

MESSAGE FROM YOUR CHAIRMAN



You may recall that the last edition of Chatter featured details of the celebratory day at Boughton House in this the year of the 40th anniversary of the Association's founding. And, along with similar events planned by other Branches and Groups, we had advertised our own contribution with a 'light up' of our local village hall. The date to which I had drawn your attention was October 4th. This should have been October 6th (the exact formation date) and was postponed until October 19th to coincide with a quiz night. The light up on October 6th failed!

So included below in this issue is firstly an extract from a newspaper article published recently concerning the Boughton House day (with a lovely photograph of the assembled attendees) and also photographs of our celebratory evening at said village hall. The Yorkshire

Dales Branch quiz team did quite well and a good time was had by all with proceeds being gratefully received (amount to be published in the next Chatter). But the lights failed again. The best laid plans!!

I was also engrossed in the world cup cricket when writing the last piece – and we won! Furthermore, Margaret and I were present at Headingley on the 'Stokes Ashes miracle day' so I'm still glowing from those two experiences. Now, as I write, for the world cup rugby ...

We've fixed the dates for our 2020 Swing into Spring and AGM social days so please make a note and transfer to your New Year diaries. Which reminds me, as this will probably be the last Chatter of 2019, may I wish you all the very best for Christmas and the New Year.

Peter Thompson



"The Yorkshire Dales Branch has a 'base' in Pannal Village Hall where it holds committee meetings and a number of social functions. It was therefore thought appropriate to ask permission from the trustees of the hall for it to be 'lit up' on an available date in October as near as possible to 6th in support of similar ventures being arranged through the country to celebrate the 40th Anniversary of the MND. They generously granted the Branch's request with a date of October 19th and

went further still in dedicating the proceeds of a quiz and fish and chips event that will be held that evening to the Yorkshire Dales Branch." Harrogate Advertiser Thursday 10th October

WINNERS OF RECENT 100 CLUB DRAWS

Thank you to all those who have renewed their membership for 2019.

Recent winners include:

July 2019 – Valerie Hooper

September - Anne Pratt

August 2019 – Amelia Martin McGill

October 2019 – Tony Gould



A FEW SNIPPETS FROM THE NATIONAL WEBSITE

Association launches new resources for Children – In response to demand from families affected by MND the Association has consulted children affected by MND, parents and healthcare professionals to create two new resources. MND Buddies <https://mndbuddies.mndassociation.org/> is a new online activity hub developed to give children aged 4 to 10 the chance to learn more about MND through games, stories, activities and galleries where they can share artwork and writing. The hub is brought to life by a team of friendly characters including Max the Monkey, Rini the Rabbit, Eric the Elephant, Carly the Cat and Ali the Alligator. There are also three family based stories on the MND buddies website, helping children to begin to adjust to some of the changes MND will bring. The aim is to encourage children to discuss worries with their family. The stories can be read and listened to on the hub, allowing people with MND who have communication difficulties to share the stories with their children. The stories are also available in a printed storybook called “Why are things Changing?” which can be ordered via the MND Connect helpline

#Scrap6Months campaign update – It is three months since the previous Department for Work and Pensions (DWP) Secretary announced a review of how the benefits system supports those with terminal illness. Since then the Association have continued to work with Marie Curie to push the #Scrap6Months campaign to ensure the review takes place as soon as possible. There has been a response to the petition handed into Downing Street and confirmation that the review of welfare benefits for people who are terminally ill is going ahead, despite the change of Secretary of State. The Association has been invited to a stakeholder engagement event with the DWP, which will take place at the end of October. The meeting will be attended and the Association will seek further details on the next steps and timelines for the engagement process and ensure those living with and affected by MND have opportunity to be involved in the review. The two most important policy priorities are (i) to push for the reform of the ‘six month rule’ governing eligibility for the terminal illness fast track process and (ii) to push for indefinite benefit awards for people applying through the fast-track process for the terminally ill claimants.

Raising Awareness during the 40th Anniversary year – As noted in this and the last edition, on Global MND Awareness day, 21 June, around 250 volunteers attended a garden party at Boughton House. An art exhibition between 2 and 6 October in the gallery@oxo on London’s South Bank showcased more than 90 pieces of art by people living with or affected by MND. Curated by the Association ‘Art Beyond Limits’ aimed to drive awareness of MND and all the work on display was available for sale with a percentage of the proceeds being donated to the Association. Among the 14 artists involved were Simon Adams, Sarah Ezekiel, Miles Pilling, Lucy Pittaway, Dr Peter Scott-Morgan, David Shaw and Ron Wheeler. The exhibition space also hosted two research talks from Director of Research Brian Dickie. More than 120 people attended a private viewing which culminated in an auction of donated pieces. Good natured bidding wars boosted the total raised to over £15,000.

KATHERINE WADE WALKING TO D’FEET



A year ago we told you that Katherine, whose mother Libby is one of our AVs, was planning to go on an expedition to Everest Base Camp, raising funds for the MND Association.

Well she has now reached Nepal and you can see Everest in the background of this photo.

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

She 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.

PANNAL VILLAGE HALL QUIZ

This took place on 19th October and our team (comprising Chairman Peter, AV's Margaret and Libby, Libby's husband Robert, committee member Ruth Paynter and her husband Tom did quite well - they were about half way down the field (better than they thought they would do!) We had planned to light up the Village Hall in MNDA colours to celebrate the 40th Anniversary (albeit a couple of weeks late) but unfortunately it all went sadly wrong and the lights just would not work. But at least the quiz and fish and chips went down well as you can see from the following photos. (the last one is Peter saying thank you!)



EQUIPMENT ROADSHOW



Equipment roadshow for people with MND

Tuesday 26 November 2019, 1pm - 3pm*
Canberra Club, Balderstone, Blackburn BB2 7LE

Come to our MND roadshow to talk to experts and see equipment demonstrations.

Stalls include:

- MND Specialist team
- MND Association staff and volunteers
- Respiratory and ventilation team
- Bowel and bladder advice
- Feeding tube advice and support
- Communication aids and technology
- Environmental controls
- Eating and drinking equipment
- Useful small equipment to use at home
- Orthotics (splints, supports and braces)
- Mobility equipment
- REMAP (bespoke equipment)

At 2pm Mark Street from communication aids company Liberator Ltd will talk about funding.



Enquiries: 01604 611821

* You are also welcome 11am-1pm, when the event is open to health and social care professionals. No need to book - just turn up on the day.

Registered Charity No. 294354

Everyone affected by MND is invited to an equipment roadshow which will be held at the Canberra Club, Balderstone, Blackburn on 26 November 2019 from 1 to 3pm.

If you can't make the afternoon session then you are also welcome to the morning session which is aimed at health and social care professionals.

There is no need to book for either session.

Lunch will be available to purchase from 11.45 to 1.45 but please note that unfortunately there are no vegan options

Directions:

Canberra Club, Balderstone, Blackburn BB2 7LE

The Canberra Club is on Samlesbury Aerodrome, at the BAE Systems site off the A59 near the village of Balderstone, northwest of Blackburn. It is signposted from both directions off the A59.



Funding for travel costs may be available, for more information please call MND Connect

FUNDRAISING NEWS

Please continue to support us via the local Lotto – the total raised so far has now reached £191!

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 recently held another coffee morning in Otley in September and it raised £80. However, if beer is more your thing then do go along to the Otley Beer Festival which is on 22nd & 23rd November - for more information have a look at their website <http://www.otleybeerfestival.co.uk/> - we are to be one of the charity recipients.

We have also finally received the cheque for £253 from the Waitrose green token scheme together with some generous in memoriam donations – thank you to those who sent them. Keep watching this space for more news!



DATES FOR YOUR DIARY



On the **first Tuesday** in the month don't forget our monthly get-togethers (From 2pm to 4pm) these are held at "The Barrows" which is in Crimble Hall on Leeds Road just outside Harrogate.

The **Christmas Lunch** will take place on 11 December 2019

(we'll let you know about 2020 lunch dates soon!)

Our **AGM** will take place in Pannal Village Hall on Saturday 21 March 2020

Swing into Spring 2020 will take place on 25 April 2020

And looking ahead

Farnley Hall is a stately home in Farnley near Otley, on the hillside overlooking the Chevin. It has been a family home for hundreds of years. We are most fortunate to have the opportunity for a group to visit the Hall in early summer 2020. We will let you have further details in our next edition of Chatter but we expect the visit to be in early June on Wednesday afternoon and it will last for about two hours. The tour, which unfortunately is not suitable for wheel chairs, is led by experienced guides and takes in all the main reception rooms on the ground floor and ends with a cup of tea or coffee in the Hall kitchen.

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
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
Treasurer, Geoff Catley - 01423 870143 treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com

National Contact Information

www.mndassociation.org

MND Connect – 0808 8026262