



Thousands of Steps, One Incredible Cause

“Every step counted as hundreds of supporters took part in the Rob Burrow Leeds Marathon, Leeds Half Marathon and Relay earlier this month, helping to raise an incredible £340,000 for the MND Association.

A huge thank you goes to everyone who laced up their running shoes, volunteered their time, or stood along the route cheering participants on. Leeds continues to be one of the most special events in the fundraising calendar, bringing together people from across the MND community in a powerful show of support and determination.

This year, a remarkable 550 runners proudly wore MND Association colours as they raced through the city. Amongst them were 10 participants living with motor neurone disease who, alongside their support teams, took part in a newly introduced ‘MND Wave’ start. The dedicated wave created a moving and memorable moment, representing the largest number of people living with MND ever to participate in a mass-participation event.

The support from spectators was as inspiring as ever. Otley, in particular, received widespread praise for its fantastic atmosphere and enthusiastic encouragement. Our Yorkshire Dales branch cheer point was packed with supporters, creating an unforgettable welcome for runners as they passed through. As well as lifting spirits, supporters helped raise valuable funds for the branch. Collection buckets at the Otley cheer point raised an impressive £654.75 for the Yorkshire Dales branch, helping us continue to support local people living with MND, their families and carers.

Thank you to everyone who took part, volunteered, donated or cheered from the sidelines. Your support makes a real difference.

Looking Ahead

Feeling inspired to take on the challenge yourself? [Places for the 2027 Rob Burrow Leeds Marathon are now available.](#)

If running isn't for you but you'd like to be part of the action, volunteer opportunities for 2027 are also open. Whether you're helping at a cheer point, supporting runners or assisting behind the scenes, we'd love to have you involved. [The volunteering form](#) has been updated with the 2027 date. Together, we can make next year's event even bigger and better.

Message from the branch Chairman, Dave

"I'm now a few months into my role as branch chair and I am really enjoying it surrounded by a friendly, helpful and knowledgeable community.

A few highlights have been the Rob Burrows Leeds Marathon when I was at the Otley stop cheering on all the runners. It was great to see so many in our colours.

I also had the pleasure of a choir festival in Ilkley run by Yorkshire Voices Choir. It was a really great night of entertainment and a very generous audience who donated to our cause that the choir chose as their charity to sponsor.

Also, with my Rotary Club we had a fundraiser on a Ripon race day that worked very well.

Lots more events are coming up. Wishing Alan Robinson all the best for his upcoming challenge , meanwhile I'm still on the learning curve.

Dave"



Coffee and a Catch up

The first Tuesday of every month we host an informal meet up for all those affect by MND.

It's a place where you can share your stories, ideas and meet others affected by MND.

The catch ups run 2pm until 4pm in the café at Weetons (was Crimple) just outside Pannal on the road into Harrogate. All are welcome, just show up, or if you want more information then do please get in touch with Libby Wade on 07803 208139.

We hope you can join us.

Upcoming dates:

- Tuesday 7th July
- Tuesday 4th August
- Tuesday 1st September



Yorkshire Dales Branch

For anyone affected by MND, join us at our monthly 'cuppa and chat'

A welcoming and informal 'cuppa and chat'. Held the 1st Tuesday of every month 2 - 4pm. Weeton's Garden Centre café, Leeds Road, Pannal, Harrogate HG3 1EW

→ Libby Wade 07803 208139

✉ Alun Owen 01604 800619

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Meet Abi our Relationship Fundraiser for North and East Yorkshire

Abi joined the MND Association in March to cover Jenn Scribbins maternity leave, and from day one she has hit the ground running. The past few months for Abi have been busy, rewarding, and full of opportunities to connect with supporters across the MND community.

Before moving into fundraising, Abi studied Zoology at university, driven by her love of animals. However, it was during a university

fundraising challenge that she discovered a new passion – and she has never looked back since and has worked in numerous fundraising roles across the charity sector.

Her enthusiasm for the role at the MND Association is deeply personal, as the cause is very close to her heart. Having seen the impact of motor neurone disease firsthand through her grandmother's experience with MND, Abi feels this connection helps her better understand and support the people she works alongside.

Abi is passionate about helping people turn their ideas into meaningful fundraising activities. Whether someone is planning their first event or looking for guidance on a larger activity, she is there to offer practical support and encouragement every step of the way. She offers advice on fundraising ideas including good practice and any legislation to consider, provides materials for fundraising events and can help source speakers for events.

"I really enjoy meeting people. I love seeing the passion in people's eyes and watching them light up as they talk about their ideas and fundraising achievements," she said.

"I like helping people draw something positive from a difficult situation and encouraging them to do something they're genuinely excited about."

Her advice for anyone thinking about fundraising is simple: choose something you love.

"If bucket collections aren't for you, don't do that. But if you've always wanted to skydive for example, let's explore together how we could make that happen."

You can contact Abi via email abi.baker@mndassociation.org or call 01134830706.



Carers' Survey – Have Your Say

Are you currently caring for someone living with MND? The MND Association would love to hear from you.

A new survey is gathering feedback from; current carers who are currently caring for a person living with MND, unpaid carers including friends and family who care for a loved one with MND and carers who receive benefits are also eligible to complete the survey.

The link to complete the survey online is [Carer's Survey – Fill out form](#)

The survey has already received some really valuable responses, and the more carers who take part, the better we can understand what support is most needed.

If you're eligible, please take a few minutes to complete the survey.

Pool Night Tribute Raises £200

David and Libby Wade recently visited Ripon Bowling Club to receive a very generous cheque for £200 from the club members. The money was raised during a fun “killer” pool evening held in memory of Steve Windle, a well-known and much-loved character in Ripon, who sadly passed away from MND last year. A huge thank you to everyone who took part and supported the event. It was a wonderful way to remember Steve while raising funds for a cause close to many people's hearts.



Padel Marathon Raises £1,300 for the MND Association

On Saturday 18 April, we hosted a remarkable 17-hour Padel Marathon at Harrogate Spa Tennis Club, bringing together players, volunteers, friends and family members in support of the MND Association Yorkshire Dales Branch.

The event began at 6:00am and continued through to 9:00pm, with four participants taking to the courts every hour. Players of all ages and abilities joined in throughout the day, creating a welcoming and inclusive atmosphere that showcased the strong community spirit of the club.

Participants were invited to make a £15 donation to take part, with all proceeds going directly to the Yorkshire Dales branch of the MND Association. The funds raised will help support local people living with motor neurone disease, as well as their families and carers.

In addition to the on-court action, attendees enjoyed a variety of fundraising activities, including a merchandise stall, tombola and raffle, all of which contributed to the day's success. A delicious selection of cakes, buns and sweet treats was also available throughout the day, thanks to generous donations from local businesses.

Thanks to the generosity and enthusiasm of everyone involved, the event raised an impressive £1,300. The marathon was exceptionally well supported and demonstrated the power of sport and community coming together for a worthy cause. A huge thank you goes to all the players, volunteers, supporters and organisers who helped make the day such a success.



Fundraising round up

Thank you again to everyone who has helped to organise, completed events and/or fundraised over the last few months. Here's a snap shot of some of the activities people were involved in to help raise funds for the Branch:

Easter cake and card sale at Allhallowgate Methodist Church in Ripon raised £377.

A stall at Co-op Jennyfield raised £160.

The Padel Marathon at Harrogate Spa Tennis Club raised £1,300.

The Leeds Marathon at Otley raised £675.

A bottle Stall and collection at Ripon Races in conjunction with Ripon Rotary Club raised £470.

Ribbon Bowling Club raised £200 during "killer" pool evening.



Dates for your diary

Here's some of our fundraising events coming up over the next few months:

June 20th Alan (pictured) is taking part in a 25k Ultra Challenge Walk in Scarborough

July 11th Stall at Morrisons Harrogate

July 19th Stall at Weeton Show

August 15th Ripon Races

August 31st Hit MND for 6 Cricket Fun Day at Bilton Cricket Club

We hope to see you there.



MND Association national news

The latest news from the MND Association can be found on the [website](#). Here are a few of the key headlines over the past few months:-

- Unpaid carers feel unrecognised and undervalued, report shows. Nearly half of unpaid carers feel their caring role isn't understood or valued by their community, according to new research released during Carers Week. [Read this story.](#)
- Tofersen appraisal update: The MND Association has supplied evidence to support the approval of tofersen as a treatment for people with SOD1 MND. [Read this story.](#)
- A global challenge prize, which aims to transform drug discovery for the treatment of amyotrophic lateral sclerosis (ALS), has awarded £2 million to twenty international teams. [Read this story.](#)
- Turnaround times fall for genetic testing results. Average wait times for genetic testing for people with motor neurone disease (MND) have dropped from 18 months to around three months, research by the MND Association reveals. [Read this story.](#)

Reader Contribution:

The challenge of living with chronic illness



“ There are elements of serious stenosis of the neck, MND and Inclusion Body Myositis and Atrial Fibrillation in my debilitating illness. Officially I have been diagnosed with MND. I have learnt that beyond labels I have accepted that I have a rare illness that is extremely debilitating. I am being cared for at home with carers coming three times a day to assist me with meals, (I have dysphagia and am on a liquid diet) and to assist me with personal care.

Despite my severe muscle weakness I regularly have physical therapy with a Neurologica Exercise therapist. This does benefit me and maintains some muscle strength albeit rather limited. I am in a constant state of exhaustion due to my very weakened muscles and battle chronic fatigue. Yet my approach to each day is one of positivity and joyousness. Yes despite my struggles embracing joy and happiness gives me a sense of perspective.

I love writing poetry and this too is a very therapeutic way of expressing the positives in my life and the challenges I must face.

The following quotes encapsulates my approach to coping with my illness and finding a sense of peacefulness.

My heart reaches out to your hearts sending love and strength. With my warmest wishes.
David “

Victor Frankl wrote that “suffering ceases to be suffering in some way at the moment it finds a meaning (Frankl, 1984).” In taking stock of our spiritual selves, we seek to find meaning. In finding meaning, we seek to transform our pain.

“Surviving the torment of chronic illness spiritually involves shifting from a focus on curing the body to nurturing the soul, finding meaning within suffering, and cultivating a sense of presence that transcends physical limitations.”

“Chronic illness often forces a shift from high productivity to a slower pace. Find purpose in daily acts of kindness, gratitude, or simply being present, rather than measuring worth by output. Many find meaning by using their experience to cultivate deeper compassion for others or by sharing their story to help others feel less alone. Release the desperate desire for certainty and control over your health. Accepting the unpredictability can lead to a state of inner peace and serenity (equanimity).”

“These “ultimate questions” include queries about the meaning and purpose of our lives, our place in the universe, and the existence of a higher power. We address these spiritual questions in a variety of ways. Some practice religion and maintain a relationship with a higher power that reveals itself through religious texts. Others find the transcendent in nature, in art, and in meditation. Still others locate the sacred in their relationships with family and friends.”

“Our journeys as spiritual people take many turns over the life course, as our search for meaning is ongoing and ever-changing. We know that illness disrupts identity, but we don’t often talk about the specific ways that illness affects spiritual identity.”

“The inner landscape of spiritual crisis is powerful and individual. Can you close your eyes and picture it? Where do you locate yourself? What does it look like, sound like, smell like? How do you feel as you exist in this landscape?”

“As you orient yourself to where you are, you eventually will want to remember and articulate where you used to be before everything changed. What gave you pleasure, meaning, a feeling that things made sense? There are many models of spirituality, and we move among them. Did you derive meaning from altruism, from belief in a Divine Power, from the community, from belief in the self, from nature or art? Are any of these spirituality models present in your current landscape?”

Yes another beautiful day.

I awoke and Light, Loveliness and happiness were here in my room.

I smiled and embraced this new day.

Fear said nothing here for me and disappeared.

So here I am smiling and hope you are too!

The power of voice banking

Episode 40 of the MND Association podcast MND Matters is now live on the MND Association website and via the usual podcast providers. This episode looks at voice banking and how rapidly evolving technology is changing the way people stay heard. The episode was shaped by questions from people affected by MND, which were submitted via social media.

Speech and language therapist Jen Benson (pictured) spoke with host Area Manager Stephanie White to unpack why our voices are such a core part of who we are, and how voice banking helps preserve that identity. The podcast also highlights the support available, funding options and the wide range of devices and access methods out there.

You can listen to the episode by visiting the [MND Association website](#). On the website you can also explore previous episodes to hear practical advice, personal stories and reflections on topics such as managing emotions, supporting family members and becoming a carer for someone with MND.



MND Friendship Group - Keighley

Tea, coffee, biscuits and chat!

Every second Saturday of the month - 10am - 12 midday
Keith Thompson Centre, Coronation Mount, Keighley, BD22 6HE

 Ziggi O'Connor 07380 192376 or

 alun.owen@mndassociation.org

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Online Bereavement Support Group

Every 4th Wednesday 11am-12.30pm. To learn more, register interest and receive an invitation please email

This is a safe, supportive and confidential online group for adults who have lost someone to MND. The group is peer led, offering understanding and shared experience, rather than therapy or counselling

 www.mndassociation.org

 Sarah.lowther@mndassociation.org



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Join the '100' Club

To help support our ongoing fundraising, we're inviting members and their families to re-join (or join for the first time!) our popular '100' Club. The Club runs from April to March each year and each month, one lucky winner will be drawn at our Branch Committee Meetings, with a prize of £25. You can have as many entries as you like – either in your own name or for family members of your choice. With great odds and monthly cash prizes, it's a fun and easy way to support a good cause. Winners will be published in 'Chatter' and contacted directly. We will be drawing the first three draws in June but you can join at any time (but sadly will only be entered into the draws that are still to come!) If your interested please email: admin@mndyorkshiredales.co.uk

Find us online



Instagram: [mnd_yorkshire](https://www.instagram.com/mnd_yorkshire)



X: [@MNDA_Dales](https://x.com/MNDA_Dales)
https://x.com/MNDA_Dales



Facebook:
<https://www.facebook.com/MNDYorkshireDales>

Website

www.mndyorkshiredales.co.uk

Your Yorkshire Dales Branch contacts

- David Stubley, Chairman - davidistubley@gmail.com
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- John Pike – 07775 586357
- Treasurer, Geoff Catley - 01423 870143
- Community Support Coordinator, Alun Owen - 01604 800619 alun.owen@mndassociation.org
- Relationship Fundraiser for North and East Yorkshire, Abi Baker - abi.baker@mndassociation.org or 01134830706

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MND Connect – 0808 8026262 or by email to mndconnect@mndassociation.org