

Message from your Chairman



Firstly, I and the organising team were so disappointed in having to cancel the planned Wellbeing Day in July. This was due to a shortage in the number of expected attendees which made it impossible to proceed as we couldn't justify the outlay given the 'free participation' nature of the day. A great shame as in years past we have had numbers attending around or over the one hundred mark. Maybe the timing was wrong and we'll have to 'think it out again' for next year.

Veronica and her husband attended the 'Shake, Rattle & Roll' evening held by our York friends which proved to be a night of fine performance and nostalgic music. We were delighted not only with the amount raised but the fact that Stephanie has successfully attained her place in a New York Academy of Performing Arts. Many congratulations, Stephanie (pictured here with Mum)!



Also enjoyed by us all was the 'Spring Swing' in Pannal which again raised a bob or two.

We have the Ripon Car Club event to come this month from which we share a proportion of the profit and we'll be in attendance with our awareness stand.

The dates of other social events are listed elsewhere.

Finally, the Branch sends every good wish to Sue Smith in her retirement. Sue has been ever-present for all the time I have been involved with the Branch so my personal thanks, Sue, for all the help and advice you have provided over the years (too many to count!).

Peter Thompson

Local Fundraising

Recent monies have included the proceeds of an event called "Shake, Rattle & Roll" held in York in April (see above) which brought in an amazing total of £2000. Needless to say we are very grateful for the work involved in organising this event.

Our own "Swing into Spring" event raised over £500 - another wonderful total from an event that was mainly intended to be a social!

We continue to receive donations in memoriam.



A Few Snippets from the National Website

Carers Week: This took place in the second week of June. On 7th June the Association attended a parliamentary reception – accompanied by campaigns volunteers Heather Smith, and Katy and Mark Styles representing people living with MND and their carers. In all, they spoke directly to about 12 MPs including Justin Tomlinson MP (Minister for Disabled People) and got across some powerful messages about the challenges they and others in their position face. On 8th June there was a roundtable event which brought together the partners of Carers Week and official bodies closely involved with the development of the Carers Strategy. It was an important opportunity to influence the development of the Carers Strategy and stress the need for recognition that cases should remain open for people with rapidly progressing conditions to ensure continuity of care for the person and reduce the burden on carers, as they are the ones who often liaise with health and social care services. Later in the day Carers Week was granted a parliamentary debate, which was great news. All the work in Carers Week and the weeks running up to it, including the success of the All Party Parliamentary Group meeting held on 24 May, came together. This meant that the MPs present were able to use the facts and personal stories they had heard to great effect. MND was strongly represented during the debate and our concerns and recommendations were heard at the highest level. The Association thanks the carer representatives for taking these essential messages to vital contacts and putting them across in powerful way that can only be achieved by someone telling their own story.

New MND Nurse Consultant : the National Hospital for Neurology and Neurosurgery has approved the funding for and recruited a MND Nurse Consultant. This is the first post of its kind in England, Wales and Northern Ireland, and closely follows a similar post in Scotland. Jan Clarke, the new post holder, is well known to the MND Association. She has been the MND Clinical Nurse Specialist at the National Hospital since 2003, and has worked very closely with the Association as well as developing education opportunities internationally. The MND Consultant Nurse post will focus on areas of best practice and research which will improve care and support for those with MND now and in future

Benedict and Eddie Show their Support for Shortened Stories: Throughout June the Association were sharing stories of real people whose lives have been, or will be, cut short by motor neurone disease. On June 21st, chosen by the International Alliance of ALS/MND Associations as Global MND Awareness Day because it marks the summer solstice which is a turning point, the Global MND/ALS community undertake a range of activities to express hope that this day will be another turning point in the search for a cause, treatment and cure of MND/ALS. The Association is proud to share special messages from our Patrons Benedict Cumberbatch and Eddie Redmayne who have both recorded special introductions to the video 'Fresh Breath', a poem written by Robert, who is living with MND. The poem is one of three stories that feature in the "Shortened Stories" Awareness month campaign. So far, the videos from Eddie and Benedict have reached 12,000 and 15,000 views respectively on social media. If you would like to see them please follow this link https://www.youtube.com/results?search_query=fresh+breath+mnd

Shortened Stories: Throughout June the Association was sharing stories of real people whose lives have been, or will be, cut short by motor neurone disease. For more information please visit <http://www.shortenedstories.org/>

Shortened Stories



Delays in Diagnosis

We are sad to report that one in five people who have been diagnosed with motor neurone disease in the last three years have had to wait a year or more to be referred to a neurologist, a critical step in receiving a diagnosis of MND – according to new research released by the MND Association on 1 June 2016 to mark the start of MND Awareness Month. Of these people, more than half (52%) had been referred to other healthcare professionals first, most commonly physiotherapists, orthopaedic surgeons or Ear Nose and Throat (ENT) specialists instead of straight to a neurologist – the professional best able to deliver an accurate, confirmed diagnosis of MND. Even once someone is seen by a neurologist the lack of a definitive test for MND continues to further add to the delays. Whilst over a quarter of patients (27%) received a confirmed diagnosis within a month of seeing a neurologist, almost one in seven (14%) experienced a delay of a year or longer.

This slow diagnosis prevents people from getting the right help to manage MND's rapid, aggressive progression, and also delays them from putting the appropriate care in place. A third (32%) of those who took part in the research – the largest survey of people living with MND in England, Wales and Northern Ireland – also said they hadn't been able to get important home adaptations done when they needed them; essential changes like stair lifts, ramps and door-widening to accommodate powered wheelchairs.

Sally Light, Chief Executive of the MND Association, said:

"This fatal and still incurable disease kills more than half of those diagnosed within two years. It is notoriously difficult to diagnose, and this new research shows many face 12 months or more of anxiety and uncertainty while their symptoms worsen - partly due to delays between a GP referral and actually getting to see a neurologist, with 16% reporting that it took over 3 months. As traumatic as a diagnosis of MND must be, once you know why symptoms are occurring you can make more informed decisions for you and your family. Swift and accurate diagnosis, most commonly from a neurologist, is crucial in ensuring the needs of people living with MND are met from the earliest possible stage. The problem is, there's still no single diagnostic test for MND and we appreciate that it is also challenging for GPs, who might only see one patient with MND in their whole career. Symptoms can be similar to other conditions, so people can spend months seeing various specialists and undergoing unsuccessful treatments until MND is suspected. However, there are things we can do to improve this."

The survey results suggest this might already be helping – those diagnosed in the last year have had on average faster referrals than in the past, but there's still too many people waiting too long. The Association will continue to strive to improve care for people affected by MND, raising wider awareness of the devastation of MND and also fund global research towards treatments and a cure."

Meet the Team

Did you know there are a number of regional staff working for The Association in different aspects of the charities work? If you have a particular interest in fundraising, care services, volunteering or campaigning in your local area then the 'North Regional Delivery Team (RDT)' are available to support you.

Regional Delivery Manager



Tracey Thompson
tracey.thompson@mndassociation.org
Telephone: 01226 765490
Mobile: 07541 963528

Campaigns Manager



Julie Compton
North
julie.compton@mndassociation.org
Telephone: 0115 9204507
Mobile: 07811 280893

Volunteering Development Co-ordinator



Sarah Milner
Manchester, Lancs and Yorks
sarah.milner@mndassociation.org
Telephone: 03453 751859
Mobile: 07501 862092

Regional Care Development Advisor



Colin Pearson
Cleveland and North East Yorkshire
colin.pearson@mndassociation.org
Tel: 03453 751837/07831 865329

Regional Fundraiser



Mandy Metcalfe
Manager (North and West)
mandy.metcalfe@mndassociation.org
Mobile: 07918 745245
Mobile: 07541 963528

Regional Care Development Advisor

This post will shortly be filled by Sal Hastings, who currently covers Lancashire and Cumbria.

Sue Smith Retiring

Sue Smith, our RCDA in West Yorkshire, is due to retire at the end of July. We will miss her greatly as Sue has been with the Association for the past thirteen and half years and during that time has made a number of important contributions to our MND work. We wish her all the best.

Sue has made significant contributions within the arena of palliative care and 'end of life' work - which we know Sue is passionate about. For example, she made a significant contribution to the 'Palliative Care Social Work' guide (APCSW), being part of the team that produced the EOL guide which received a BMA award. She is also continuing her efforts to produce a training module around bereavement & loss for the AV training course, before she leaves us for pastures new. Her dedication and passion for her direct work with those living with MND, their carers and families also stands out and is a real strength of Sue's delivery on the ground, rooted within her social work training and experience.

Dates for Your Diary

The next **Social Lunch** will take place at The Old Spring Well, Skipton Road, on **19th July 2016** – please note this date which has been changed from that circulated in earlier editions of Chatter, future dates include 12th October and (to be confirmed) the Christmas lunch on 14th December.

Ripon Classic Car Club are holding a **Classic Car Gathering on 24th July 2016** raising funds for the Branch at Ripon Racecourse. For more information please visit www.riponclassiccargathering.org or see the poster here!

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 (2pm – 4pm).



RIPON OLD CARS
PRESENT THEIR TWENTYSECOND ANNUAL
CLASSIC CAR GATHERING
at
RIPON RACE COURSE
On
SUNDAY 24th July 2016
The gates are open from 10am to 5pm - Free Car Park
The entertainment Starts at 10:15 a.m.
Admission Charge £5.00 - children under 14 free if accompanied by an adult
Proposed features of the show include:-
Home Made Refreshments - Classic and Vintage Cars - Motorcycles
Military and Commercial Vehicles - Auto Jumble - Trade Stands
Vintage Tractor Display - Kit Cars - One Make Club Stands - Tombola
Singing Duo - Eric and Anna - Ripon Junior Operatic Singers
Plus, face painting, crafts and games, fairground organ and birds of prey and exotic animals, and Ripon Toy Library area for young children and parents.
"The Crazy world of Magic" with Uncle Mal
For further information call 07896-701223
or email phil@riponclassiccargathering.org,
or check our web-site
www.riponclassiccargathering.org for an entry form.
**All Proceeds from this event go to the
Motor Neurone Disease Association
and numerous local Charities.**

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
Treasurer, currently vacant treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com

National Contact Information

www.mndassociation.org MND Connect – 03456 626262
Up to date News <http://www.mndassociation.org/news-and-events/latest-news/>