

MESSAGE FROM YOUR CHAIRMAN



Welcome to the first edition of 2024. It marks the end of an era because, after more years than they would wish me to mention, Margaret Thompson and Libby Wade retired as voluntary MND Association Visitors (AVs) in December 2023.

We are grateful that Margaret and Libby are staying on as Branch committee members, and have agreed to be Support Meeting Coordinators which is not a new role for them as they have been doing it in practice for many years! It means for example that we will still see them at coffee mornings and lunches.

Margaret and Libby have contributed a huge amount of time and effort as AVs, not least during the Covid pandemic. It was a huge challenge to support and stay in touch with the MND community then, with so many feeling lonely and isolated. We thank them.

A new MND Research Institute, launched officially in November, aims to discover new treatments that could ultimately mean MND becomes a curable condition. It is a virtual Institute bringing together a network of MND labs, clinical centres and researchers conducting MND research across the UK. Part of the £50M pledged by the Government for targeted MND research is already supporting some of its programmes and initiatives. The MND Association is also funding peer-reviewed research programmes made possible by the significant sums raised through Kevin Sinfield's challenges. (source: Thumbprint).

A report on the first leg of Kevin's 7 in 7 in 7 challenge appears below. These challenges are as much about raising awareness and involving the MND community, as fundraising. There are short films about each day of 7 in 7 in 7 on YouTube. The closing words to supporters at the end of each day make this very clear. The longer speeches at the end of the sixth day, at Brighton College in Brighton, are particularly powerful.

Finally, at the end of January the MND Association launched its first television advert for more than a decade as part of a wider awareness campaign. Coronation Street has an ongoing fictional storyline following the journey of one of the characters who was diagnosed with MND last summer. The adverts will bring home to Corrie's 6M or so viewers stories of the journey of people for whom MND is a reality.

John Pike

KEVIN SINFIELD SEVEN IN SEVEN DECEMBER 2023

Kevin Sinfield seems to do so many fundraising events that they have become a regular feature of this newsletter! In early December 2023 Kevin Sinfield, who now earns his living as defence coach of the England rugby union club, set off to run seven ultramarathons in seven days in seven cities across the UK and Ireland. Each leg included an “ExtraMile”, to allow members of the MND community to join him. These extra miles were designed to symbolise the bond between Sinfield and Rob Burrow and how they are both prepared to go the extra mile for each other.

The opening leg started at Headingley in Leeds, heading to York. Our Chairman John Pilke was joined by Committee Member Libby Wade to run the extra mile, they are pictured below right warming up after the event, on the left Kevin looks very fresh still at mile 25!



Some of the participants involved in York had lost husbands, wives and other relatives to MND. Others have the condition and ran, walked or used their wheelchairs to complete the mile, an extraordinary feat in itself. Another of our Committee Members captured the following images on the day



CHRISTMAS 2023

Once again we were selected to have a tree displayed at the Otley Christmas Tree Festival, donations in our collection tin came to just under £240, an excellent result. Thanks to Committee member Ruth Paynter who organised this and to Committee member Veronica Ace who helped her decorate the tree.



Various members and Committee members also enjoyed a Christmas lunch in mid December – in fact they enjoyed themselves so much they didn't take any photos !

PHIL WARD “JELLY MAN”

In September Phil Ward who is a friend of the Yorkshire Dales Branch and is also living with MND took on an “Ironman” challenge. Before the event he noted “as MND increasingly takes its toll, I am unable to do sports I have loved over many years. The traditional ironman triathlon is 2.4-mile swim, 112-mile bike ride and a full marathon. On Friday 22nd I will row (instead of swim) the English channel (La Manche) on my rowing machine – 20 miles, on Saturday 23rd I will cycle Hadrian’s Wall on my exercise bike – 73 miles and on Sunday 24th I will take part in the Avove Yorkshire Run at Swinsty Reservoir – walking (instead of running) - 5 kilometres. Phil raised an amazing £1500 for the Association. Here are a couple of photos of him in action plus one at the end of the Swinsty race about to head home for some well earned rest.



HARROGATE BOWLING CLUB

We were delighted to be presented with a cheque for £3226 by Judith Chappel the president for 2022-23 as a result of their fundraising for the year.



Committee member Veronica Ace is at the right hand end of the cheque and Judith Chappel is at the left end, with other bowling club members around them.

FUNDRAISING UPDATE

Once again we say thank you to anyone who has raised funds for the Branch. Some of the donations are detailed elsewhere but we also need to mention £170 received from the Driving Instructors Association and £210 received from a gentleman who took the trouble to sell some vintage copies of MG Club magazine. We also acknowledge a donation of £220 from a M Redhead but unfortunately we have no idea what this was for as the money just popped up in our bank account.



We must also say thank you to those who have sent such generous donations in memorium, also various other donations linked to such things as not sending Christmas Cards.

Finally, not forgetting the monies from the Local Lotto, on average we receive at least £30 every month. If you would like to join in and boost our monies then please have a look at the website and buy some tickets!

<https://www.thelocalotto.co.uk/support/motor-neurone-disease-association>

A FEW OF SNIPPETS FROM THE NATIONAL WEBSITE

Turning the Tide — A new documentary, giving an insight into the scientific research process to find new targets for treatments of MND, was released in October 2023. ‘Turning the Tide’ was produced by Mark Fielder and backed by MND charities and the MND scientific community, including the MND Association. The documentary follows the progress of a research team at University College London (UCL) and the hope is to secure further funding to highlight the process of getting a treatment from the lab through clinical trials to people living with MND. The film also shares first-hand the impact on the lives of people living with the disease and their hopes for ongoing research in the field. The project, led by Professor Pietro Fratta, aims to develop a cutting-edge gene therapy to slow down, stop or potentially reverse disease progression in MND. The potential treatment being investigated is an emerging area of drug development that targets a key disease pathway at the genetic level.

Lack of support from Local Authorities - On Carers’ Rights Day in November 2023, a report by the Association laid bare the difficulties local authorities are facing delivering carers’ assessments and their lack of awareness of the number of carers in their area. The report used insights from Freedom of Information requests to all upper tier local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland to assess the ability of local authorities to deliver carers’ assessments. These important assessments are how carers can access vital assistance with their caring responsibilities including respite, and financial and wider support. The report reveals local authorities are unaware of most of their carer populations, with almost one-third of local authorities (31%) not holding a register of carers in its area. This means that local authorities are only identifying between 6-13% (636,373) of carers in their local area, based on Census and Carers UK figures. Without understanding of how many carers there are in their areas, local authorities will not be able to put in place effective support for those that need it. In addition the report also details the long waits people are having while waiting for a carer’s assessment. Over the last five years the average wait time between requesting an assessment and receiving one has been over six weeks – too long in the context of a disease like MND where needs can change dramatically over a short period. There is also a postcode lottery for how quickly people will receive an assessment, ranging from weeks to shockingly over a whole year depending on where people live. Finally, the report shines a light on where performance is below what is required for people with MND: 71% of local authorities do not provide routine reassessment for people with severe progressive diseases like MND to ensure that the level of support can change as their needs do / 82% of local authorities do not have fast-track routes to assessment in place to account for the progressive and fast changing nature of MND symptoms / 85% of local authorities do not have ringfenced budgets for carers’ assessments which would ensure guaranteed funding for these assessments.

Honours – In September 2023 the documentary “Rob Burrow, living with MND” was shortlisted in the National Television awards, in October 2023 Rob Burrow, his wife Lindsay and Kevin Sinfield received special recognition in the Pride of Britain Awards. Finally, in the King’s New Years Honours list both Rob and Kevin were honoured. The Leeds Rhinos legends have worked tirelessly since Rob’s diagnosis with MND in December 2019 to raise money and awareness for the MND community, including the MND Association. Rob’s achievements saw the Queen previously award him with an MBE while Kevin, whose latest 7 in 7 in 7 fundraising challenge has raised more than a million pounds, had been honoured with an OBE. Now both will join the ranks of His Majesty’s Commanders of the British Empire. They will be entitled to use CBE after their names. Their sitations read: Rob Burrow MBE, for services to motor neurone disease awareness. Kevin Sinfield OBE, for services to motor neurone disease awareness.

EVERY MONTH IT IS TIME FOR A GET TOGETHER



The first Tuesday of the month from 2 until 4
Just show up or if you want more information then
Do get in touch.
We hope you can join us

ANOTHER DATE FOR YOUR DIARY

We had planned a fun evening in November
but sadly had to cancel due to various circumstances
so we are trying again in May
and would love to see you there

Beetle, Bingo and Buffet
On 18th May 2024 at 7pm
In Pannal Village Hall

Tickets will be on sale soon
More information will be
published on our website
and on our facebook page

If you are interested just get in touch

In aid of
mnda
motor neurone disease
association
YORKSHIRE DALES BRANCH
BEETLE, BINGO AND A BUFFET
(there will be a bar too!)



Saturday 18 May 2024 at 7 pm
Pannal Village Hall

Tickets £15

More info on where they can be purchased to follow

[mndassociation](#) [@mndassoc](#)

www.mndassociation.org
Francis Crick House, 6 Sunningdale Road, Northampton, NN3 0EJ
Registered charity no. 294354 | Created in RightMarket - 2/8/2023 - 15:22:27



CHATTER

We aim to publish Chatter at least three times a year – apologies once again that this edition is a little later than planned – if you have anything to contribute the next one is planned for publication in May / June so do get in touch!

WINNERS OF RECENT 100 CLUB DRAWS

We have been drawing more winners and here they are

October – Simon Benyon
November – Millie Thompson
December – Colin Chapman
January – Phoebe Rose White



BRANCH WEBSITE AND OTHER INFORMATION

Please let us know if you would like to publish something on either our facebook page <https://www.facebook.com/MNDYorkshiredales> or our website www.mndyorkshiredales.co.uk

Or perhaps you might like to contribute to Chatter? It would be lovely to publish something from one of our members - just send your article to Ruth Pridmore

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 Ruth know.

Branch Contacts

Branch Contact, Veronica Ace – 01423 569754 versace412@gmail.com

Chairman, John Pike – 07775 586357

Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk

Treasurer, Geoff Catley - 01423 870143

MNDA local contact – Michelle Malouf 07876 575032

National Contact Information

www.mndassociation.org

MND Connect – 0808 8026262