

MESSAGE FROM YOUR CHAIRMAN



Our Summer Edition already – where does the time go?! Those who know me well will recognise my current distractions with all the cricket activities, and as I write I await nervously for England to play their World Cup semi-final and just hope the weather is kind.

You will notice in this edition that there are more than usual dates for your diaries. We have to plan well in advance for the ‘major’ events such as our annual ‘Swing’ etc, and on 4th October, for our contribution to the celebrations of the 40th anniversary of the Association, we are arranging for Pannal Village Hall to be ‘lit up’. Other Branches and Groups are planning similar such events, so if you are passing Pannal Hall on 4th October you will know what it’s all about! The Hall management has also very kindly nominated us as the charity for their

autumn quiz (which takes place two weeks later) at which the Branch will be fielding a couple of tables. Let us know if you’d like to join in.

And talking of fielding, I must get back to the cricket!

Peter Thompson

FUNDRAISING NEWS

We are still waiting for the cheque for £253 from Waitrose Harrogate as we were in their Green token scheme in January – apparently it has got lost in their system but we are promised a replacement!

We must also say thank you to those who are buying tickets in the Local Lotto – the total raised so far is now £109.50! 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>

Ruth Paynter had another successful coffee morning in April raising £75. Swing into Spring (photos published in last Chatter) raised £591.50 and we already have 25 April 2020 in our diaries for the next one!

Ruth Paynter’s partner Tom took part in the Anne Walker Memorial Shield Fishing Day on 29th June and will be kindly donating all the money he raises to the Branch. We are also grateful to Pannal Village Hall who are holding a quiz night on 19th October with funds raised being donated to our Branch and we will also be one of the beneficiaries of the Otley Beer Festival which is on 22nd & 23rd November. We have also recently received some generous in memoriam donations – thank you to those who sent them. Keep watching this space for more news!



WINNERS OF RECENT 100 CLUB DRAWS

Thank you to all those who have renewed their membership for 2019, even though you have missed 3 draws if anyone would like to join in please get in touch.

Recent winners include: April 2019 – Elaine Bradley
May 2019 – Nicholas Clark
June 2019 – Colin Chapman



A COUPLE OF SNIPPETS FROM THE NATIONAL WEBSITE

Parliamentary drop in attracts more than 60 MPs and Peers – They accepted an invitation to meet people with MND, Association volunteers and health and social care professionals at a Parliamentary drop in focusing attention on a new report which found the current benefits system for people with a terminal illness is 'not fit for purpose'. The report found that the current rule, that only people with a life expectancy of six months or less can get fast access to benefits, is 'outdated, overly time consuming and demeaning'. The report adds further weight to the MND Association's [Scrap 6 Months campaign](#) being run alongside Marie Curie. Association representatives shared their stories and Television and radio presenter and MND Association Patron Jeremy Vine was in attendance to listen to moving speeches from the chair of the APPG Drew Hendry SNP and Madeleine Moon MP who is the chair of the All Party Parliamentary Group on MND. The drop in was held on the same day that Good Morning Britain presenter Charlotte Hawkins, whose father died from MND, appeared on Lorraine to urge people to sign the Association's petition calling for a change in the law so everyone with a terminal illness can use the fast track process to access the benefits they are entitled to

Family Carers 'work' a 100 hour week - Research conducted by the Association has found that a third of unpaid carers (33%), often family and friends, spend more than 100 hours a week caring and nearly half (45%) don't receive benefits to help support them in their vital roles. Alarming, it also found that 62% of carers have not taken any planned breaks, even for as short a time as two hours. Carers often find it challenging to take care of their own wellbeing, and the impact of caring on all aspects of life from health to financial worries should not be underestimated, according to the MND Association. Findings within the report showed that over 40% of carers who responded worry about money, and nearly 60% feel stressed as a result of caring. It also found that more than half are physically and mentally exhausted. Nick Goldup, Director of Care Improvement for the MND Association said: "It's extremely upsetting to realise that those caring for their loved ones are also experiencing financial worries, exhaustion and huge impacts on both their physical and mental health." The Association is aiming to raise awareness of rights, whether it's a carers assessment or benefits and allowances. Also seek to provide information, offer grants to improve their quality of life, and connect carers with others in their local area through our Branch and Group network." As part of its support to carers the Association is trialling a volunteer role focussing on supporting carers and past carers of people with MND called [Carers' Champions](#). These volunteers will build up knowledge of the services available in their community, liaise with carers to identify what issues they face, explain how the MND Association can support them. The volunteers will also identify and create opportunities to bring new, existing and past carers together.

KETA'S JOURNEY

Keta's Journey

The Street family's 352 mile walk for Motor Neurone Disease Association from Hartlepool via Oxford and Battersea to Godalming.

Day one: 23rd July Hartlepool to Hutton Buddo
Day two: 24th July Hutton Buddo to Hutton Buddo
Day three: 25th July Hutton Buddo to Boston Spa
Day four: 26th July Boston Spa to Compstall
Day five: 27th July Compstall to Worswick
Day six: 28th July Worswick to Nottingham
Day seven: 29th July Nottingham to Leicester
Day eight: 30th July Leicester to Braunston
Day nine: 31st July Braunston to Battersea
Day ten: 1st August Battersea to Christ Church, Oxford
Day eleven: 2nd August Oxford to Stokenchurch
Day twelve: 3rd August Stokenchurch to Uxbridge
Day thirteen: 4th August Uxbridge to Battersea
Day fourteen: 5th August Battersea to West Allbury
Day fifteen: 6th August West Allbury to Munsford Court, Godalming
Munsford Court, Godalming

Please support Kevin, Hebe and Violet as they retrace Keta's journey from her hometown of Hartlepool to Oxford University, to Battersea where the girls were born, and finally to their home in Godalming. The epic challenge is to walk for 24 miles each day for 15 consecutive days across every terrain.

In memory of Keta, let's raise a further \$100k together for MND. To assist vital research and provide support for other families having to cope with this terrible disease.

JustGiving streethansfamily

Please join the challenge

By walking with us for a day, by donating and raising whatever you can, and by sharing this story as widely as you possibly can!

And please follow our progress on Facebook @ketasjourney

A memory walk is taking place at the end of July and on 25th July they will be in our area having lunch at the Anchor Inn in Whixley.

The attached flyer gives you a great overview of the family's plans. Kevin and Keta Street featured on some of our new legacy materials last year for the Association. Sadly Keta lost her fight with MND earlier this year. But the family in spirit with which they have always stood up to MND are about to undertake their biggest challenge yet. Kevin and his two daughters and a few other family members are undertaking a 350 mile walk to be completed in 15 consecutive days.

Starting in Hartlepool where Keta was born and taking in several locations that are of significance to the family they will finish Godalming where the family now live. They have a target of £100k in sponsorship.

So, if anyone is free to meet them in Whixley as a "cheering squad" they would be really grateful of your support.

40th ANNIVERSARY GARDEN PARTY

Tracey, an AV from West Yorkshire Branch, and Libby Wade, one of our own AVs, went down to Boughton House in Northamptonshire for the 40th anniversary garden party of the MND. This took place on Global MND Awareness Day.

Volunteers from all over attended and had a very special day. They were welcomed by the Duke of Buccleuch and were given a guided tour of the house and beautiful gardens.

They were also very privileged to have Jane Hawkins and Lucy Hawkins (Stephen's daughter) talk to them. They also heard from four of the people who had started the Association 40 years ago which was very interesting.

At the end of the day we were invited to spend as long as we wanted strolling round the gardens (pictured below, the photo on the right is people seated on the lawn)



Jane Hawkins



The four original founders of the MND



Boughton House and rose garden



Libby and Tracey

“A Walk in the Garden” at Harlow Carr

The Rotary Club of Harrogate have invited members from this area of the MND Association to an event for people with disabilities and their carers on **Thursday 12th September**. The format of the day will be the same as that held last year. People with disabilities and their carers from a variety of organisations are invited to RHS Harlow Carr to enjoy a day out in the gardens in the company of others who share their experiences and challenges. Harlow Carr Gardens has a number of paths with good wheelchair access, and also has suitable disabled toilet facilities.



Each participant plus one carer would have free access to the garden. Additional companions would pay for admission at the normal rate, except in cases where more than one carer was required for a person with complex needs. Participants would be identified with a wrist band to distinguish them from the paying public. This event is not intended as a race, fundraiser or sponsored walk, simply as an opportunity to enjoy a day out with friends.

Catering on site is provided by Betty's. Unfortunately there is no provision for making reservations and queues may be long, so they recommend that participants bring a picnic lunch. They have a room reserved in the learning Centre to use as a base, meeting point and as a place to leave picnics etc whilst exploring the gardens.

Because the event is being held earlier than last year, Harlow Carr is expected to be busier than last time. For that reason they have requested that the number of people attending should be limited to 100. This should not present a problem as it is still higher than last year's total. However to avoid disappointment you need to make contact as possible to confirm your interest in taking part. Please contact Maurice Bull from the Rotary Club directly by email at Dunvett1n@outlook.com or by phone 01423 866819 and please tell him you found out about the event via the Yorkshire Dales Branch of MNDA.

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 Crimble Hall on Leeds Road just outside Harrogate.

The next **Lunch** dates are 21 August 2019 & 16 October 2019
The **Christmas Lunch** will take place on 11 December 2019

Pannal Village Hall will be lit up in **MNDA colours** on 4 October 2019

The **Quiz Night** in Pannal Village Hall is on 19 October 2019

Swing into Spring 2020 will take place on 25 April 2019

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

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
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