

MESSAGE FROM YOUR CHAIRMAN



Although this is our autumn issue of Chatter, I have just ordered my tickets for this year's Harrogate Messiah performance which has brought it home to me just how quickly time flies past. And we are now enclosing invitations to the Branch annual Christmas lunch which moves the timescale further on still! So I suppose that this is the last chance I have to wish all our members and friends the very best for the Christmas period from all of us on the Branch Committee.

We do hope that as many possible will join us on December 12th at the Millstones for what has been a very enjoyable get-together for the past few years, and the appropriate reply slip is enclosed.

Elsewhere in this issue you will notice an appeal for 'more hands on deck'. We really do need a few new faces to join our very happy band in order for us to be a bit more adventurous in what we do and to tackle awareness-making with a larger set of resources. So we raise a mug to you and hope that you may be able to respond in the affirmative if only to lend an occasional hand. Cheers!!



Peter Thompson

DATES FOR YOUR DIARY

On the **first Tuesday** in the month don't forget our monthly get-togethers (2pm – 4pm) which are held at "**The Barrows**" (previously known as Christians) in Crimple Hall on Leeds Road just outside Harrogate.

Hope everyone is looking forward to the **Christmas Lunch** which will take place at **Millstones** on 12th December 2018. The next "normal" lunch after that will be on 13th February 2019



Apologies that due to circumstances beyond our control the planned Autumn social event did not happen.

ANOTHER WALK TO D'FEET

Katherine Wade, daughter of one of our AVs (Libby) is planning to go on an expedition to Everest Base Camp in 2019 to raise funds for the MND Association.

As part of her preparation Katherine recently climbed Snowdon, Scafell Pike and Ben Nevis. The picture on the right is of Katherine on the top of Ben Nevis.

She was inspired to take on this challenge partly because of her mother being an AV, but mainly because her Grandad died of MND.

Katherine has a just giving fundraising page to which anyone can contribute – here is a link <https://www.justgiving.com/fundraising/katbasecamp>

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 or follow this link <https://www.mndassociation.org/get-involved/fundraising/>



HELPING US TO HELP

Recently some of our Branch Committee members attended a networking day which gave them some ideas about trying to enlist help. The Branch Committee is a happy, hardworking team but we only have 9 members and we would like to do so much more to raise funds for research and to raise awareness of MND but we need more people!



We don't necessarily need you to join the actual Committee - though of course you would be more than welcome to do so - but perhaps you could sign up to help with events. For instance back in 2010 we organised a 'Walk to d'feet MND', but to do so requires lots of helpers to marshall and organise and thus is something we cannot do at the moment.

You might even get to meet someone famous – here are Peter and Margaret with the Stig at a Ripon Old Cars show!! Maybe you have contacts - does anyone you know work somewhere that might be able to have a collection tin in a works canteen or similar? Might you know someone on the board of a company who are looking to improve their social responsibility image and are looking for a charity to support? Is there an annual rotary event which we could link to?

Maybe you have media contacts – once we have an event such as a walk organised we would need publicity on local radio stations, in the local paper etc.

There are so many possibilities – we look forward to hearing from you!

A FEW SNIPPETS FROM THE NATIONAL WEBSITE

Doddie Weir - the former British and Irish Lion, and Scottish international, is using funds raised through the "My Name's Doddie" Foundation to work with the Association and support people with MND across England, Wales and Northern Ireland. In August the foundation donated £100,000 to the MND Association which follows a one-off donation for the same amount to MND Scotland.

New Communication Tool - A new communication aid tool is due to be launched later this year which uses a person's eye gestures and audio feedback to help them communicate. EyeControl is a wearable personal communication device that gives a voice to people with neurological disorders including MND. It uses a head-mounted infrared camera to track eye movements which then sends the information to a small unit which translates the movements into communication.

Marathon Portrait Project - Miles Pilling is an ex-BBC cameraman who was diagnosed with motor neurone disease in 2013. He and photographer friend Cristian Barnett have been spending the last three years photographing and interviewing various people who have been affected by MND as part of a project called "26 Miles 4 MND". This consists of a 26 mile run, 26 portraits and 26 stories created to raise awareness and funding for the MND Association. The collection of 26 portraits and stories features Miles in each image alongside a diverse group including people living with different types of MND, professors of neurology, researchers, nurses, carers, volunteers, artists and even a professional puppeteer who used MND as the inspiration for the 'CELL' show. Some famous names have also been supporting the project including singer Kim Wilde, actor Hal Fowler and TV presenter Nick Owen. A book is also being created that will be published to coincide with the MND Association's 40th Anniversary in 2019. The 26 Miles 4 MND project culminated with Cristian running the Tallinn Marathon in Estonia on Sunday 9 September 2018. The project has its own website <https://26miles4mnd.co.uk/>

Allied Health Professionals Competency Framework – The MND Association, MS Trust and Parkinson's UK have joined together, in consultation with allied health professionals (AHPs), to develop a competency framework for progressive neurological conditions. This aims to recognise the activities and responsibilities of allied health professionals when working with patients with progressive neurological conditions and has additional sections which focus specifically on Parkinson's disease, multiple sclerosis and motor neurone disease. The framework – currently for dietetics and occupational therapy – provides a standard list of the knowledge and skills required within each level of practice. It sets out a clear career progression pathway. It might also be used to inform effective commissioning of specialist allied health professional services. The output of the project is an accessible resource for use by practitioners and those who manage and commission services which it is hoped will assist practitioners to develop their practice, and to improve knowledge about specialist Allied Health Professionals neurology roles along with an appreciation of their importance, and how the most effective team can be constructed through judicious use of the appropriate staffing levels and their associated skills.

New Awareness Campaign – A new hard-hitting film 'The Ride', is the centrepiece of a new campaign asking supporters to help #TakeOverMND. Starting at a birthday party at which Luke has much to celebrate with his young family, the two minute film follows the two year roller coaster journey that follows from his diagnosis until at his 40th birthday Luke is in a wheelchair unable to walk, speak or move. The Ride, which was rolled out across social media and online platforms during September, marks a new, bolder approach to awareness raising by the Association and has been developed with award-winning creative agency Don't Panic. The Association is calling on people to hold an MND Takeover to show support for us and help. The Association's campaigning activity gives a voice to people living with MND which makes life better for them and their carers.

Another good year at the BMA Patient Information Awards - This year, Eating and drinking with motor neurone disease (MND), (<https://www.mndassociation.org/wp-content/uploads/Eating-and-drinking-with-MND-final-web-PDF-2017.pdf>) was both highly commended and shortlisted to the final five in the Self Care category. This brightly presented 'cook book' with information, easy-swallow recipes and a companion web app was found to be "a good resource for patients." The reviewer even "...tried a couple of the recipes with my family and found them enjoyable" before passing the printed guide to one of their MND patients. The Association is grateful to all those with or affected by MND and their expert panel for tips and recipes, attending our cookery event and reviewing of content. At their launch, the guide and web app were endorsed by the British Dietetic Association (BDA), so received expert recognition too, along with generous funding for development from Morrisons and The Worshipful Company of Cooks of London. Celebrity chefs Prue Leith, Dan Doherty and Levi Roots also supported with easy-swallow recipes.

MPS MEET TO DISCUSS MND RESEARCH

On 17 October 2018, the All-Party Parliamentary Group (APPG) on MND met to discuss MND research. Dr Brian Dickie, MND Association Research Director, spoke to MPs about the research funded by the Association and the annual International Symposium on ALS/MND, the world's premier scientific meeting on the disease, organised by the MND Association. Dr Dickie highlighted the Association's strong track record in supporting clinical and healthcare research. However, despite the positives, there are serious concerns around research capacity within the UK health system to sustain the increased number and complexity of emerging treatment trials and Dr Dickie called for greater Government support for this.

Professor Chris Shaw, Professor of Neurology and Neurogenetics at King's College London, spoke about genetics and MND. The number of gene discoveries in MND has increased dramatically over the last few years and gene therapy offers future hope for families affected by this devastating disease. Gene therapy has been successfully used in a childhood condition, Spinal Muscular Atrophy, establishing 'proof of principle' that motor neurons can be successfully targeted using these cutting-edge technologies.

Liz Tredget, who is living with a genetic form of MND, spoke about having MND in her family, losing her brother last year at the age of 54 and the implications for her children and grand-children. Liz spoke passionately about the urgent need for more research into MND and the willingness of people with MND to be involved. The MND Association has written to the Secretary of State for Health and Social Care making the case for greater Government support for research capacity and seeking a meeting to discuss this. The Association wishes to thank over 1,000 supporters who emailed their MPs about the meeting.

The following MPs were represented at the meeting: Peter Aldous MP (Waveney), Dan Carden MP (Liverpool, Walton), Julie Cooper MP (Burnley), Caroline Dinenage MP (Gosport), Dr David Drew MP (Stroud), Tim Farron MP (Westmorland and Lonsdale), Margaret Greenwood MP (Wirral West), Christine Jardine MP (Edinburgh West), Gillian Keegan MP (Chichester), Karen Lee MP (Lincoln), Andrew Lewer MP (Northampton South), Liz McInnes MP (Heywood & Middleton), Andy McDonald MP (Middlesbrough), Madeleine Moon MP (Bridgend), Anne Marie Morris MP (Newton Abbot), Andy Slaughter MP (Hammersmith), Gary Streeter MP (South West Devon), Mark Tami MP (Alyn and Deeside), Nick Thomas-Symonds MP (Torfaen), Michael Tomlinson MP (Mid Dorset and North Poole), Rosie Winterton MP (Doncaster Central).

WINNERS OF RECENT 100 CLUB DRAWS

Recent winners include:

August 2018 – Jasmine Davey
September 2018 – Judith Farrar
October 2018 – Lottie Shuler

Well done everyone and thank you for taking part .



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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