

Message from your Chairman



Yes – the photo is still me but, having been told off for using a slightly ‘younger version’, I’ve succumbed to the ‘advice’ and utilised a ‘more recent’ version!

Nothing else has changed, though, since our last edition, except that the committee has welcomed a new volunteer to its ranks who we were lucky to meet at the AGM. So welcome to Ruth Paynter who will be a huge help as an extra presence for our awareness-making. And talking of that, when you read this we will be preparing for an imminent presence at the Ripon Old Cars Gathering at Ripon racecourse. If you have even the slightest interest in classic cars do come along as it really is a very good way to spend an enjoyable day out.

We will be similarly represented at the Nidderdale Show on September 25th which is a new involvement for us and one we are again looking forward to with much interest.

Now which of you has failed to return to us as a member of our 100 Club or forgotten to complete the slip and send it into us? We are well down on last year so urgently seeking more members; remember, the odds are very short on your winning, especially if you have more than one family number, so don’t let us down! We are holding the next two draws back in the hope that more will join having read this appeal and entry forms are included again.

We have been fortunate again to receive a joint legacy with the South and West Yorkshire Branches and, having discussed our good fortune with Brian Dickie, discovered that the project we have been funding at SITraN was still not financially complete, so the committee agreed unanimously to award the shortfall amount in full. We hope that Dr Tennore Ramesh will be able to attend a future meeting to let us know how the project is going/has gone and we will let you know when this occurs.

My thanks as ever to Ruth (secretary as opposed to our new ‘recruit!') for putting this edition together and we would love to have something from our membership sometime to include in Chatter – please do give that a thought!

Peter Thompson

Parliamentary Reception 2017

The annual parliamentary reception is taking place on 17 October 2017 in the QEII Centre, Westminster, London. This is an important event in the Association calendar where branch and group representatives travel to Westminster to meet with MPs and share their personal experiences of MND. Last year, over 100 representatives from almost 50 branches and groups attended - this was an amazing turn out – the Association is hoping to beat that this year!

All branches and groups are invited to nominate three people to attend. You can also take your carer with you (who won’t count as one of the three). If you are interested, please get in touch and we will help you with registration, and can also offer help with any travel costs. Registration has to be completed by 1st October.

Even if you are not attending, you can still help make this event a success by inviting your MP to go to the reception and meet other people affected by MND.

Winners of recent 200 Club draws

Recent winners include: April 2017 – Matthew Hooper
May 2017 – Hannah Lowther

Although you have missed two draws you can still join in if you let us know really quickly.
We won’t be drawing the June and July winners until 20th July!

A Few Snippets from the National Website

Another Illuminating Performance from Eddie Redmayne: On 21st June Eddie Redmayne turned the Coca-Cola London Eye 'blue and orange' to raise awareness of Global MND Awareness Day that occurs every year on 21 June. The Coca-Cola London Eye joined other iconic landmarks lighting up in the colours of the Motor Neurone Disease Association, including the Blackpool Tower, Emirates Spinnaker Tower in Portsmouth, Gateshead Millennium Bridge, Norwich City Hall, Stockport Town Hall, Manchester Town Hall, Royal Border Bridge in Northumberland and the NOMA Earth Tubes in Manchester. Eddie attended the event as a patron of the Association, and as part of our **#MyEyesSay** – MND Awareness Month campaign which is running throughout June. Eddie also appears on a poster for the campaign on the digital screens in Waterloo Station until June 24. Find out more about the campaign by visiting www.mndeyes.org.

What does the Queen's Speech mean for people with MND and their families? With the Government's agenda dominated by Brexit, the speech included a more limited set of measures than we have seen in previous years. From the point of view of people living with MND, their carers and families, the most significant proposal may be the Government's commitment to press on with reform of the social care system. The Government intends to consult on measures to improve the social care system, in order to develop a sustainable funding system and address issues related to the quality of care and variation in practice. This is a welcome and overdue commitment to address a social care funding crisis that must not be ignored any longer. However, previous consultations and commissions on this issue have not led to concrete action. This time, the Government must take decisive steps. The planned timeline for the consultation is not yet available and the Association will monitor the situation closely to ensure that the Government delivers on its commitment and develops a fair, sustainable and sufficient funding system for social care services. In addition, it is essential that social care reform takes into account the needs of disabled people of working age. Caring for the older population is a key function of the social care system, but it is also relied on by thousands of younger adults living with disability, whose needs and concerns must be properly taken into account alongside those of older people.

New Survey: The Association launched a new survey in May which focuses on carers and people living with MND. If you've not yet completed the survey, you can do so online from a link on the news page.

Champion the Charter: In April / May two more councils have adopted the MND Charter bringing the total signed up to 44, the latest "recruits" are Ealing Council and Medway Council.

Mutations in ANXA11 gene takes us closer to understanding ALS: A new research paper was published early in May in the Science Translational Medicine journal, describing a new gene implicated in developing MND. Dr Bradley Smith and his colleagues from King's College London found that mutations in ANXA11 gene are associated with the development of amyotrophic lateral sclerosis (ALS), the most common form of motor neurone disease (MND). The function of the ANXA11 gene is to form small fluid-filled sacks that have the ability to transport cargoes within and between motor neurones. Its mutations cause the associated protein – annexin A11 – to reduce its ability to bind to a protein called **calcyclin**, affecting internal structure of annexin A11. These findings provide a new insight into the mechanism of MND, which will now be further investigated by the lab. If you want to read more about the findings and what they mean, please read our research blog article at <https://mndresearch.wordpress.com/2017/05/04/anxa11-another-gene-closer-to-understanding-als/>

MND Awareness Month: On 1st June a new campaign **#MyEyesSay** was launched as part of this years awareness month. The campaign shares the experiences of Gemma and Dave who are living with the disease, and Vivienne, whose husband Tony died in 2016. Posters featuring Gemma and Dave were displayed across England, Wales and Northern Ireland. Association Patrons Stephen Hawking, Benedict Cumberbatch and Eddie Redmayne were also involved in helping to raise awareness and featured on prominent advertising sites in Victoria, Kings Cross and Waterloo stations in London. There is a website with more information at <https://mndeyes.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/>

MND Costs

People with MND are being forced to fund care themselves and wipe out their savings because:

- ◆ Benefits and entitlements are not enough to cover the costs MND incurs.
- ◆ Accessing financial support is too difficult and overwhelmingly complex to apply for and the system can also be too slow to respond. This is resulting in some people getting support when it's too late, in some cases after the person with MND has died.
- ◆ Not enough people are being made aware of the financial support they are entitled to.
- ◆ Until now the cost of MND and the impact on people affected has been largely hidden, and not fully seen or understood by those with the power to change it.

The National Association is now campaigning to end the financial hardship faced by plwMND and their families. This comes under several headings.

A new report (accessible online at <https://www.mndassociation.org/wp-content/uploads/continuing-to-care-report.pdf>) by Parkinsons UK in association with the Continuing Healthcare Alliance, which the Association is a member of, has found that the CHC system in England is failing people with MND and other conditions. They are subjected to an exhausting, complicated and intimidating process which has led to inadequate care packages, or being denied CHC altogether. In some cases, the process has been so slow, that when CHC funding has finally been granted the person with MND has died, or died mere days later. With the progression of MND, it can be difficult for people to manage their health needs and so they require extra professional care. This care can be provided through CHC – care that is arranged and paid for by the NHS, in the person's own home or sometimes in a nursing home. This free care can make a huge difference to the wellbeing of people with MND and their families. Only 30% of people with MND currently receive continuing healthcare (CHC) and a further 33% are not aware of it or know that they may be entitled to it.

In April this year the Prime Minister announced that the UK would be holding a snap General Election. In response to this the Association ran an election campaign which focussed on benefits and ending reassessments for Employment and Support Allowance (ESA) for people living with motor neurone disease. An incredible 700 supporters took action and 607 candidates pledged their support (this is a link to the list <https://www.mndassociation.org/get-involved/campaigning-influencing/candidate-support-scrap-benefit-reassessments/>), 50 of these are now MPs.

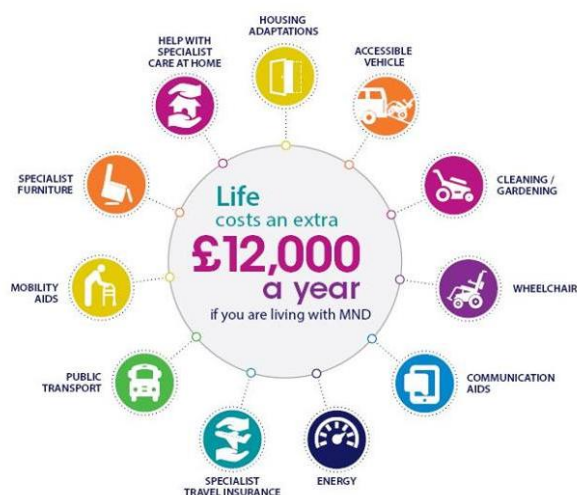
The Association launched the campaign because reassessing people with MND for disability benefits is pointless. The reassessments are unnecessary, cause avoidable stress and anxiety for people with MND, and are a waste of public money. The public campaign on this issue has closed for now. However, the Association will continue to lobby the Government until this policy is implemented.

As well as running a public-facing election campaign, the Association wrote to the three largest UK parties ahead of publishing their manifestos, asking them to commit to ending ESA reassessments. As a member of the Disability Benefits Consortium (DBC) we supported and attended a disability election hustings and promoted the DBC's campaign action (hosted by the MS Society) to sign up to an open letter against further cuts to disability benefits. The open letter was signed by over 16,500 people and received media coverage.

Following the election the Association will continue to campaign on benefits issues and anticipate the following:

- Publication of the All Party Parliamentary Group's inquiry into Personal Independence Payment (PIP) and MND
- Further details of the DWP's policy on exempting people with severe conditions from ESA reassessments
- Ongoing activity following the Green Paper on work, health and disability which we responded to earlier in the year.

We will publish any further information that we become aware of in future editions of Chatter



Life with MND is tough enough without being pushed into financial hardship

Join the campaign www.mndassociation.org/mndcosts

Fundraising

Our friends in York recently organised a wonderful Family Day at Pool Bridge Farm and the partner of our latest BMC Volunteer took part in the sponsored fishing event which was part of this. Hopefully more information – and possibly a photo of Tom – will follow in future editions of Chatter.

On Saturday 29th July, starting at 9.45am, the Morecambe Bay Walk to D'Feet MND will kick off. Places are still open for branch and group volunteers and supporters to join the 8 mile walk across the famous sands from Arnside to Kents Bank. You'll be guided by Cedric Robinson MBE, the Queen's only official guide, who for 54 years has escorted thousands of people across the beautiful day – it's set to be a day to remember! Interested in joining? Email fundraising@mndassociation.org for more information.

Dates for Your Diary

The next **Social Lunch** will take place at The Old Spring Well, Skipton Road, on **26th July 2017**

The next one after that is 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!

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).

It's the Classic Car Event in Ripon again on 30th July. We will have a stand there to raise awareness. Last year we were the fortunate recipients of £6000 from the funds raised. This year they are supporting the Teenage Cancer Trust. It is a great day out and if you go along you might run into the Stig as Chairman Peter and Branch Contact Margaret did last year!



We are also going to have a stall at the Nidderdale Show on 25th September, if you have any spare time and would like to help with (and thus get free entry to) either of these events then do get in touch.

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, 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

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