



MESSAGE FROM YOUR CHAIRMAN

Firstly - greetings from all of us on the committee and volunteers for the New Year of 2018 and we trust your Christmas was able to be enjoyed to the fullest extent.

A new year brings continuing demands for us to progress with our Branch activities, but this issue is to a large extent one of a campaigning nature. We do hope that our readers will take note of the message(s) that follow and by all means do ring one of us if you'd like to discuss further. Our band of volunteers is not getting any younger and some 'fresh blood' to support our endeavours would be most welcome!

Secondly - I owe you an apology for completely mixing up my message in the last edition with reference to the details of the Chief Executive's Appeal! The categories I listed were in fact those of the previous year's appeal and so I must make the necessary correction now. The categories we recently supported, from a list of six, were:

Welfare Benefits Service: Last year the Association piloted a Welfare Benefits service in Greater Manchester and a telephone advice service in the East Midlands. Following a full evaluation it was agreed that the most effective way forward was to establish a telephone service which, whilst dealing with basic claims and provision of information, could also support in dealing with complex benefit cases. That service was contracted to Cardiff and the Vale of Glamorgan Citizen's Advice Bureau for England and Wales, and to Advice Northern Ireland. The services commenced on 24th April this year, and to the end of July 2017 the Association has helped people to claim £293k of new benefits. We need to raise £77k per annum to continue to provide this vital service.

MND Connect: We need to raise £235k each year to continue to provide our Helpline.

Association Visitors (AVs) and other support volunteers: £60k will help us recruit and train future AVs and other care volunteers.

Research into the impact of gut bacteria on microglia: Motor neurones are supported to send messages from our brains to our muscles by a group of cells known as glial cells. In the early stages of MND microglia (a particular type of glia) help protect motor neurones from damage. However, as MND progresses, the role of microglia changes and they become toxic to the motor neurones. Incredibly, researchers have found that the bacteria that live in our gut appear to be able to influence microglia in the brain and wonder whether gut bacteria could be a target for an effective treatment. To fund further studies looking at the specific balance of the types of bacteria in the gut of people with MND, in terms of how this is different to healthy people and how it changes over time, a research grant of £98k is needed from the Association.

I hope you agree with the Branch's decision to support these causes and hopefully we can give you an update at our forthcoming AGM. Please do join us for that if you can (date and place noted elsewhere) and I am delighted to inform you that the Association's Chief Executive, Sally Light, will be joining us and hopes to meet as many as she can from the Branch. So an event not to be missed (especially the tea and cakes!) and advance notice is also given of this year's 'Swing into Spring'.

Peter Thompson

WINNERS OF RECENT 100 CLUB DRAWS

Recent winners include:

September 2017 – Peter Johnson

October 2017 – Simon Benyon

November 2017 – Millie Thomson

We will be drawing the December winner at our Branch Committee meeting on 18th January, winners for January and February at BMC meeting mid March and the final winner for the year at the AGM on 25th March. After that it will start all over again so watch out for forms in a couple of months so you can join in!

TAKE ACTION AND CAMPAIGN!

Introducing Julie Compton (whom everyone calls JC!) who is the campaigns manager for the north of England. Julie supports MND Association campaigners to raise awareness of MND with decision makers, such as councillors and MPs, in order to improve services for people with MND and their families.



Come to Julie for:

- Information about how to get involved in our campaigns both nationally and locally
- A chat about issues with local services (NHS, social care, housing etc.) that you think might be raised or resolved through campaigning
- Advice on meetings with politicians such as MPs or councillors, and other decision makers
- She also supports MNDA campaigns contact volunteers across the north

How to contact Julie

Email: julie.compton@mndassociation.org

Phone: 0115 920 4507 **Mobile:** 07811 280893

Campaign with us to help create positive change to the lives of people living with MND and their carers. The MND Association is committed to campaigning and raising awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by the wider society.

We campaign on national issues that affect people with MND and our campaigns managers make sure that everyone has the opportunity to get involved locally with these campaigns. Additionally, our dedicated campaigns contacts volunteers have a passion for campaigning and want to bring about positive change for people with MND. They take the lead on specific campaigns such as Champion the Charter and MND Costs.



We currently have 34 campaigns contacts across the UK and we are looking for a campaigns contact for the Yorkshire Dales area. You can read more about this on the national webpage

<https://www.mndassociation.org/get-involved/volunteering/raise-awareness-create-change/>

If you would like to have a chat about the campaigns contact role please contact Julie

Join us in campaigning

Volunteers are critical to our campaigning work and there is a role for everyone. You can do as much or as little as you like. Discover how you can help make a difference to people with motor neurone disease by campaigning.

Sign up to the MND Association's Campaign Network for details about our campaigns and how you can get involved. Whether it's signing a petition, writing a letter or speaking to your local politician – you decide how much time and commitment you spend on campaigning. It's free, and you can do as little or as much as you like. You will receive regular updates on our campaign activities and how you can participate. You can sign up easily online at

www.mndassociation.org/get-involved/campaigning-influencing/join-us/campaign-network/

**If you can
help a little,
we can
change a lot.**

themndcharter

Achieving quality of life, dignity and respect for people with MND and their carers



You may be aware of the Champion the Charter campaign. This is a very positive step and we hope this will enable us to work in partnership with the council to both raise awareness of MND and to improve or maintain services. North Yorkshire County Council has been very willing to work with us on issues affecting people with MND despite having declined to adopt the Charter. District councils in North Yorkshire also deal with Disabled Facilities grants and some adaptations, but have not been approached to adopt the MND Charter, as we currently have no campaigners nor a campaigns contact in that area. If you would like to get involved with this campaign please do contact Julie for more information.

CHRISTMAS LUNCH

On 13th December 2017 a group of 23 Branch members and friends gathered at Millstones Restaurant for the annual Christmas Lunch, and as you will see from these pictures a jolly good time was had by all!



“Normal” lunches are planned for 21st February 2018 and 16 May 2018. Everyone is welcome just let Margaret or Libby know you are coming so we can book enough room for everyone.



Life with MND is tough enough without being pushed into financial hardship. We are campaigning to end the financial hardship faced by people with MND and their families.

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.

To find out how you can get involved go to <https://www.mndassociation.org/get-involved/campaigning-influencing/mnd-costs/> or email campaignsmaterials@mndassociation.org if you would like a hard copy of the leaflet.

Campaigning continuedSend for our Campaigns Toolkit

The MND Association Campaigning Toolkit offers guidance for the Association's campaigners and volunteers on running different campaign activities and events. It also includes guidance on arranging meetings with key political decision makers and health organisations. The campaigning toolkit is the brain child of Katy Styles, one of the Association's many dedicated Campaigns Contacts, who volunteers for East Kent group.

The toolkit is fully downloadable and can be found on the national website at <https://www.mndassociation.org/get-involved/campaigning-influencing/join-us/campaigning-toolkit/> but please email campaignsmaterials@mndassociation.org if you would like a hard copy or ring the Connect line and they will help you.

DATES FOR YOUR DIARY

The next **Social Lunches** will take place at The Old Spring Well, Skipton Road, on **21st February and 16th May**. As mentioned earlier just get in touch if you want to come along (Margaret or Libby).

This is an early notification that our **AGM** will be held on Sunday **25th March** in Pannal Village Hall, 2.00pm for 2.30. Official papers will be sent out nearer the time but please put the date in your diary and do come along as there will be (amongst other things) homemade cake to enjoy with a cup of tea or coffee!

We are also in the initial stages of planning another **"Swing into Spring"** music and supper evening (with quizzes!) for **28th April**. Tickets will be on sale in a few weeks, look out for more info on our website.

And of course on the **first Tuesday** in the month are the monthly get-togethers (2pm – 4pm) and we are delighted that these are once again being held at **"The Barrows"** (previously known as Christians) in Crimple Hall on Leeds Road just outside Harrogate. If you have never been then here is a map so you can find it. (or have a look at their website <http://www.crimplehall.co.uk/cafe-bistro/>)



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