

Message from your Chairman



How quickly the time flies by and here we are sending you our Autumn Newsletter – where did the summer go?! Margaret and I have just returned from Menorca (hence new look mug shot!) and even there the weather was very mixed.

Libby, Ruth and Veronica recently represented us at the Nidderdale Show Open Day where, unlike at the Ripon Old Cars Gathering in July, they had idea to include a tombola on our gazebo. This had the desired effect of enhancing our MND awareness-making but in the process also achieved a return of over £200 for the Branch – rather more than the £9.50 at Ripon!

There is not a lot more to report (although there is a fishy story to read about later on!). The 100 Club still remains disappointingly supported and there's still time to join - at very short odds! Financially we are in a sound position and at our next meeting will discuss giving support to the Chief Executive's Appeal. Donations this year are being sought from Branches and Groups towards

- 1) Supporting people with cognitive changes and FTD (Frontotemporal Dementia)
- 2) Using NICE Guidelines to audit service quality
- 3) Single-point-of-contact for wheelchair or AAC (Augmentative and alternative communication) problems
- 4) Welfare benefits advice
- 5) At the trustees' discretion

We will look at the detail in those categories and usually support three of the causes. Last year's total support from all Branches and Groups for the nominated causes came to an amazing £57,000!

We are at the planning stage for event(s) next year and will let you know the outcome in the next Chatter.

Peter Thompson

North and East Joint Regional Conference York, Saturday 11 November 2017

Chief Executive of MND Sally Light hopes that as many people as are able will attend the regional conference at York Racecourse. To register please visit www.mndassociation.org/regionalconference or email conference@mndassociation.org or contact the events team on 01604 611837. There is no fee for people living with MND, their families and carers, and registered Association Visitors (AVs). For other delegates the registration fee is £15 which includes lunch and refreshments. Parking is free.

The event is an excellent opportunity to learn more about MND, meet others affected by the disease and find out what is new in MND care, research and campaigning. It starts at 9.00 am with registrations, 10.00 am for Welcome, then there are various other presentations ending at 3.15 pm with refreshments before everyone goes home.

If you can't make it then you can watch all the key presentations – which will be streamed so you can watch them live or catch up later - online at www.mndassociation.org/regionalconferences

A Few Snippets from the National Website

MND Association patrons join forces to celebrate the first London City Swim: Benedict Cumberbatch offered his support for the inaugural London City Swim, an international sponsored swimming event which took place on Friday 22 September and which has already raised millions of pounds in other cities around the world towards research and awareness in aid of motor neurone disease. The event is supported by The Stephen Hawking Foundation and the MND Association, and to date, City Swim events have raised over £7.5m in aid of research and support for those living with MND. Benedict, who stars this Sunday evening in the eagerly anticipated BBC1 feature length drama *The Child In Time*, said: "As someone who stripped off and got doused in ice cold water SIX times as part of the Ice Bucket Challenge three years ago, I remember very vividly how so many millions of us did our bit to help raise awareness of MND and support those people living with the disease. A fantastic amount of money was donated but scientific research is incredibly expensive, and my friend Professor Stephen Hawking and his team want to raise money to analyse the genomes of 15,000 people with MND, including thousands of people living in the UK with the disease. This work will get the world closer to finding a cure to MND. City Swim is an annual fundraiser that started in Amsterdam in 2012, after a group of friends decided to find a way to raise money for a colleague suffering from MND. It soon took off, with thousands of like-minded locals jumping into Amsterdam's canals to take part in the inaugural event – including Princess, now Queen, Maxima of the Netherlands – and has now become an annual crowd puller in the city. Organisers took the event to New York two years ago, with swimmers taking part in the Hudson River – and it has now reached London where the water is apparently tested every two weeks against EU bathing regulations to ensure perfect purity for open water swimming – apparently it's slightly salty but really clean and pleasant to swim in!

Awards for MND information: The Association has had another positive year at the BMA Patient Information Awards. After scooping top honours with Patient Information of the Year in 2015 and 2016, it was extremely positive to reach the finals again. This year the guide for 13-18 year olds, *So what is MND, anyway?* was highly commended and short-listed to the final four in the Information for Young Adults category. The review said, "...It is an excellent resource: the effort put into creating this resource is exceptional." The booklet *Supporting children and young people close to someone with motor neurone disease (MND)* was also highly commended as "...an excellent resource and the sources of other information/support are outstanding...it is superb." Huge thanks to everyone who contributed, especially young people affected by MND and students from the Kings School, Wolverhampton. Their help has made a huge difference for others facing the challenges of this disease. MND continued to pull huge focus at the BMA this year, with Sheffield's video website *MyTube* about tube feeding. The resource won the Information by Trusts category and the User Engagement category and was also runner up for Decision Making. Their review admired its ambition and "...clearly stated objective to use patient stories to encourage change." The top award for Patient Information of the Year 2017 was awarded to *It starts with me* from the Terence Higgins Trust, an innovative, educational 'supercampaign' to help reduce the number of HIV infections.

All party group on MND elects Officers: The APPG on MND held its AGM in Parliament on Wednesday 12 July and elected its officers for the coming year. The elected officers are: Chair: Madeleine Moon MP (Bridgend); Vice Chairs: Paul Blomfield MP (Sheffield Central) and Mary Robinson MP (Cheadle); Secretary: Chris Evans MP (Islwyn). The MND Association was appointed to provide the secretariat to the Group. Following the AGM Susie Rabin, Head of Policy and Campaigns, talked to MPs about our new report *MND Costs: Evaluating the financial impact of motor neurone disease*. Susie said: "It was great to have the opportunity to talk to MPs about the extra costs of living with MND and the importance of access to financial support for people with the disease and their families. There was commitment from around the table to help us campaign for better access for everyone affected by MND". The Group also discussed its inquiry into access to Personal Independence Payment (PIP) for people with MND. The report from the inquiry will be launched at a joint reception between the APPG and the MND Association in October. You can write to your MP about the financial impact of MND and invite them to attend the reception via our online action. For further information please contact Alison Railton, Public Affairs Manager on alison.railton@mndassociation.org.

If you can get online then follow this link for many more interesting news items
<http://www.mndassociation.org/news-and-events/latest-news/>

Fundraising

As mentioned in the last edition in July the York Branch organised a family fun day and fun sponsored fishing match at Pool Bridge Farm near York and Tom the husband of Ruth, our latest BMC volunteer, took part since he's been fishing since he was a lad.

It was a beautiful sunny day and as well as the fishing match, which anyone could enter experienced or not, there were taster sessions for fishing, fly casting lessons, tombola, a bouncy castle and lots of other fun activities for children and families such as face painting and wild wood activities.



The day ended with a falconry display during which one of the birds decided it preferred to perch on the barn and observe what was going on rather than fly back to the handler but eventually it came back down.

As to the fishing, well it was slow going being a bit warm for the fish and, as ever, it was the ones that got away that would have made all the difference....But the real result was that around £6000 was raised for MNDA.

And if you fancy a dabble at fishing and to have your own tale of the one that got away it's planned to be an annual event so look out next year for publicity.

MND Charter Update

The Association is delighted that the number of councils which have adopted the MND Charter to date has reached 53! This is fantastic, and we couldn't have achieved this without the campaigning efforts of our volunteers. Recent adoptions include: Newcastle City Council, Cumbria County Council and Durham County Council – all in the north!

Newcastle Councillor Karen Kilgour, cabinet member for Adults and Health, said:

“As a council we can shape and adapt many of the services that people with MND will interact with, including social care, health and housing. It is important we embrace the Charter and use our influence over these services to make sure they support people with MND in the most suitable way. We can also play an important role in ensuring that all our staff understand MND and can work with people in the city who may be living with the disease. I hope by adopting the Charter and working closely with the MND Association we can turn Newcastle into a city that supports people suffering from MND and has better outcomes for themselves and their families.”

Newcastle City Council is working closely with partners such as Newcastle Carers and the British Red Cross to ensure they are aware of the Charter and how it can be used across their services.

Winners of recent 100 Club draws

Recent winners include:

June 2017 – Peter Stroud

July 2017 – Colin Chapman

August 2017 – Abigail Shuler

Can we also say a special thank you to Peter who was so pleased with his win he promptly bought two more numbers and sent us a £20 donation! Well done that man. Also sorry that we have been calling it a 200 Club in previous editions of Chatter – the editor was confused!

Dates for Your Diary

The next **Social Lunch** will take place at The Old Spring Well, Skipton Road, on **18th October**

The **Christmas Lunch** is planned for **13th December 2017** at Millstones – more information to follow but get the date in your diaries now!

We are also in the initial stages of planning an event for early in 2018 – look out for more information as soon as everything is sorted!

And of course on the **first Tuesday** in the month are the monthly get-togethers (2pm – 4pm) at venue to be confirmed as we were saddened to hear that Christian's may be closing! (we'll let you know where in good time!)

Since the last edition we have had stands at the Classic Car Fair and also, more recently at the Nidderdale Show on 25th September – where it was very very wet. Here is a photo of our new Ruth with AV Libby braving the rain!



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? We would be delighted to publish items from Members in the next edition, just 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).

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

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
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National Contact Information

www.mndassociation.org

MND Connect – 0808 8026262

(note that the number for MND Connect has recently been updated)