

## THE GLITTER BALL



Many thanks to all who attended and helped with The Glitter ball on Saturday 12th April 2025. This was the first event I have organised since joining the West Yorkshire Branch in August 2024. I was delighted to join as a volunteer after my first initial chat with the lovely Michelle Malouf. I explained to her that I wanted to make a contribution to the West Yorkshire Branch. I considered fundraising and volunteering because three people I knew personally had been diagnosed with MND. I wanted to help as much as I could and had recently closed a local charity after 20 years, called Reuben



and Friends, which was a local charity based at Gomersal, Cleckheaton. This charity raised funds for local children with rare blood disorders and has raised £180,000 over the years for local hospital wards, hospices and helped to fund a research project at the

John Radcliffe Hospital, Oxford. After 20 years as Chairperson, with the help of a few friends, we decided to close, as our mission had been accomplished. We had had such good fun at the same time as raising funds at many various events.

I feel now that I want to make a real contribution and help people and their families with MND. It was a great opportunity to organise The Glitter Ball and almost 120 people attended. My friends Gill, Suzanne and Helen, who I had worked with at the previous charity, helped me and a big thank you to Michelle, Tracy, Jenn and Colin from The West Yorkshire Branch who also helped with various aspects of the evening. A big shout out to Colin and my hubby Richard who were doormen for the

evening at The Park Plaza Hotel, Leeds, guiding everyone to the event.

A huge thank you also to Tanya Arnold, who did a fantastic job hosting the whole evening; thank you so much Tanya and a special thank you to Pete Emmett who was our comedian / auctioneer. We had a three-course dinner after everyone was welcomed by The Glitter Ball Heads, provided by AJK Entertainment and Janet Jaye performed songs from Whitney Houston and Tina Turner, whilst guests enjoyed a three-course dinner. The auction was also well supported, which included family tickets and a meal at Leeds Rhinos stadium,



followed by watching a live game. A meal and an overnight stay for two at Rudding Park Hotel, Harrogate, to name but a few prizes. A huge thank you to all the companies and individuals who donated prizes for The Grand

Auction and raffle. Dancing continued until 12 am and Janet Jaye really encouraged many to take to the dance floor. It was a truly great evening. Also, huge thanks to Hanna Mistry who was our social media photographer for the evening.

We had very good feedback from the event and delighted to announce that a total of £6700.00 was raised on the evening for The West Yorkshire Branch. Thanks to everyone involved; I'm really looking forward to doing the same event next year.

The Park Plaza Hotel were very good to work with and the team couldn't do enough for us as a charity, they were excellent. We are their chosen charity for the year which is also fantastic. I am really looking forward to arranging more fundraising events over the next couple of years and hopefully beyond. A great evening was had by all. Many thanks once again to all involved.

Karen Jeffery



## REGISTERED BLIND AND TAKING ON THE LEEDS MARATHON



Tim Gates took on this challenge in memory of his wife Angela. 18mths ago he had eye surgery to hopefully improve his sight, however he's been left with limited vision. This didn't stop him from taking on the Leeds Marathon challenge on the 11th May. He was there last year and in Newcastle for the

Great North Run last September. "I lost my wife to MND 6yrs ago, I was the sole full-time carer for my wife so I saw everything that the disease did to her. I still see people affected by MND at the monthly Get-Togethers. I know times are tough but if you could please donate whatever amount you can afford to help people with MND living in West Yorkshire. Thank you." £115 raised  
[https://www.justgiving.com/page/tim-gates-9?utm\\_medium=FR&utm\\_source=CL](https://www.justgiving.com/page/tim-gates-9?utm_medium=FR&utm_source=CL)

## CLAN GOUGH'S MARATHON TEAM



Clan Gough also took on the Rob Burrow Leeds Marathon on 11 May 2025. Before the event Matt tells us that, "As a team we will be pushing

my Dad, Andrew Gough, around the 26.2 mile course in a Delta Run Assisted Wheelchair supplied by Delichon Limited and kindly donated by GFS. Andrew was diagnosed with Primary Lateral Sclerosis (PLS), a rare form of Motor Neurone Disease (MND) last year and we have taken inspiration from Rob Burrow and Kevin Sinfield to take on the challenge of the Leeds Marathon and the hills of Otley. Our team consists of Richard, Sam, Arran and myself, Matt. This will be a first marathon for all of us! In memory of Rob Burrow and his iconic shirt number, 7, we have set an ambitious target of £7,777. Every penny raised will help support those affected by MND and fund critical research to find a cure." £11,222 has been donated to the WY Branch.

<https://www.justgiving.com/page/clangoughpushforrob>

## THE CHUBBY LAD THAT RUNS



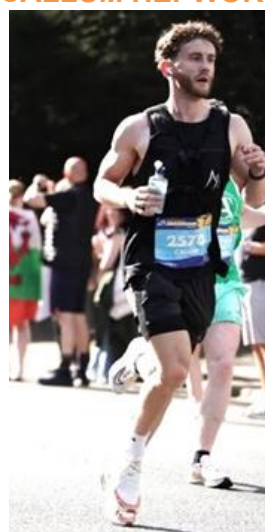
Paul Strafford was another competitor running on behalf of our Branch raising £117. He says, "Why the West Yorkshire branch? All my MND heroes have come from West Yorkshire, and have been helped by the branch to make memories with their loved ones. So, if me running 26.2 miles helps just one more family, get one more memory, then every step is worth it. The Branch is run by friendly, experienced and dedicated volunteers who aim to provide

the best possible support to local people with MND including families and carers. They do not have a central base of operation, instead, hold relaxed and informal meetings in various venues around West Yorkshire. For more information about ways to get involved on behalf of people affected or living with MND through volunteering, fundraising, campaigning, or providing care and support please visit the website here:

<https://www.mndassociation.org/support-and-information/local-support/branches/west-yorkshire-branch>



## CALLUM HEPWORTH'S LEEDS MARATHON



Tracy Sanderson tells us about her great nephew, Callum, who ran in the Leeds, Rob Burrow Marathon. Any sponsorship raised will be donated to the West Yorkshire Branch of the MND Association. "His great uncle David, who died from MND nine years ago, would have been very proud of him, as am I. I cheered him on from our cheer point at the Box, Otley Road, Headingley.

Thank you, Callum." 2hrs 51mins, a personal best. A fabulous £430 raised. You're awesome, says Great Auntie Tracy.

### PAULA HOYLE & THE 3 PEAKS



On July 12th, Paula and her friend Ginny will be climbing the 3 Yorkshire Peaks, 24 miles. They are raising money for our West Yorkshire Branch, in memory of Paula's husband

Peter, who sadly lost his battle with MND in July 2024. Having never been keen walkers or ever climbed mountains, this will be a big challenge. Paula says, "Peter was such a positive person and even in his darkest days he found light! He battled this disease with such courage & bravery and he never, ever complained or said why me, he was such an inspiration to everyone especially me. Peter spurred everyone on so I know he'll be spurring us on too. The MND Association do great work for families, who sadly find themselves in the same position as we were in; they need funds for much needed research until one day, hopefully finding drugs that will slow progression & eventually find a cure."

### RICHARD BENNY SHAW IS AT IT AGAIN



A Marathon every day in 7 different ways. Row a marathon, run a marathon, ski a marathon, run a marathon on a treadmill, cycle a marathon, a marathon around Yorkshire's 3 peaks

in under 7 hours, walk a marathon with the community, people around Huddersfield. Benny, Ryan & Craig came up with this crazy challenge, not to just run 7 marathons for 7 days, which would be hard enough and unthinkable but to do it using different body parts, as MND affects the whole body. This time we wanted to think outside of the box and really push ourselves to the limit while trying to spread awareness and raise funds for people and families living with MND. £580 raised so far.

<https://www.justgiving.com/page/richard-shaw->

### LEAH DOBSON



On Saturday 14th June, myself, Chris Barr and a few friends will be completing a 5km inflatable obstacle course in Leeds, to raise

money for the MND association. My mum was diagnosed 5 years ago at just 36. The MND Association have provided grants, to help us create memories with my mum and improve her quality of life which has meant so much to us.  
<https://www.justgiving.com/page/leah-dobson-1...>

### PADDY'S STORY

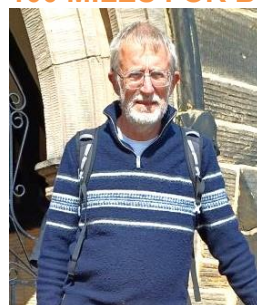


Paddy Towson-Sheehy's Uncle Alan, passed away in 2019 from MND. I have since completed various challenges in order to raise as much money and awareness as possible, including the 2023 Rob Burrow's Leeds Marathon. My goal is to play 7

rounds of golf in a day, everyday, for 7 days in a row, at golf courses around Yorkshire. 882 holes, 126 each day. Taking inspiration from the incredible efforts of Kevin Sinfield, I have decided to do my very own "7in7". Any donations to this incredible cause would be greatly appreciated, not just by me, but the MND community as a whole!

<https://www.justgiving.com/page/paddy-towson-sheehy>

### 100 MILES FOR BILL



Cynthia Ferguson says, "David Coulthard finished his '100 miles for Bill' arriving back at Christ Church, South Ossett at 2.25pm on April 22nd. Thank you David, and thank you to people who joined him for some part of his journey and to those who provided lifts." Bill was Cynthia's husband who passed away from MND. Just over £1,500 raised.

## ROB BURROW MEMORIAL RIDE OUT



On July 6<sup>th</sup>, the second annual Rob Burrow ride out will assemble at the White Swan and the Cricket Club in Yeadon. Hundreds of scooters and motor bikes will join forces to raise awareness & to support the MND Association, especially the West Yorkshire Branch. A sight

not to be missed will be our Chair Person, Tracy, riding a motor trike. Turn up on the day from 9am, setting off at 12.30pm, travelling along the A65 to Kirkstall, and then up to Headingley Stadium to lay a wreath. Finishing at the Ings pub in Guisley. Axle Foley, the organiser says, "This year's event will hopefully be bigger and better after raising £8,400 for the MND Association last year."

## LEEDS RHINOS



Huge thanks to everyone who attended the annual MND Awareness Day game between Leeds Rhinos and Wakefield Trinity at Headingley on May 31st. The match was won by the Rhinos 22-18. Taking place two days before the first anniversary of Rob Burrow's death, the day itself was not only a wonderful and fitting tribute to Rob, but a heartening reminder of how the Rhinos have continued to drive his mission to help support those living with MND and to try to find a cure. Stacey Kirkpatrick, our new MND regional Relationship Fundraiser, was presented with a cheque by Betfred, for £10k. Thanks to Neil Thompson, Jonathan and Louise



Griffiths, Sue and Steve Lodge for their help with the bucket collection and all those who generously donated.



## ART EXHIBITION



Kevin Sinfield, visited the Saddleworth Art Trail on Sunday 4th May. As part of the trail, he called in at the Saddleworth Picture Framing and Millyard Gallery in Uppermill, to support artist Adrian

Lord, whose son Jonathon, sadly passed away from Motor Neurone Disease in 2012. Adrian says, "Kevin has worked tirelessly to raise both funds and awareness for the MND Association, and we are honoured by his support. In a generous gesture, Kevin donated a signed rugby shirt to be framed at the gallery and raffled during the event, with all proceeds going directly to the charity." £500 was raised from the raffle of Kevin's running vest. The final total from the whole event is likely to be in excess of £2500.00.

## RUNNING FOR ROB FILM PREMIER



Great to attend Thursday night's premiere of the latest film 'Running for Rob', capturing behind scenes footage from Kevin Sinfield and team's last challenge. It was an honour to be interviewed for the film alongside Lindsey Burrow and some familiar faces from the MND community. Special thanks also to the West Yorkshire Branch Motor Neurone Disease Association's Tracy Sanderson for coming along with a stand and speaking to guests about the local Branch. A huge thank you to Jimmy, Joe, Steve and the team at RAM Films for continuing to bang the drum for MND with another moving film capturing the highs and the lows of the challenge alongside the harsh realities of MND and why we need to keep raising funds and awareness. Jenn Scribbens, Relationship Fundraiser.



Mary Johnson Green started her training on April Fools Day! Nevertheless raising £430. Tx

### DRIFHLINGTON JUNIORS RUGBY TEAM

Drighlington Juniors Under 10s showed their support for the MND Association in May at The Rhinos Challenge in Skegness.

Alfie, Henry, Jack, and Carter, along with their teammates and coaches, wore specially designed kits featuring the MND logo.

Sam Pickles, Team Coach, said: "The coaches are extremely proud to support a cause so close to the hearts of so many in Rugby League."

The team joined over 350 rugby league teams from across the UK on tour.

All 20 players were outstanding, and together the lads lost only 1 out of 12 games!

A big round of applause to the team – amazing.

### NEW FRIENDSHIP GROUP IN KEIGHLEY



First meeting attended by Robbie Moore MP, supporting the new venture in his Keighley, Ilkley and Worth Valley constituency.

**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

 mndassociation
  @mndassoc or MND\_A\_WestYorks

[www.mndassociation.org](http://www.mndassociation.org)  
MND Association, Trinity's Cuck House, 8 Sunningdale Road, Northampton, NN3 6BU  
 (Registered charity no. 294354) (Created in RightMarket) 18/10/2020 - 15/04/2021


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**MND Friendship Group - Keighley**




**Saturday 10-12noon (second Sat of month)**

**New Keith Thompson Centre, Coronation Mount, Braithwaite, Keighley, BD22 6HE**

Accessible parking and toilets. Tea and coffee provided.

**Ziggi O'Connor** [ziggiocconnor@mndassociation.org](mailto:ziggiocconnor@mndassociation.org)  
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**Michelle Malouf** [michelle.malouf@mndassociation.org](mailto:michelle.malouf@mndassociation.org)  
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 mnd\_yorkshire or West Yorkshire Branch
  @MND\_A\_WestYorks or @MND\_Dales

[www.mndassociation.org](http://www.mndassociation.org)  
Trinity's Cuck House, 8 Sunningdale Road, Northampton, NN3 6BU  
 (Registered charity no. 294354) (Created in RightMarket) 18/10/2020 - 15/04/2021


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## A SAD GOODBYE TO MICHELLE



In May, we sadly said farewell to Michelle Malouf, on the right, our wonderful Community Support Co-ordinator. Michelle worked for the MND Association, specifically the West Yorkshire Branch, for five years. She joined us in lockdown having worked in the MND field for five years in Australia. During this time, the West Yorkshire Branch has grown, not only with the number of people living with MND, but in terms of the number of volunteers Michelle has recruited. We now have 10 Association Visitors covering our region, whereas there was only one when she came into post. We have more fundraising volunteers, a Campaigns Team and volunteers who look after our social media output. Michelle made it her mission to get to know every person living with MND and their carers in our patch. She supported the Current Carers Group and set up The Cornflower Group for recently bereaved Carers, both of which meet monthly. She encouraged the MND Care Co-ordinators and MND Clinical Nurse Specialists in West Yorkshire to communicate with each other, linking them together by organising regular meetings. And, of course, she got us through the 'Rob Burrow Years'. Being at Headingley Stadium pretty much the full week following his death to offer comfort and support to those of us who were somewhat overwhelmed by the outpouring of grief. Contending with questions from the media and getting them the answers, all the while organising an extra Support Get Together that week, so there was a safe space to come and grieve. The Branch will miss her terribly, I will miss her, she's always had my back! We wish Michelle all the best in her future, whatever path she takes.

Tracy Sanderson, West Yorkshire Branch Chair

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### HOW ARE THE FUNDS YOU RAISE SPENT?

Last year (2024) the West Yorkshire branch funded or part funded £89,727 in Care Grants, Quality of Life Grants, Carers and Young Carers Grants & Children & Young Persons Grants.

These grants included funding for lightweight wheelchairs, wheelchair accessories, specialist chairs, wet room adaptations, WAV hire, mobility scooters, stairlift rental, holidays and break aways, items of technology, TVs, transport costs (to appointments), neater straws and much more.

All this could not have been achieved without the wonderful work of all the dedicated fundraisers in West Yorkshire.

Grants are divided into different categories as follows:-

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.

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 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, more information can be found on Financial Support Grants at <http://www.mndassociation.org>

With best wishes,

Sue Starkey, Branch Treasurer



**July 9th** the AMT Cafe St Michaels Lane, Headingley LS6 3BR

**August 13th** Skelton Lakes Services M1 J45, Leeds LS9 0AS.

### YOUR WEST YORKSHIRE BRANCH COMMITTEE



Colin, Tracy, Neil, Sue, Jonathan, Karen, Michelle  
& Cath

### 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, 1.00 - 3.00pm.

July 9th the AMT Cafe St Michaels Lane, Headingley LS6 3BR

August 13th Skelton Lakes Services M1 J45, Leeds LS9 0AS.

**Cornflower Past Carers Group** Last Wed in the month, Skelton Lake Services, M1 Junction 45, 1.00-3.00pm

**Friendship Group** Second Saturday in the month, New Keith Thompson, Coronation Mount, Braithwaite BD22 6HE 10-12noon

**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

**Veterans Group** on Zoom 3rd Thursday 1.30-3.30pm

**Black Indigenous People of Colour Support Group** 12noon - 1pm 3rd Tues in the month  
**Evening Online Carers Group** 6.30pm last Thursday in the month

<https://www.mndassociation.org/online-support-group>

### WEST YORKSHIRE BRANCH WEBSITE

Katy Carter, our new Webmaster has given the website a revamp. Take a look at the website for contact details, dates of support meetings and more.

<https://www.mndassociation.org/support-and-information/local-support/branches/west-yorkshire-branch>

### SETTING UP A FUNDRAISING PAGE?

**Don't forget to include 'raising funds for the West Yorkshire Branch'** in the wording on your page, if you wish the money to be used locally. You can register your event at:

<https://fundraising.mndassociation.org/fundraise-your-way>

### FORGOT TO ORDER LEAFLETS FOR YOUR FUNDRAISING EVENT?

MND Branded Materials can be downloaded and printed at:

<https://fundraising.mndassociation.org/fundraising-zone/keydownloads>

### FAMILY SUPPORT FACEBOOK GROUP



**The Children and Young People (CYP) Team** has set up a private and supportive space for parents who have been affected by MND, and have children under the age of 25.

The dedicated Facebook group provides a compassionate community where you can share experiences, ask for advice, and connect with others who truly understand your journey. Whether you need advice, encouragement, or just someone to listen, the group is there to support you.

It is moderated by CYP specialists and isn't open for MND staff or volunteers, only family.

The link to join the Facebook group is:  
<https://www.facebook.com/groups/cypsupportmndassoc>

### THE CAVENDISH SPENCER TRUST

CS Disabled Holidays gives grants to people who are severely physically disabled with neurological or neuromuscular illness, enabling them to enjoy life-changing holidays of their choosing.

<https://www.csdisabledholidays.co.uk/>

### THE TONY RAMPTON TRUST

Are you or were you employed by Freemans, Grattan or a related business? They provide help to qualifying current or former employees and close members of their families in times of misfortune or hardship, both physical and economical. Help is given in many ways according to personal and domestic circumstances that arise, which the person concerned cannot reasonably afford to meet from their own income or savings and to support staff and former staff in their efforts to raise funds for charities or when doing voluntary work for them. <http://www.tonyramptontrust.org/>



West Yorkshire Branch Motor Neurone Disease Association



@mnd\_west\_yorkshire



[https://twitter.com/mnda\\_westyorks](https://twitter.com/mnda_westyorks)

### HOLIDAY IDEAS/REVIEWS YORKSHIRE AND BEYOND

<https://www.facebook.com/groups/1140328413425016>

### BRANCH CONTACTS

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Website

<https://www.mndassociation.org/support-and-information/local-support/branches/west-yorkshire-branch>

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