

MESSAGE FROM YOUR CHAIRMAN



Our first issue of the year coincides with what I can only call a time of change. A significant study of the Association's current structure was made last year the results of which seeing significant changes to the roles that were in place. The Regional Care Development Adviser (RCDA), Volunteer Development Co-ordinator (VDC) and Local Campaigns Manager/Co-ordinator and Lead (LC) roles have been replaced by three new roles: Area Support Co-ordinator (ASC), Service Development Manager (SDM) and Senior Campaigns Advisor (SCA).

Some of you will have come into contact with either or both of the existing first two position-holders who are both very familiar to your Branch committee. Inevitably at times of change not all fresh thoughts and plans meet with total approval. We therefore need to express our thanks and gratitude to certain familiar faces that have been of tremendous help to us during my time on the Branch committee (over twenty years!) and we are sorry to see them go. So many, many thanks to our current RCDA, Sarah Milner, and those we have known over the years in Chris Noble (I was actually on the interview panel who made her original appointment) and Jane Evans. We also recently learned of the departure of 'JC' Julie Compton and to each and every one of them we wish the very best for whatever route their lives takes them.

Talking of interview panels, as I write Libby and Margaret are in fact taking part in the process of selecting one of the new applicants for the ASC post in the Yorkshire area along with Sal Hastings who we are thrilled to learn has been appointed as our SDM and we have already welcomed aboard Jenn Dodd as our newly-appointed Regional Fundraiser.

Time will tell how all this works out, but we live in hope that it will improve the Association's efforts in the support provided to those living with MND and their families, together with ever-increasing awareness of the disease and its dreadful effects. And not least a continued increase in research funding to at last find a cure for MND.

OTLEY BEER FESTIVAL



We are very grateful to Committee member Ruth Paynter and her husband Tom Raper for their help at the Otley Beer Festival, this took place on 22 and 23 November 2019 and we were one of the benefitting charities thanks to Ruth's enquiry.

Apparently it was a very wet weekend (both weather wise outside and for those drinking!!) Here are Ruth and Tom ready and waiting to serve some thirsty customers. For those who are into their beer, Wilde Child Brownie Hunter was the winner of "Beer of the Festival"

Not only will we be receiving a large donation at the presentation evening on 22 January but they continue to support the Association with various re-tweets on their twitter feed @Otley_BeerFest

A FEW SNIPPETS FROM THE NATIONAL WEBSITE

Technology breakthrough offers hope for people silenced by disability – The Association has partnered with Rolls-Royce and its data innovation catalyst, R2 Data Labs, and some of the world's leading technology companies, including Accenture, Dell Technologies, Intel and Microsoft, to pool technology and expertise to improve the lives of those living with extreme disabilities. For the first time, those living with MND will be able to have a conversation through a computer using their own voice, words, colloquialisms and accent, without pausing to type answers or being restricted to a prescribed set of words. The new technology, called Quips, uses voice-banking and AI to learn a person's unique language style and use it in conversation. Quips is in its early stages, but Rolls-Royce is aiming for it to be implemented into some of the leading augmented and alternative communication packages that already exist, such as those used by Professor Hawking. Quips listens to the conversation, suggesting words and phrases that the user is likely to want to say, based on its understanding of their previous conversations. The user can quickly select sentences which are read out in their own voice instantly, with their own accent and local colloquialisms, without gaps for typing. It even includes slang and can adapt to different situations and people, such as work, home, or even the pub.

Dodie Weir Honoured – Scotland rugby giant Doddie Weir was honoured with the Helen Rollason Award at the BBC Sports Personality of the Year show in December, presented by Royal Patron of the Association HRH The Princess Royal. He gave an inspiring and emotional acceptance speech and highlighted the huge support he's received since he revealed his MND diagnosis in 2017. His charity, the My Name's Doddie Foundation has raised nearly £5m, funding much needed research into MND. Doddie and his foundation have worked closely with the Association to make financial grants available to people living with MND, helping to improve quality of life and supporting with care needs.

The MND Association has been awarded the prestigious 2019 UK Biobank of the Year Award – The national accolade recognises the Association's work on the UK MND Collections, previously called the UK MND DNA Bank – a resource of biological samples collected from people living with MND and controls between 2003 and 2012. Case studies for two projects that use samples from the MND Collections were submitted as part of the application. UK MND Collections began in 2003. Participants had two blood samples taken alongside clinical information. One of the blood samples had DNA extracted and stored for genetic testing. The second blood sample had the white blood cells removed and stored in liquid nitrogen (a form of suspended animation) to act as a back up sample to replenish the stocks of DNA if they were ever to run out. As the study progressed researchers found that they were able to wake the blood cells up from their suspended animation and grow them in a dish to see the effect the DNA variations were having within the living cells. Science has moved another stage further, and the cells can now be converted into motor neurons in a dish. This enables researchers to see how the genetic variation in the DNA is causing the motor neuron to die as well as enabling the testing of potential drug treatments directly on the motor neuron.

THE ANNUAL CHRISTMAS LUNCH



The Annual Christmas lunch took place in mid December and as usual a good time was had by all as is illustrated by this photo!!

As has happened in previous years Millstones restaurant very generously donated the results of their raffle to the Branch – this year £190.

KATHERINE WADE WALKING TO D'FEET



As mentioned in previous editions of Chatter Katherine, whose mother Libby is one of our AVs, has travelled to Everest Base Camp, raising funds for the MND Association. Here are a couple of photos from the trek and we are delighted to have received nearly £1000 for the Branch as a result. She took on this challenge partly because of her mother being an AV, but mainly because her Grandad died of MND.

There are lots of other UK based and international challenges - just in case this inspires someone else to get involved - for more information have a look at the national website fundraising area.

AN OPPORTUNITY TO VISIT FARNLEY HALL



The Georgian East wing, designed by John Carr and painted by J M W Turner

Farnley Hall is a stately home in Farnley near Otley, on the hillside overlooking the Chevin. It has been a family home for hundreds of years.

The original seventeenth century house as added to in the 1780s by John Carr who also designed Harewood House. The house is now a Grade 1 listed building.

The hall is perhaps best known for its connection with the painter J M W Turner who visited for the best part of twenty five years and whose painting were inspired by the scenery of wharfedale.

Nowadays the hall is actually two houses, the east wing and the old Farnley Hall at the northern end. It still houses a wonderful collection of Turner paintings.

We are most fortunate to have the opportunity for a group visit (ie 20-25 people) on 10 June 2020. The tours are led by experienced guides and take in all the main reception rooms on the ground floor. The tour lasts about two hours. The cost per person will be £15 and this will include a cup of tea or coffee, with cake, in the Hall kitchen. Unfortunately the Hall is not suitable for wheelchairs.

Please get in touch as soon as possible if you would be interested in taking part, this will not only be an interesting afternoon but will also raise some funds for our Branch.

WINNERS OF RECENT 100 CLUB DRAWS

Thank you to all those who have renewed their membership for 2019.
Recent winners include:

November 2019 - Millie Thompson
December 2019 - Peter Stroud
January 2020 – Nicholas Clark



FUNDRAISING NEWS

We have received a cheque for £285 from Pannal Village Hall – the profits from their quiz night as featured in the last edition of Chatter. We are very grateful for this.

We are also grateful for several in memoriam donations, and for the monies received from Katherine's trek and the Otley beer festival as previously mentioned

Please continue to support us via the local Lotto – the total raised so far has now reached over £250
If you would like to join in then have a look at the website which is

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

DATES FOR YOUR DIARY



On the **first Tuesday** in the month don't forget our monthly get-togethers from 2pm to 4pm). These are held at "**The Barrows**" which is in Crimple Hall on Leeds Road just outside Harrogate.

The next two **lunches** will take place on 11th March and 19th May. Please let Libby or Margaret know if you are interested

Our **AGM / Social** will take place in Pannal Village Hall on Saturday 21 March 2020, 2.00 pm for 2.30pm (your invite is being sent with this edition of Chatter)

Swing into Spring 2020

will take place on 25 April 2020

With Spa Sax, Quiz and Fish & Chip supper

Tickets on sale soon for just £15 each

mnda
motor neurone dis
association
Registered Charity 294354

**YORKSHIRE
DALES
BRANCH**

**SWING INTO
SPRING**

**SATURDAY 25th April 2020
at 7.30 pm
PANNAL VILLAGE HALL**

featuring

SPA SAX

Including Fish and Chip Supper
plus Bar & Quiz

Tickets: £15.00

from Crimple Fresh / Pannal Post Office
or Tel 01423 870130

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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