team and meeting amazing people living with and alongside MND. I work two days a week, usually Wednesday and Thursday and my role is there to support the person affected by MND and their family. I don't have a clinical agenda, but a good listening ear and am led by the family's needs, for example, I have been helping some families and young people with memory making, exploring accessible days out, providing grant information, attending the MNDA support groups, signposting and working with Michelle and Colin to start a new "Cornflower Group" for those people who are bereaved by MND to name but a few things. I attend the MDT clinic, hopefully providing a friendly face and welcome refreshments. This is a development role and I'm happy for suggestions and ideas on what might be useful going forwards. I can be contacted by email:
samanthaoakes@nhs.net Tel:- 07717701229
Don't hesitate to get in touch with me – I love a chat and to meet new people and aim to learn, develop and help however I can.

TOUCH RUGBY & MORE





Martyn Clarke, 750+ miles 5 countries and 2 time zones in 7 days. Starts June 24th in Germany. 3 sports. Swimming, cycling and running. Raising funds for four MND charities & the MND Association is one of them. Good Luck Martyn

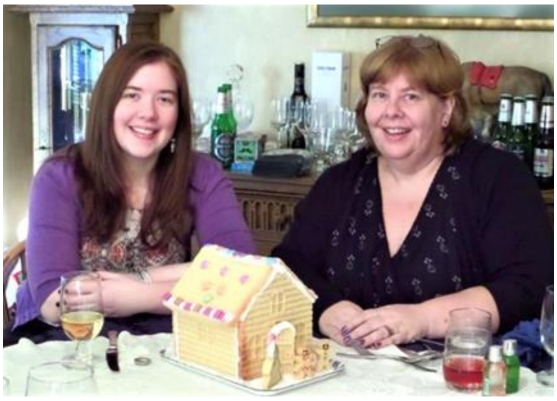
BAILDON GOLF CLUB

Tracy Sanderson collecting a cheque for £3,159.90, from Baildon Golf Club; MND was their Charity of the Year. Thank you so much for the support. A lot of golf must have been played!

AND ON THE SEVENTH DAY

Richard Benny Shaw will embark on a truly awe-inspiring mission - running seven miles every day for six days and on the seventh day, Richard will run from the John Smith Stadium in Huddersfield to the start line for the Rob Burrow Marathon in Leeds, where he will be joined by Craig, Olly and Claire to finish his ultra-marathon. At the finish line Richard will have completed a total of 43 miles in one day.

ASSOCIATION VISITOR RUNNING IN THE ROB BURROW MARATHON



Emma Smith, one of the Branch's lovely volunteers is running in the Rob Burrow Marathon in Leeds to raise funds for the West Yorkshire Branch. Her Mum, Karen, diagnosed in 2013, sadly passed away in 2014. She says, "The MND Association provides incredible support for families living with MND. I am an Association Visitor and support individuals who are either living with or caring for someone with MND. There is so much support available through the MND Association and it can make such a big difference. Funds raised will go to the West Yorkshire Branch." https://www.justgiving.com/fundraising/Emma-Smith440

SUPPORT FROM THE CO-OPERATIVE BANK

The Co-operative Bank in Leeds City Centre, invited the Branch to fundraise on their premises. Colin Hey managed to raise £33.40. Thank you to the bank for their support

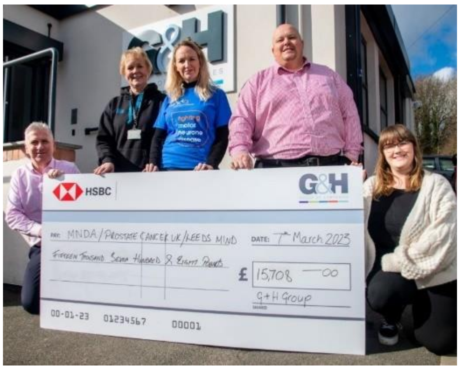
RACING DURING RAMADAN

The Ramadan fast wasn't broken by Emon during the Manchester Marathon on April 16th Then on Sunday 23rd, after Ramadan had finished, Emon Choudhury also ran the London Marathon, all to raise funds for MND and the West Yorkshire Branch. Emon and his nephew Jamiul were crowned winners of BBC Two's Race Across the World at the start of the first lockdown, March 2020. £3,847 raised to date. Thank you Emon.

RUN 70 MILES IN 2023

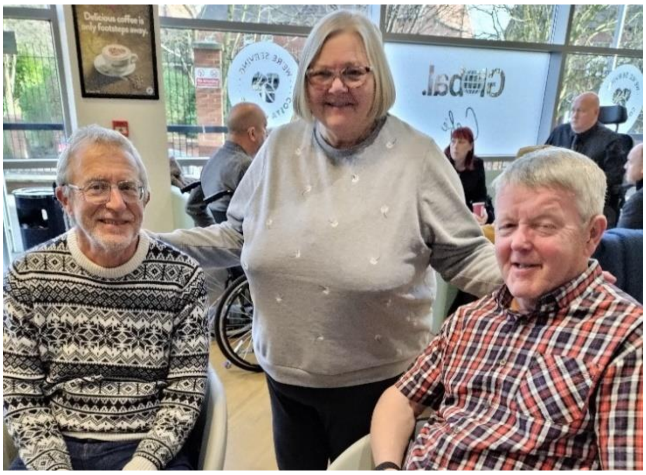
Since we heard from her last, Kirsty Hudson has raised £253.50 from a Christmas Hamper Raffle and £152 from two World Cup Sweepstakes. Her Grand National Sweepstake raised £125, making £6630 so far. In honour of what should have been her Mum Carolyn Hudson's 70th Birthday, on Dec 31st 2022, she and her friend Sarah Parker are running 70 miles throughout 2023 – 5ks, 10ks, and the Great North Run, ending with a Santa Dash. Keep going Kirsty.

G&H GROUP PUDSEY



G&H Group Pudsey donated £5,240 to the West Yorkshire Branch, raised from a golf day held last year. Sarah Marshall went along to thank them at the cheque presentation.

90 MILES FOR BILL



In Memory of Bill Ferguson

Former Minister at Christ Church and the Baptist Church in Ossett, David Coulthard, planned a route attempting to visit 24 churches over a 90 mile trek in West Yorkshire. Commencing 2nd April 2023, David and Keith Thompson, supported by friends, undertook the walk in memory of a dear friend, Bill Ferguson, who was taken by MND at the age of 54. They completed the walk, raising their target of £1,800. Bill's wife Cynthia is seen here with Keith and David. Hope your feet have recovered!

FINAL TOTAL

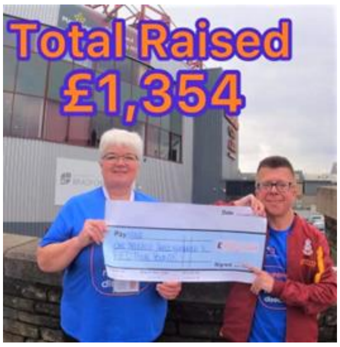
Photos of Dale Moorhouse and his team who walked from the John Smith's Stadium Huddersfield to Odsal Stadium in Bradford. Supported by volunteer Mike Bridgman with his collecting bucket.

£1.000 raised. Fantastic effort.

OSSETT CHURCH LENTEN LUNCH

Tracy Sanderson gave a talk about MND to the ladies at Ossett Church where she thanked them for raising £202 for the Branch. Homemade soup and a roll plus freshly baked scones for lunch.

15,000 STEPS A DAY



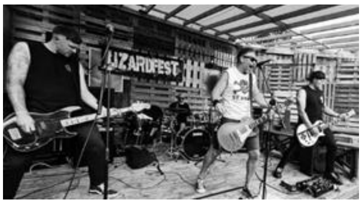
Nick Kitchen, Bradford City supporter, was inspired by Steven Darby and Rob Burrow to take on the 15,000 steps a day challenge. Nick's employer, Keighley Asda, contributed £300 and in all he raised a fabulous amount of £1,354. Tracy is receiving the cheque at Bradford City Football Club.

SILENT AUCTION

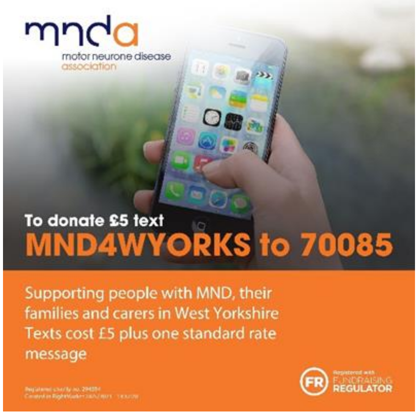
18th March 2023
SILENT AUCTION
mnda
motor neurone disease association

Debbie Briscoe organised this event. The winners of the Silent Auction at Silsden were announced on March 18th. £1,770 raised. Thanks to the generosity of local companies and individuals who donated items to the auction.

ROCK THE LOFT



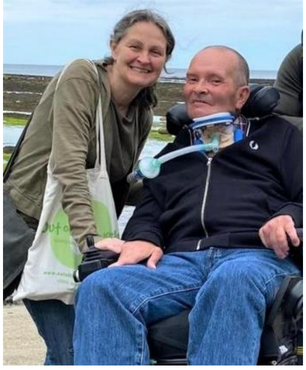
On Saturday, February 25, the Rock the Loft festival saw several original bands from Cleckheaton and the surrounding areas came together at The Loft to raise funds for MND. It was organised by the local heavy rock band, Motor City Murder, in partnership with the Loft music venue. There was a mixture of metal, rock, punk, indie-rock and heavy-rock music from bands such as Mr.Shiraz, Zapiain, Dead Monarchs, Mundi Club, River Bleed and The Hijacked. All the bands played free of charge and The Loft donated the money raised at the door. £806.74 for the West Yorkshire Branch and £623.75 for the MND Association.



To donate £5 text
MND4WYORKS to 70085

Supporting people with MND, their families and carers in West Yorkshire
Texts cost £5 plus one standard rate message

DAN & PATRICK TO RUN THE LEEDS MARATHON



“Patrick and I have decided to run the Rob Burrow Leeds Marathon this May to raise money and awareness for Motor Neurone Disease.
Our uncle Nick, was diagnosed with MND in December 2017. In less than a year, he went from being a really fit, athletic, 55 year-old, to being unable to walk and given months to live.
But because of technology advances, great support from the NHS and his carers (see more below), and Nick's relentless positivity, he's still squeezing every last drop out of life. He goes to gigs every week (sometimes even pushing himself to the front row), gets to as many Villa games as he can (which is probably shaving off his life expectancy) and has stepped up his climate activism getting himself arrested in the process.
He couldn't have done it all without the funding that has gone towards improving treatment and support for those with MND.
But he also couldn't have done it without his carers, and in particular our aunt Juliet, who has given up her job (and many other things) to support Nick, which is a full time (and mostly unpaid) role.
Carers are often the invisible heroes behind those with life changing diseases, and don't get the attention or support that they need and deserve.
For this reason we are fundraising for Motor Neurone Disease Association - West Yorkshire where our aunt Juliet runs a group for carers funded by this branch.”

SUPPORT GROUP HELD AT BRADFORD CITY FC

NORMANTON GOLF CLUB

David Ryley, the new Captain, has chosen the West Yorkshire Branch as his charity of the year. Branch volunteers Colin and Tracy, attended the Captain’s Drive In on Saturday April 1st when £569 was raised from the raffle, guessing how far the Captain’s drive would be and the sale of golf balls with the MND logo on them. Thank you to David, the golfers and our two volunteers for a great result for people of West Yorkshire affected by MND.

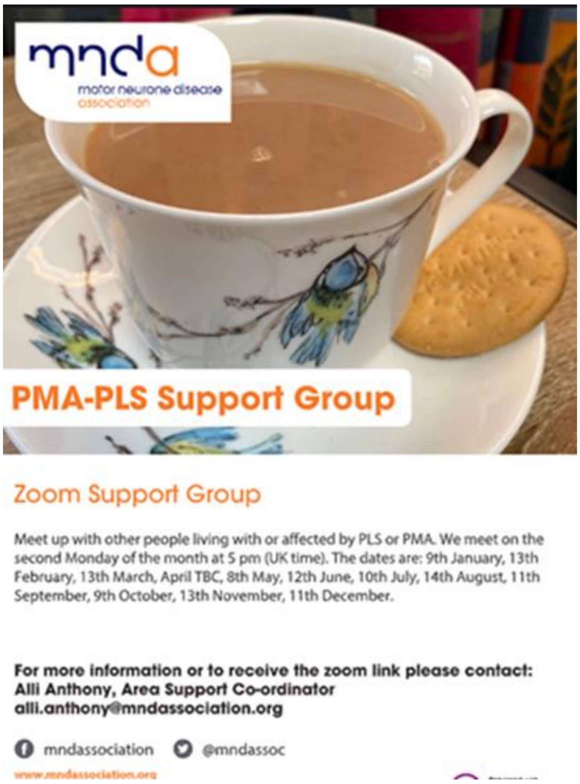
Anne Walker Memorial Shield Fishing Match 2023
Saturday 15th July from 10 am

At 100 Oaks Caravan Park, Sutton upon Derwent, York, YO41 4BY
Pegs for serious anglers and pegs for kids and non-anglers to spend an hour or so under the supervision of qualified angling coaches. All you have to do is to raise sponsorship money to take part.
5* Campsite with cafe and toilets on site.
Scan the QR code or visit https://www.justgiving.com/team/grahamwalker-21 to set up your JustGiving page. Help raise funds for your local branch and group to support local people with MND.

To take part contact Graham Walker on 07957 818534 or gbw@grahamwalker.org

mndassociation @mndassoc

www.mndassociation.org



PMA-PLS Support Group

Zoom Support Group

Meet up with other people living with or affected by PLS or PMA. We meet on the second Monday of the month at 5 pm (UK time). The dates are: 9th January, 13th February, 13th March, April TBC, 8th May, 12th June, 10th July, 14th August, 11th September, 9th October, 13th November, 11th December.

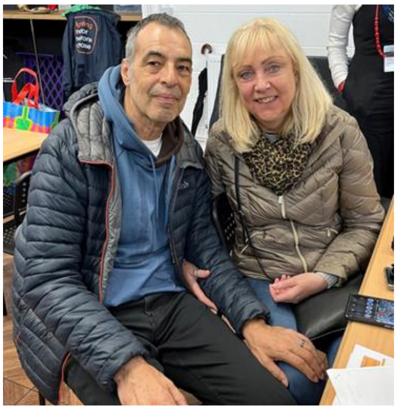
For more information or to receive the zoom link please contact:
Alli Anthony, Area Support Co-ordinator
alli.anthony@mndassociation.org

mndassociation @mndassoc

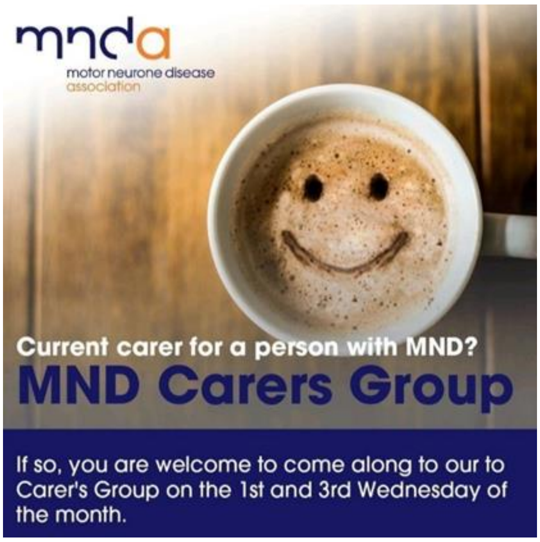
www.mndassociation.org

West Yorkshire Branch
Support Group Meeting

GET-TOGETHERS are held on the second Wednesday of the month. These gatherings are very informal and open to all those affected by MND. Time for a chat and a cuppa. MND Association staff & MND volunteers there to help. Wednesday May 10th Global Café, Headingley Stadium, St Michael's Lane, Leeds LS6 3BR 1.30-3.30pm.



Brian & Jane Hamilton at the Support Group held at Bradford City FC.



Current carer for a person with MND?
MND Carers Group

If so, you are welcome to come along to our to Carer's Group on the 1st and 3rd Wednesday of the month.

CARERS ONLY.
Please enquire about dates and venues, see the contact details below.

West Yorkshire Branch
Set up an online fundraising page for us

Don't forget to include on your page 'all funds raised for the West Yorkshire Branch' to help raise vital funds for the local area

Vice Chair: Tracy Sanderson
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Michelle Malouf - Wakefield Group
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West Yorkshire Branch Motor Neurone Disease Association

https://twitter.com/mnda_westyorks

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