



Message from your Chairman

A very Happy New Year to all our readers! How time flies, particularly if you are involved in moving home which Margaret and I achieved successfully recently – more problems caused by telecom and TV installers than the actual move itself! Happily we're 'up and running' and can get back to matters in hand such as our latest newsletter for which thanks go again to Ruth for its compilation – however did we manage without her?!

Items to note in this issue are the dates of the next two lunch socials and of course the April AGM but in particular two other events namely the 'Spring Fling' and the Well Being Day. For the latter we are combining with the West Yorkshire Branch for a day of family involvement for MND sufferers, their carers, families and friends which some of you may remember from a few years back when the similar days were organised for three successive years – more will follow in our Spring issue. Before that comes the 'Swing into Spring' event in Pannal Village Hall when we shall be joined by students from Harrogate High School who will be our musical entertainment for the evening performing as 'High Jazz' (which speaks for itself!) and there will also be a quiz to test our brain power which will welcome the presence of a full bar and a fine buffet. The dates are June 18th and April 16th respectively.

Meetings at Christian's continue on the first Tuesdays of the month so if you fancy a cup of tea and a chat do pop in (2pm to 4pm) where you'll be greeted by Libby and Margaret.

The new financial year sees the re-introduction of our 100 Club in which, by joining for an annual contribution of £15, you will be entered into a monthly draw with cash prize of £25 – odds on winning are very good! So if you wish to join, please complete the enclosed form - as soon as possible, please, so we can set it all up for the first draw at the AGM. Happy winnings!

Peter Thompson

Local Fundraising

Recent monies have included a welcome £355 from the sale of golfing items thanks as ever to Peter Wallis. We have also received a donation of £75 from Bishop Holgate School which was entirely un-expected!

Angela Drizi, our previous Secretary, has kindly sent a donation and we continue to receive monthly amounts from various sources including the Monday Club. We were delighted to receive a donation from Millstones restaurant following the Christmas Lunch.

We continue to receive donations in memoriam.



A Few Snippets from the National Website

Survey: From 11 January 2016, the Association will be asking people with MND to tell us what it's like to access support from NHS, social services and the Association itself. This will be done via a comprehensive survey sent to people with MND. It hopes that this will help inform priorities so that the Association can set objectives for raising the standard of care. It should also provide evidence to influence statutory services. The questionnaire will have been sent either by email or in the post by the Picker Institute and responses will be treated anonymously and confidentially. The closing date was 7 February - hopefully if you had one you have sent it back. The findings of the survey will be shared later in 2016.

Campaign - The campaign *Don't let me die without a voice* was a finalist for 'Voluntary Sector Campaign of the Year' at the Public Affairs Awards. The awards were held at a black-tie event in London early in December. This recognition is testament to the 1,000s of supporters who made this campaign such a success. From blue-haired Charlie Fletcher providing an iconic image for the campaign to the individuals who posted a 'selfie against silence', people with MND and their families were at the heart of the campaign. Mark Stone, who is living with MND and who attended the awards dinner, said "It's been an incredibly powerful experience to be part of the campaign *Don't let me die without a voice*. I don't think I've ever felt so passionately about the justness of a cause – enabling people with MND to communicate before they die. I felt honoured to be able to play a part in the campaign and proud that it was a finalist in these prestigious awards". The campaign was launched in September 2014 to improve access to communication support for people with MND.

Parliament - On 1 December 2015 the All-Party Parliamentary Group on MND met in Parliament to discuss access to benefits for people with MND. MPs heard from the Association's External Affairs Director Chris James and the Association's Policy Officer Ellie Munro about the impact of the Welfare Reform and Work Bill on people with MND and their carers. Lord MacKenzie of Culkein has tabled an amendment to protect benefits for people with MND from the proposed freeze to Employment and Support Allowance. Campaigners Katy and Mark Styles, who is living with MND, spoke very movingly about the financial impact of a diagnosis like MND and emphasized the importance of financial support through benefits. Katy said "Having MND is bad enough, living with the financial impact is even worse". She called on MPs to support the removal of Carer's Allowance from the benefits cap. Many thanks to everyone who emailed their MP asking them to attend the meeting. Twenty parliamentarians were represented.

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Where do all your Donations Go?

It's thanks to everyone who raises funds that the MNDA is able to continue with its work in funding research; providing care as well as campaigning and raising awareness of MND.

Donations received are spent in a number of different ways:

In the previous financial year 68% of our expenditure went directly and immediately to fund the MNDA's programme of research, care, as well as campaigning and awareness raising.

13% was spent on support costs e.g. IT, rental of the national office, finance and governance.

19% was spent on fundraising.

For every £1 spent on central fundraising the MNDA raised £3.60 so more than the original value of each donation went to fund our programme.

On top of this, which commenced in 2015, the Association is proceeding with its declared £8.5m / 6 year programme of new work, spending the proceeds from the Ice Bucket Challenge.

We have been asked to draw this event to your attention

Communication Aids & Information Event



A free to attend event hosted by the Motor Neuron Disease (MND) Association for people living with MND, their carers and families, speech and language therapists and other health professionals.

This is an opportunity for people to ask questions about Augmentative and Alternative Communication (AAC) options, and gain a better understanding of the systems in place and challenges faced surrounding AAC provision for people living with MND. The day will feature:

- Presentations from service users, care professionals and the MND Association
- Exhibitions from the leading AAC suppliers, running throughout the day
- Opportunities to find out more about AAC and associated equipment

When & Where?

Thursday 17 March 10:00-15:15

Acklam Green Centre
Stainsby Road, Acklam, Middlesbrough, TS5 4JS

Interested?

If you would like to attend please register online at:
www.bit.ly/COMMSAIDS16

If you are unable to register online please call our Conference & Events team on 01604 611837 quoting reference CE16MH1703

@mndassoc mndassociation



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Merry Christmas Gathering

Some twenty diners gathered at Millstones Restaurant on the 16th December for the Branch Christmas Lunch and a great time was had by all - so much so that all those who had come armed with their mobile 'phones etc completely forgot to take any photographs! So we've had to find a substitute!!



Dates for Your Diary

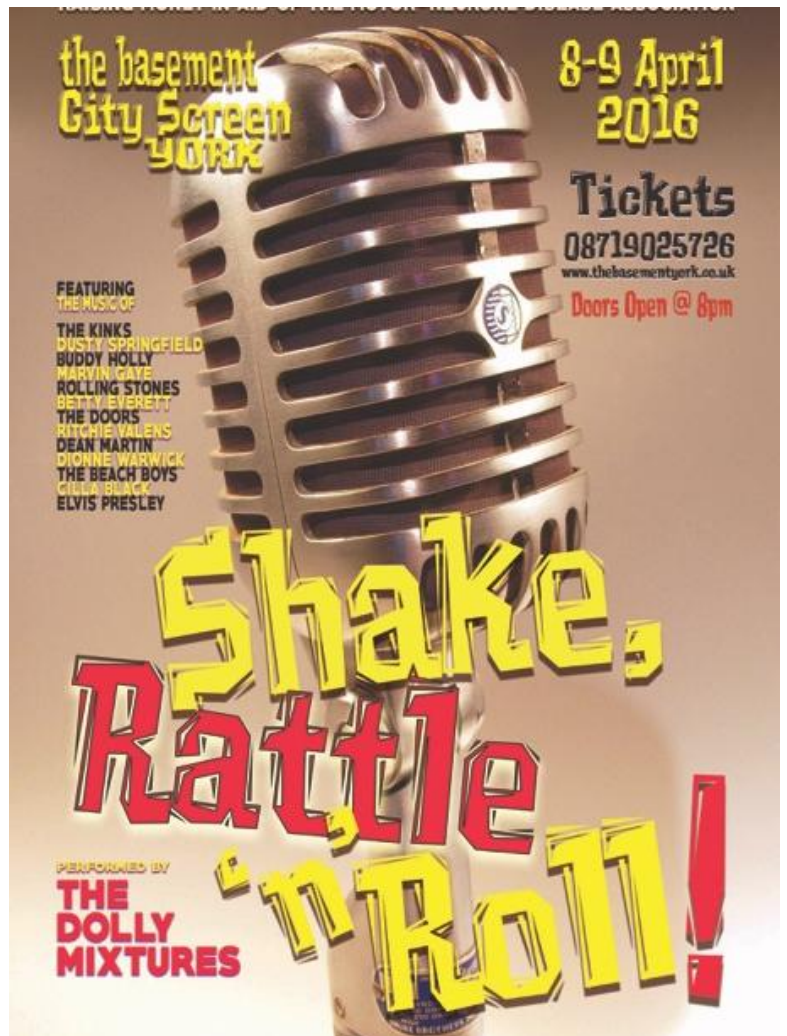
The next two **Social Lunch** will take place at The Old Spring Well, Skipton Road, on 9th March and 4th May 2016.

'**Swing into Spring**' jazz evening with supper 16th April 2016 at Pannal Village Hall, Tickets will be on sale soon priced as per last year's similar event at £12.50.

A Fundraising **event in York** (see the poster on the right from which we will receive the main proceeds). Let Ruth know if you'd be interested in going.

The **AGM** will be held on 24th April 2016, papers will be sent out from Mid March onwards

And of course on the **first Tuesday** in the month are the monthly get-togethers at Christian's Cafe in Crimble Hall on Leeds Road, Pannal (2 – 4pm).



Branch Website and other Information

Just a quick reminder that our website www.mndyorkshiredales.co.uk and our facebook page <https://www.facebook.com/MNDYorkshiredales> are now getting regular updates. We are always on the lookout for interesting tidbits so if you have anything you would like to add please let us know.

Maybe you would rather see yourself in print! If you have something you would like to tell everyone about, if so we would be delighted to publish it in the next edition of Chatter, please send your article to Ruth Pridmore (if you don't have email then give her a ring and she will let you have her address).

We are also still updating our contact lists and would love to be able to contact **you** by email, for instance by sending Chatter by email rather than in the post so if you have an email address we can use please send a message to secretary@mndyorkshiredales.org.

Branch Contacts

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
Treasurer, Kate Stewart - 07841 677881 treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com

National Contact Information

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Up to date News <http://www.mndassociation.org/news-and-events/latest-news/>