

YORKSHIRE DALES BRANCH NEWSLETTER

CHATTER

OCTOBER 2025

We're Here for you

MND Connect Helpline can help provide information and support for anyone affected by Motor Neuron Disease (MND).

MND Connect is available Monday to Friday between 9am - 4pm. Calls to this number are free from landlines and mobile phones within the UK and are confidential and do not appear on itemised bills.

Call: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect provides information about MND, emotional and practical support, social, practical and financial information, information about local support, information about how the MND Association can support you and signposting to other appropriate services.

For more information about MND Connect please visit the [MND Association website.](#)



MND Matters: The MND Association Podcast: Sometimes emotional, sometimes humorous, always honest. Turn to [page 8](#) to read more.

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Message from your Chairman, John Pike

"Welcome to the third edition of our new look Chatter. Responses to the new layout have been very positive, and we hope everyone enjoys reading it.

We are very pleased to welcome Alun, our new Community Support Coordinator who is profiled in the next article. Alun has really hit the ground running since his appointment as successor to Michelle Malouf, and attended his first Branch committee meeting last month. He is very experienced and we are looking forward to working with him. We also welcomed Sheridan Charles at the same meeting. Sheridan has a background in fundraising and marketing and is a member of our fundraising team.

There are often some stories behind the headlines when it comes to our fundraising round up. Our volunteers went to Weeton Show with more than half an eye on the weather. As forecast, the heavens opened for the first real downpour of the summer. They eventually had to call it a day having got thoroughly wet but not before raising £275. At Ripon Races an incredible £2,906 was raised, largely through bucket collections and mainly as people were leaving at the end.

Our volunteers were literally weighed down by the amounts in the buckets. We are very grateful to all our volunteers for turning out in all weathers, and for the support they receive.

I have stepped down as Branch Chairman after five years. I feel more strongly now than when I became Chairman about the need to support the MND community in our area, and to find a cure. I am remaining on the committee as a volunteer, and until a successor is found I will continue to assist with the Chairman's responsibilities.

John"



Meet Alun Owen, Community Support Coordinator



"Hello everyone, my name is Alun Owen and I am the new Community Support Coordinator for the Yorkshire Dales and West Yorkshire branches. My previous career has been 20+ years working in education, mainly supporting young people with additional needs and behavioural issues and, more recently, six years as Executive Corporate Director of a hospice in St Helens. Although I am new to this job, I am not new to the MND Association. I have been a volunteer for the last 24 years, based in the Northwest, as Chair of the Merseyside branch, an Association Visitor and a Connect helpline volunteer, amongst other roles. This helps me to understand the drive and motivation that all our volunteers have and now as an employee for the MND Association, it will be the perfect opportunity to build on our shared goal of maximising the help and support for everyone affected by MND."

My role at the MND Association is to work alongside the Health and Social Care professionals and our volunteers to make sure we can implement best practice in care for patients. This includes understanding the needs of patients across the locality, knowing how the various services work across West Yorkshire and the recruitment, training and development of new volunteers alongside developing and supporting our existing volunteers. I will also be focusing on identifying opportunities for the West Yorkshire and Yorkshire Dales branches to make sure their growth and long-term sustainability, whilst keeping everyone affected by MND at the heart of everything we do. It has been a long-held dream of mine to work for the MND Association and even after seven weeks in post, I still can't quite believe it! I look forward to getting to know you all in our shared MND community over the coming weeks and months.

If you would like to get in touch, I can be contacted via email at alun.owen@mndassociation.org or via the phone on 01604 800619."

Fundraising Round Up – What a Summer!

We've been busy bees out and about, raising funds and flying the flag for both the MND Association and the Yorkshire Dales Branch. Thanks to your support, we've had an amazing summer so far. Here's what we've been up to...

Stalls Galore!

We love a good stall – and it turns out, you do too!

- Morrisons Ripon – £197 raised
- Weeton Show – £275 raised
- Co-op Jennyfields - £159 raised

Stalls are not only a great way to raise funds, but also brilliant for spreading awareness. Plus, it's always lovely to meet our supporters face-to-face!

Harrogate Pythons Rugby Day

A big shoutout to the Harrogate Pythons for hosting a fantastic Rugby Day! £598 raised. We were there with our information stand, cheering the players on and chatting to locals about the work we do. A brilliant day of sport and fundraising.

Ripon Races

We had the chance to raise funds at Ripon Races, where we held collections, ran a tombola, and talked to lots of racegoers about MND. £2,906 was raised. A huge thanks to everyone who supported us (and those who donated even after their horse didn't win!).

Join our Team of Volunteers

We're always on the look out for volunteers at our events. If you would like to join #TeamMND please contact Alan Robinson, Fundraising Volunteer and Committee Member on either 07377 383926 or at alan.robinson@mndassociation.org.



Fundraising Round up Continued...

100KM for MND!

Samantha George (our newsletter editor), her sons aged 5, 10 and 13, and their friends ran an incredible 100KM in June – yes, 100! They raised over £3,000 for the MND Association. We're so proud of this group and their brilliant effort. Rest those legs – you've earned it!



Donations

We've also received some truly generous donations recently.

- Richmond Rotary Golf Day – £600
- Wetherby Golf Club – an incredible £11,320
- Booths of Ripon – £925 from their Pennies scheme

These donations make a real difference, and we're so grateful to everyone involved for choosing to support the MND Association.

What's Coming Up?

Here's what's coming up over the next few weeks:

- October 9th Harrogate Pythons Annual Dinner & Auction for MND. Another brilliant show of support from the Pythons. Good luck to everyone taking part – we'll be cheering you on!
- October 24th - Yorkshire Dales Bingo & Raffle night. Please book as soon as possible as places are selling out quickly. Email clubsecretary@biltoncc.com more information about the event is on [page 9](#).
- October 30th Coffee & Cakes, St Mary's Church, Craven.

Thank you

Thanks again for all your support – whether you've donated, volunteered, cheered us on we couldn't do it without you.

Snippets of MND Association National News

Tofersen receives MHRA approval

Tofersen, the first drug for 30 years proven to slow progression of a form of MND, is one step closer to being available on prescription.

The drug has been granted marketing authorisation by the Medicines and Healthcare products Regulatory Agency (MHRA) for the treatment of SOD1 MND.

This means it is now licensed for use in the UK.

Biogen, the company responsible for the development of tofersen, has confirmed it will

now submit the drug to the National Institute

for Health and Care Excellence (NICE) to determine if it will be made available on the NHS.

Thanks to the MND Association successful Prescribe Life campaign, NICE will appraise tofersen via the Highly Specialised Technologies (HST) route, which the MND Association and other experts believe gives it the best chance of being accepted for use on the NHS.

MND Association Director of Engagement Richard Evans said: "Tofersen has been described as a game changer for the 2% of people whose MND is caused by a variation in the SOD1 gene, so the licensing of the drug is a really important step forward and one which, of course, we welcome.

"However, it is important to stress that just because it has MHRA approval, it does not necessarily mean it will be available on the NHS, as it will be for NICE to decide if it considers it value for money.

"What we need now is for tofersen to be appraised as quickly as possible by NICE and for it to be approved for use on the NHS.

"Only then can we be confident that everyone with SOD1 MND – we think that's around 60 to 100 people – can access the drug which could save their lives."

Read more on the [MND Association website](#).

emerging treatments

MND-SMART trial opens new centres and adds new drug

York & Scarborough Teaching Hospitals NHS Foundation Trust has joined pioneering clinical trial platform MND-SMART. Recruitment to the trial is underway (June 2025).

Led by Principal Investigator and Consultant Neurologist, Dr Malcolm Proudfoot, York and Scarborough Hospitals are the newest centres to open recruitment to MND-SMART. The MND-SMART team has also announced a new drug has been added to the trial for testing. The new drug, Tacrolimus, is already used to treat some immune system disorders and prevent the body from rejecting organ transplants. Laboratory studies into Tacrolimus in MND have suggested that it may be able to stop faulty proteins from forming clumps in cells and reduce inflammation in the central nervous system.

Read more here.

Snippets of MND Association National News

First nurse recruited into MND Association's Research Nurse Network

The Motor Neurone Disease Association has welcomed its first fully funded MND research nurse into its ground-breaking Research Nurse Network.

The Association's ambitious £7.2 million Research Nurse Network will give more people diagnosed with motor neurone disease (MND) the opportunity to take part in vital research across England, Wales and Northern Ireland.

MND Association Research nurses offer people with MND information about research, identify trials they are eligible for, explain what is involved, and provide ongoing support if they choose to participate.

The role, based at the MND Care and Research Centre in Newcastle upon Tyne Hospitals NHS Foundation Trust, will integrate with the existing multidisciplinary team, which currently supports more than 170 people living with MND in the Newcastle region.

Experienced research nurse Andy Hamilton is the first to be recruited to the Network and is part of the Newcastle Care Centre team based at The Royal Victoria Infirmary.

Andy said: "I feel privileged that my role is the first in the country to receive funding from the MND Association. The funding will help Newcastle continue to provide the latest clinical trials and potential treatments for this devastating disease, something I feel passionate about."

Read more on the [MND Association website](#).



MND Association research investment reaches record high

The MND Association is funding more research than ever before, underlining our ongoing commitment to funding world-class research to drive forward our understanding and treatment of motor neurone disease (MND).

As of 31 May 2025, the value of the Association's research grants portfolio totalled a record £26.9 million, covering 138 rigorously selected projects. The increased investment has meant the value of the grant portfolio has increased by 66% in just three years, with funds invested into an additional 50 projects.

This growing investment supports an expanding network of researchers. Around 320 clinicians and researchers are involved in MND Association-funded projects including 80 early-career researchers. Read more about [MND Association research here](#).



Coffee and a Catch up

The first Tuesday of every month we host an informal meet up for all those affected 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 7 October
- Tuesday 4 November
- Tuesday 2 December



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 Molouf 07876 575032

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MND Matters: the MND Association Podcast

Sometimes emotional, sometimes humorous, always honest – MND Matters gives people affected by MND the chance to share their stories.

With more than 30 episodes available, the podcast offers a wealth of information and insight from experts and members of the MND community.

You can listen to the latest episode or dip into the library of [previous episodes](#) to hear informal advice, information and real-life experiences about a range of topics including managing emotions, family support and becoming a carer for someone with MND.

Guests include people affected by MND, VIP ambassadors of the Association and health and social care professionals.

Listen to episodes of MND Matters using the links on the [MND Association website](#) or search MND Matters in your chosen podcast provider.



MND Matters

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

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Michelle Malouf michelle.malouf@mndassociation.org

01604800619

[@mndyorkshiredales](#) or West Yorkshire Branch

[@MNDA_WestYorks](#) or [@MND_Dales](#)

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Yorkshire Dales Branch Bingo Night



Friday 24th October 2025
Bilton Cricket Club

6.30pm for 7pm start

Tickets £10 per person includes Bingo Cards, Pie & Chips Supper and Bar access

Great Cash prizes to be won, plus Raffle & Auction following the Bingo

Spaces limited so booking essential

All monies raised to go to supporting people living with MND in the local area

To book tickets, email 'clubsecretary@biltoncc.com' or call Jane on 01423 561199 or 07854 434222 (text)

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'100' Club Winners

Congratulations to the 100 Club Winners:

April 25 – Paul Catley
May 25 – Elizabeth Meyrick
June 25 – Katharine Wade
July 25 – Julie Thompson
August 25 - Adryenne Hope
September 25 - Helen Clark

There's still time to join. If you're interested please email:
secretary@mndyorkshiredales.co.uk

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>



Tell us your views

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 December. 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:



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
- Community Support Coordinator, Alun Owen - 01604 800619 alun.owen@mndassociation.org.
- 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

