

MESSAGE FROM YOUR CHAIRMAN



My name is John Pike, and it is a privilege to take over from Peter as Chairman. You all know better than me how much Peter has done for the Branch over many years. He has been a massive help with the handover, meeting me in person and providing much wise advice and documentation. I also met with Michelle, who helpfully briefed me on the work of MND nationally, and on the documentation and support available for those with MND.

I have attended my first Branch Committee Meeting on Zoom, which means I have yet to meet many of the members in person. I have seen many of them before though, as a guest at Sing with Swing for many years. I too have regularly been defeated by Ruth's fiendish quiz!

I have been involved almost all my adult life as a volunteer in the charity sector, mainly in the education or environment sectors. I have not been affected personally by MND but I am well aware what a cruel disease it is, with no known cause or cure.

The BBC documentary on Rob Burrow, previous coverage on BBC Breakfast and the follow up before the rugby league Challenge Cup final on BBC have laid bare the effect MND has on so many people. Jenn had a very busy week as a result. To cap it off, on 18 October she ran her first marathon in and around Ripon and has raised well in excess of £1000 to date : a fantastic effort. My wife Rosemary and I were able to join a number of friends and supporters to see her finish.

The AGM of MND was held online on 13 October. Not surprisingly the presentations focused on the effect of the pandemic. The work and the challenges have increased but income has decreased. Despite that, the messages were upbeat. MND is rising to the challenges and the financial position is positive. As for most charities, the concern is for next year given there is still so much uncertainty.

That uncertainty means the Branch Committee has postponed, for now, decisions on dates for social events in 2021. In these difficult times, I conclude with every good wish for Christmas and the New Year.

WINNERS OF RECENT 100 CLUB DRAWS

At our Branch Meeting held (online by Zoom) in early October we drew three more winners and they are.

July – Alastair Wade / August – Peter Johnson / September – Thomas Raper



Well done all three, we will be drawing winners for October, November and December at our Branch Meeting on 8th December.

MEET THE TEAM / OPPORTUNITIES

In the last edition we introduced you to the volunteers on the Branch Management Committee so this time we thought you might like to know a little about two lovely people from the Association who work with us.

Incidentally following our plea in the last newsletter for people to join us we are delighted to welcome two more volunteers Jane and Cheryl – more about them in a future edition – and of course our new Chairman John who has told you all about himself on the front page. If you are interested in helping it is always a case of the more the merrier so do get in touch (we are particularly looking for someone to help keep our facebook page up to date and to launch and run a twitter feed for us.



Michelle Malouf - MND Association Area Support Coordinator

“Hi, I’m Michelle Malouf and I’m new’ish into this role for West Yorkshire and Yorkshire Dales.

Starting a new job always brings a challenge, starting one in lockdown has been bizarre and brought it’s own set of challenges none of us could have predicted! By now I would have met many of you, sadly this will have to wait until safer times.

A bit about me; I’ve had a couple of careers to date, switching from the business world in Yorkshire, London and Holland to studying and working in the welfare and social work sector after moving to Australia 16 years ago. I learned to sign and worked for the Deaf Society NSW and National Relay Service (Text-Relay), here my interest in communication and neurological diseases piqued after working with people living with motor neurone disease. Such was my interest, I sought out a job with the MND Association of NSW and covered beautiful Sydney and its busy suburbs working directly with people living with and affected by MND. I was sad to leave my lovely members but delighted to join the MND Association and return to the motherland.

I like to stay fit, do the gardening, do lots of dog walking, find quirky places for a coffee or pint and watch my boys play football and cricket with my husband. It’s lovely to reconnect with family and discover Yorkshire again and I look forward to the day when we can all do a bit more discovery. Until then stay safe



Jenn Dodd – MND Association Regional Fundraiser

I'm Jenn Dodd and I'm the Regional Fundraiser for Yorkshire, Humberside and the North East. I am based in Ripon and have been working for the Association since September 2019. I work with branches and groups in the area, as well as individuals fundraising in the area.

Before joining the Association I was working as a research scientist. I did my PhD at the Sheffield Institute for Translational Neuroscience (SITraN) where I was carrying out research into MND. This is when I first started raising awareness and fundraising for the MND Association.

FUNDRAISING UPDATE

We have gratefully received more monies in memoriam and even more money from grass cutting. Many thanks to various other people for various other donations (for a wide variety of reasons - including one from the USA relating to a fundraising quiz organised by Jenn). Jenn herself has been joining people around the country to run at least 125 miles finishing with a marathon around Ripon on 18th October. This was part of [Mission 5000](#) as detailed in the last edition of Chatter and all her miles will be added into the national total, aiming for 5000 miles. Photos of Jenn’s run in the next edition!

SOME BITS AND BOBS FROM THE NATIONAL WEBSITE

Special Memories - Children and young people who are close to someone with motor neurone disease (MND) are being given the chance to create, capture and store memories of their loved one thanks to a pilot project launched in August. The Association has partnered with the Nick Smith Foundation to develop Treasure Boxes, for children aged four to ten, and Memory Boxes, for those aged over ten. Filled with a range of activities aimed at prompting memories to be made and captured for the future, children and young people can now create a life-long resource to treasure. They join a catalogue of specialist resources for children and young people offered by the Association, which include the 'MND Buddies' web hub, workbooks and information guides. The trial is part of a joint project, funded by the Nick Smith Foundation - a charity formed in 2018 after the death of father-of-two Nick Smith from Calderdale, West Yorkshire who died from MND aged just 38 MND only 101 days after being diagnosed.

Peter the Human Cyborg - The journey of Dr Peter Scott Morgan who has pledged to 'thrive' while living with MND is was featured on a Channel 4 documentary shown at 9pm on Wednesday 26 August and still available on catchup. The programme follows Peter as he undergoes a series of surgical procedures to manage his bodily functions, and then works with hi-tech experts from around the world to investigate how robotics, voice synthesis and virtual reality could be employed to support what he calls his 'Right to Thrive'. Peter is a former Trustee of the MND Association, whose original artwork was displayed at the Oxo Gallery during the Association's 40th Anniversary exhibition in October 2019. He also has a blog which you can access from this link <http://www.scott-morgan.com/blog/>

Pandemic Problems – Act to Adapt - The Association has launched its Act to Adapt campaign, calling for more accessible homes and a faster and fairer system for delivering housing adaptations for people with MND. This follows publication of a report which revealed people with MND are becoming trapped in inaccessible homes due to a failure to deliver essential home adaptations – others have died waiting for basic adaptations and there are fears the situation has been made worse by the pandemic. The length of time, cost and lack of support were highlighted in the pre-pandemic report, as the top three challenges people faced when trying to organise adaptations, such as hoists, ramps and wet rooms, to enable them to live with dignity and comfort in their home environment during their final weeks and months. Such adaptations are offered by local authorities in England and Wales, and the Northern Ireland Housing Executive. To qualify a person must demonstrate the work is 'necessary and appropriate' and 'reasonable and practicable'. The grants are means tested, but the means tests doesn't consider the additional financial burden of coping with a progressive and disabling condition such as MND. In many cases homeowners must fund adaptations themselves or fund a shortfall between the grant and the cost of the work. There is an Act to Adapt hub with more information <https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/>

Association Fundraiser in Birthday Honours List - Inspirational fundraiser Richard Pollins who walked 40km around London on artificial legs, has been awarded a British Empire Medal in the delayed Queen's Birthday 2020 Honours List, marking his services to the Association, Richard raised almost £70,000 during his four day journey, undertaken as part of his 40th birthday celebrations and inspired by his Mum who is living with MND. En route he visited landmarks in the capital with special personal meaning. Richard, who was born without legs, said: "There were fears I'd never be able to walk. There are many reasons why, over the last 40 years I have been able to go from proving those fears unfounded to now taking on this challenge. Most of those reasons are down to my mum." He was joined on various stages of his walk by friends, family and representatives of the MND Association – and his mum was on hand to welcome him across the finish line, along with television cameras, further boosting awareness for the charity.

KATE ADAMS

For those who don't see the Harrogate paper you might find this article interesting, our Association Visitors Margaret and Libby work very closely with Kate who also recently raised some funds for the Branch selling Neals Yard remedies.

How services have adapted amid crisis

Saint Michael's cares for people living with any terminal illness and throughout Covid-19, Motor Neurone Disease (MND) Clinical Nurse Specialist Kate Adams has been busy finding innovative new ways to support patients and their families - including adding technology to her toolkit. Motor Neurone Disease is a progressive, terminal condition which affects the brain and nerves, and Kate (pictured) is there to support people living with this illness and their families to lessen the impact on day-to-day life.

While many patients were happy initially to receive telephone support, Kate says she found not being able to see people and assess them in person quite challenging.

Through use of technology, using video conferencing platforms such as Zoom, the service has been able to keep in touch with patients and their families. However, not all patients are able to communicate in this way - so for some people, a Covid-19 safe socially distanced chat in a



MND Clinical Nurse Specialist Kate Adams.

garden, with the use of appropriate PPE, has been an option. Saint Michael's also provides a special MND telephone support line, provided by the HOME Service, to answer general con-

cerns and queries from patients about their condition, equipment and to arrange support from Kate. Call 01423 879687 or visit www.saintmichaelshospice.org to find out more.

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 and she will add it to the database.

Branch Contacts

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