Registered Charity 294354

YORKSHIRE DALES BRANCH NEWSLETTER

CHATTER

JULY 2025

Kevin Sinfield CBE Announces Sixth Challenge Supporting MND Charities

MND Association Patron Kevin Sinfield CBE will be back on the road this December for his sixth 7 in 7 in 7 Challenge in support of MND.

The exciting challenge will see him attempt to complete seven marathons in seven regions of the UK and Ireland in just seven days. This year's challenge will start on 1 December in Bury St Edmunds and will see Kevin and his team visit Ipswich, Cork, Swansea, Sheffield, Workington, Whitehaven, Dundee and North Yorkshire before arriving in Leeds on 7 December. As in previous years, Kevin is aiming to raise £777,777 which will be split between the MND Association, the Leeds Hospital Charity, Irish MND Association, the My Name'5 Doddie Foundation, MND Scotland and The Darby Rimmer Foundation. Read more on the MND Association Website.

Check out our **fabulous fundraisers** on page 4 and 5.

In this issue:

Message from your Chairman, John Pike

Welcome to the second edition of our new look Chatter. I hope you will enjoy our next article about our newest volunteer Association Visitor (AV), Emma. It is a helpful brief summary of the great work done by all our AVs. Their support for people living with MND and their families includes signposting the range of grants that may be available to make a difference to their everyday quality of life in a variety of different ways.

The Yorkshire Dales Branch gives priority to meeting the cost of all the grants approved by the MND Association for applicants in our Branch area. I have written before how the number of applications has been increasing rapidly since the covid epidemic. In May alone we agreed to fund eight different applications at a cost of approximately £4000. We know from feedback just how much these grants mean to the recipients.

We have recently received fantastic support from three golf clubs. The captains of Ilkley, Skipton and Wetherby golf clubs all nominated our Branch as their charity of their year. It was a joint nomination by all captains in each playing section so all the charitable giving was concentrated on us.

The years having ended, we have received a staggering total sum of approximately £26,075!

We are applying this money to the award of quality of life grants. We can't thank the captains and all the members of those golf clubs enough for the difference they are making to the lives of the MND community in our area. With their help we expect to fund all the quality of life grant applications we receive this year.

John Pike.

Meet Emma, Association Visitor (AV)

Tell us a little bit about your role?

I support people living with MND and their families in whatever way I can. Mostly, checking in with them however often they wish, being a listening ear, talking with them to help them navigate challenges they are facing. I also signpost them to practical information, resources, or services that can make a difference to their everyday life.

How long have you been volunteering for?

7-8 months now - wow that's gone quickly!

What training did it involve?

I did a lot of online training and some one-on-one training with some Community Support Coordinators.

In what ways do you support people with MND and their families?

It really depends on what each person or family needs so it can vary. Sometimes it's just being there to listen and offer emotional support, especially when things feel overwhelming.

Other times, it's helping people understand what support is available — like local services, equipment, or financial help — and signposting them to the right place. I always try to be a steady, reassuring supporter.

What inspired you to be a AV?

My Dad had MND and passed away 12 years ago. For a long time, it felt too close to home to get involved, but when Rob Burrow began sharing his story so openly, something in me shifted. I felt inspired, not just by his bravery, but by the way he brought MND into the public eye. It made me want to do something meaningful to help others facing what we went through as a family. Volunteering with the MND Association has allowed me to give something back, and it's given me a sense of purpose and fulfilment to my life.

What do you enjoy most about the role?

I'm quite a social person, so I value the chance to connect with people. For me, it's all about that human connection — just being there to listen, chat, and offer support. I find it rewarding to think that even if I've done something really small to help someone, it might make a difference to their day. I really consider it a privilege to be trusted during such a personal and difficult time, and I am grateful to be able to help in any way I can.

How can others who are interested find out more?

Have a look on LinkedIn at the MND Association page or on the MND Association website - there is lots of information about what we do and the different ways you can get involved with volunteering.

Fundraising Round Up

A big thank you to everyone who has helped/attended events and 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 Yorkshire Dales Branch:

- Leeds Marathon raised £1,240.
- Flower arranging demonstration raised £1,160.
- Easter egg and card sale raised £414.
- Asda collection raised £121.
- Morrisons collection raised £138.
- Pie and peas quiz night, raffle & auction raised £2,061.
- Ilkely golf club members donated £3,983.
- Otley garden centre stall raised £149.

There are lots of different ways you can get involved and support fundraising, from joining an existing event to organising your own. We are always looking for additional volunteers/helpers for events, either on an ad-hoc basis or in a more structured role. For more information please contact Alan Robinson, Fundraising Volunteer and Committee Member on either 07377 383926 or at alan.robinson@mndassociation.org

Fundraising Round Up Continued...

Eggcellent Fundraiser

Julia Samways from Boston Spa, has raised £500 for the Yorkshire Dales Branch to support families living with Motor Neurone Disease in our area.

Julia made over 100 knitted easter chicks with a cream egg inside. She sold them with the help of local businesses and through friends. She even made bespoke ones for both the Sandal juniors rugby team, featuring the teams colours, and for Bensons Engineering in their work colours.

All the eggs were donated by her husband.

Run for All's MND Mile

On Saturday 10th May Michelle and Phil Ward both completed the Run for All's MND mile. They have both raised over £15,000 since 2019 taking part in a number of fundraising activities!

Wetherby Golf Club

The Wetherby Golf Club Joint Captains Charity for the year ending April 2025 was our Branch.
Paul Jackson men's captain, Maria Carnazza ladies captain and Don O' Mahoney rabbits captain, agreed the nomination.
We understand approximately £12,765 has been raised!
Arrangements will be made for a cheque presentation when we can thank all members for this fantastic achievement.

Snippets of MND Association National News

MIROCALS: what’s next?

emerging treatments

MND Association recently posted an update on the results of the MIROCALS trial, investigating the impact of a low dose of interleukin-2 in people with MND. This blog explains the results and what they mean. The MNDA also asked the UK MND Clinical Studies Group (CSG), which includes leading neurologists, researchers and people with MND, to discuss the findings, and share their advice and guidance before deciding next steps.
The CSG has since published its statement, which you can read here. In summary, the CSG reached the consensus that while the drug might improve life expectancy for those with slower progressing MND, more data is needed to confirm this. They have recommended this needs to come either from a phase 3 trial - likely led by the pharmaceutical company - or from a funded early access scheme.
MNDA is grateful to the CSG for prioritising these discussions and providing clarity in terms of a concise overview of the results and next steps. As a charity, the MND Association is committed to working with the CSG, and with My Name’5 Doddie Foundation and MND Scotland, to explore those next steps as quickly as possible
Read more in the MND Association website.

Join us today

The MND Association is calling on supporters to join our campaign to ensure people living with SOD1 MND can access a life-changing treatment.
People are unfairly missing out on tofersen, the first effective new motor neurone disease (MND) treatment to be identified for decades.
Over 30 patients are accessing tofersen through an Early Access Programme (EAP) supported by Biogen, the developer of the drug. But the MND Association believes 12 people are being refused access, despite having the same level of need.
Tofersen has been shown to slow, and in some cases, halt progression of symptoms in people living with a rare form of MND caused by a variation in the SOD1 gene. To find out more and to sign the petition addressed to Karin Smyth MP, Minister of State at the Department of Health and Social Care, asking her to intervene immediately and help ensure that nobody misses out on this vital treatment visit the MND Association website.

Snippets of MND Association National News

New support around accessing continuing healthcare (CHC) funding

The MND Association has launched a new project to help support people living with MND access specialist advice about available funding.

The pilot project aims to help individuals navigate the process of applying for continuing health care (CHC) funding. People calling the MND Connect Helpline with queries about CHC funding will be offered a direct referral to Beacon, an independent specialist service.

Beacon experts will then provide 90 minutes of free, personalised advocacy support. This could include advice, support with applications or following up with CHC funders about individual cases. Read more on the MND Association website.

Ice Bucket Challenge makes waves among a new generation of supporters

A new generation of supporters are learning about the success of the Ice Bucket Challenge following the return of the social media fundraising phenomenon. More than a decade after it was launched in the US to raise funds and awareness of MND/ALS, the challenge is once again making waves around the world, this time raising awareness of mental health.

Back in 2014, the Ice Bucket Challenge was a pivotal moment in the MND Association's history raising more than £7.2 million to support people living with MND and their families while funding important progress in genetic research.

Now 11 years on, that money continues to have an extraordinary impact on our work having helped to fund key research projects which have identified 15 new genetic profiles with an increased risk of developing MND and research into potential new treatments. The money was also used to confirm a biomarker for MND – neurofilament light chain – which is being used regularly in clinical trials.

Read more on the MND Association website.

Rob Burrow Leeds Marathon runners raise more than £500,000

'He will be looking down on us, proud as punch of what we've created.'

Those were the words of Association Patron Kevin Sinfield CBE as he addressed a crowd of more than 14,000 runners at the start of the third Rob Burrow Leeds Marathon which took place in Leeds. It was an emotional start to the event, which is the first to take place since Leeds Rhinos legend Rob Burrow CBE died from motor neurone disease in June last year. More than 1,000 people took part in the event on behalf of the Association, raising more than £500,000. Read more on the MND Association website.

Coffee & Catch Up

Yorkshire Dales Branch Support Group

First Tuesday of the month 2-4pm

Crimple Hall Garden Centre Cafe
The Carr Leeds Rd, Pannal, Harrogate HG3 1EW

Libby Wade 07803 208139
Margaret Thompson 07704 421513
Michelle Malouf 07876 575032

www.facebook.com/MNDYorkshireDales @MNDA_Dales

www.mndassociation.org
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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. We hope you can join us.

Upcoming dates:
- Tuesday 1 July
- Tuesday 5 August
- Tuesday 2 September

New MND Friendship Group

A new friendship group is up and running in Keighley for anyone affected by MND that would benefit from a break from reality for a couple of hours.

Ziggi O’Connor (volunteer) has set up the group. She said: “I really want the group to be a relaxed and supportive space where we can meet, natter and hopefully build new friendships and support systems for each other.”

If you want any information please contact Ziggi on 07380192376.

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 ziggioconnor@mndassociation.org
07380192376
Michelle Malouf michelle.malouf@mndassociation.org
01604800619

mnd_yorkshiredales or West Yorkshire Branch @MNDA_WestYorks or @MND_Dales

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
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Study on Psychological Care

The University of Sheffield is researching how to improve psychological support for people living with MND and their informal carers. This is part of a larger study iDeliver MND: Improving Delivery of Psychological Services for MND, which is funded by the MND Association. The survey takes approximately 15-30 minutes and can be found at the the following link: Survey Link.

Join the '100' Club for the 2025–26 Season!

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 for the 2025–26 season.

Each month, one lucky winner will be drawn at our Branch Committee Meetings, with a prize of £25. The Club year runs from April 2025 to March 2026, and the enrolment cost remains just £20—the same as the past three years.

The final draw of the 2024–25 season has now taken place. We're holding off on the April and May draws for the new Club until our next meeting in July, giving everyone time to sign up!

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.

If your interested please email:
secretary@mndyorkshiredales.co.uk

New Facebook Group for Parents

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 Association staff or volunteers, only family.

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

The Local Lotto

On average we receive at least £30 every month from the Local Lotto.

If you would like to find out more or join in and boost our monies then please have a look at the website and buy some tickets! The website is:
https://www.thelocallotto.co.uk/support/motor-neurone-disease-association

Dates for your diary

Stalls

We will be manning a stall at:

- Morrisons, Ripon on Saturday 21st June;
- and the Weeton Show on Sunday 20th July.

Come and say “hi” if your in the area.

Keighley MND Friendship Group

- Saturday 12 July, 10 till noon, New Keith Thompson Centre, Keighley
- Saturday 9 August, 10 till noon, New Keith Thompson Centre, Keighley

Coffee and Catch Up

- Tuesday 1 July, 2pm-4pm,
  Café at Weetons
  Leeds Road Pannal, HG3 1EW
- Tuesday 5th August, 2pm-4pm,
  Café at Weetons
  Leeds Road Pannal, HG3 1EW
- Tuesday 2nd September, 2pm-4pm,
  Café at Weetons
  Leeds Road Pannal, HG3 1EW

Global MND Awareness Day - 21 June

Each year, the MND Association collaborates with the MND community across the world to mark Global MND Awareness Day, a day to honour everyone affected by motor neurone disease. This year, the MND Association is shining a light on the hidden realities of living with MND. The Association is inviting our community to share what they wish others knew about MND and taking time to pay our respects to the people who are no longer with us but always remembered.

You can find out more on the MND Association website.

Tell us your views

mnda motor neurone disease association
YORKSHIRE DALES BRANCH NEWSLETTER
CHATTER
FEBUARY 2024

We hope you have enjoyed reading our newsletter. We would love hear your views; what you enjoyed, didn't enjoy or would like to see more of. Please email your views to samantha.george@mndassociation.org. The next edition is due to be published in October. We would really like to share stories from across our Yorkshire Dales MND Community. We want to share fundraising events and support activities your doing for the branch, any stories, poems, pictures of artwork. Email your ideas to samantha.george@mndassociation.org Can you help us save money by sending you paperwork by email instead of the Royal Mail? If you have an email address just let us know.

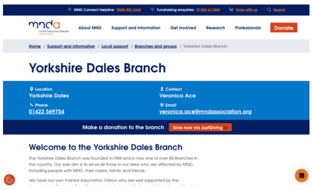
Find us online

Yorkshire Dales Social Media Channels are:

Instagram
mnd_yorkshire dales

X: @MNDA_Dales
https://x.com/MNDA_Dales

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



Yorkshire Dales Branch

Location
Yorkshire Dales
Phone
01423 569754
Contact
Veronica Ace
Email
veronica.ace@mndassociation.org

Welcome to the Yorkshire Dales Branch

The Yorkshire Dales Branch was founded in1988 and is now one of over 80 Branches in the country. Our sole aim is to serve all those in our area who are affected by MND, including people with MND, their carers, family and friends.

We have our own trained Association Visitors who are well supported by the

Website
www.mndyorkshiredales.co.uk

Your Yorkshire Dales Branch Contacts

- Branch Contact, Veronica Ace – 01423 569754 veronica.ace@mndassociation.org
- Chairman, John Pike – 07775 586357
- Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
- Treasurer, Geoff Catley - 01423 870143
- Local Relationship Fundraiser for North and East Yorkshire, Jenn Scribbins - 01134 830706, jenn.scribbins@mndassociation.org

National Contact Information:
www.mndassociation.org
MND Connect – 0808 8026262 or by email to mndconnect@mndassociation.org