



MESSAGE FROM YOUR CHAIRMAN

We enjoyed a very good get-together for our AGM recently for which we were delighted that Sally Light was able to join us. It was unfortunate that some expected attendees had to cry off on the day for various reasons and they really missed a treat in the assortment of cakes and biscuits that were on offer to go with the excellent cup of tea! You will see photos taken of the event later.

The existing committee members were re-elected for the next year but a priority is to find some new members to join our happy band – there must be one or two out there with a little time to spare who could bring some fresh ideas to our activities and the commitment centres on a meeting (day time) about six times per year. Please give it some thought and let me (or Ruth) know and we'd also be happy to have a chat at any time.

It's also 100 Club time again! We have to renew membership every year (the year starting in April) and regrettably the numbers have been dwindling with each successive renewal. It really is a worthwhile project to be involved in as it not only makes a bit for the Branch but also has very short odds on the chances of a win – the more family members involved the shorter the odds and two of your committee's members have been delighted to see the smiles on their grandchildren's faces when presented with a cheque for £25! Application forms were sent out with the AGM papers, but if you need replacements please email or ring Ruth or myself and we will get one to you very promptly.

So we move into another Branch season and as usual the popular Swing into Spring event will be soon upon us. Let us know if you'd like to come (01423 870130) and we can assure you of a very good evening of music, grub and quizzing!

Peter Thompson

WINNERS OF RECENT 100 CLUB DRAWS

Recent winners include:

December 2017 – Barry Foster
January 2018 – Hazel Holdsworth
February 2018 – Richard Pratt
March 2018 – Lottie Shuler

Thank you to those who have already signed up for the 2018 Club, there is still time to join in as we won't be making the first draw, for April, until our next BMC meeting on 17th May.

THE ULTIMATE WALK TO D'FEET

An "old" member of the Branch committee, Liz Burnley, with her partner Simon is planning the ultimate "Walk to d'feet" and they are walking the Pennine Way in June / July this year, to raise money for the MND Association. This will of course involve walking through the Yorkshire Dales "patch".

Many of the days will be quite long but they have a lovely short one on Wednesday 27th June when they will be walking just from Margrave to Malham. If any of Liz's old friends from the Branch fancy a leg stretch with them for part or all of that day, or maybe just fancy meeting up for lunch at the Town End cafe in Airtton, she would be very pleased to see them! If you are interested please let Secretary Ruth know and she will put you in touch with Liz.

VOICE BANKING

One of our Association Visitors, Libby Wade, reports: "I recently went on a workshop for voice banking which is a new innovation for people with MND. Very often people living with MND lose the ability to speak. A process called AAC - augmentative and alternate communication - is an important step forward in communication. With modern technology it is now possible to record your own voice so that when and if you have to use a speech generated communication, it can be your own voice. The process involves recording between 600 and 3500 phrases over a period of time and can take between 6-8 hours to record. It can be done over a long period of time. The phrases are carefully selected to incorporate different sounds. It is a wonderful example of how modern technology can help people living with MND. The Association has recently had sponsorship and we have been able to get two specially trained volunteers for Yorkshire to help with training and setting up the voice banking."

If you would like more information please get in touch with our Regional Care Development Adviser Sal Hastings on 03453 751841 / 07876 575029 or by email sal.hastings@mndassociation.org



VOICE BANKING - TAKE CONTROL

Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so.

This recording is then converted to create a personal synthetic voice. When the person is no longer able to use their own voice, they can use the synthetic voice in speech-generating communication devices to generate an infinite number of words and sentences.

The voice created will be synthetic and not a perfect replica of the person's natural speech, but it will bear some resemblance.



Derek
Living with MND

"Regardless of which system I used, the problem I had was with the dexterity of my hands. I managed it but I am guessing that if someone has less mobility in their hands that it would be an issue.

My advice is as soon as you're diagnosed, bank your voice, even if it's not affected because that's obviously the best time to do it. You will have a clear voice and it's very easy to do."



Michael
Living with MND

"I am very pleased and relieved I banked my voice in case I experience communication difficulties in the future. My wife is delighted I've banked my voice; she didn't want to listen to anyone other than me.

To others thinking of banking their voice, I'd say it's easy to put it off and say 'I don't need it now'. It's an investment you make, but once it's there it will always be there.

WHAT'S REQUIRED?

- A PC or laptop with an appropriate web browser
- A headset microphone that keeps a constant distance from the microphone to the mouth
- A quiet recording environment with no background noise

The same recording environment should be used throughout the voice banking process.

SOME OPTIONS

- CarePro
- my-CWN-voice
- ModelTalker



DO IT EARLY

The clearer your voice is when recording, the better the synthetic voice will be when produced.

SPEAK TO YOUR SLT

They may be able to support you with advice or get help or information from others.

WHY DO IT?

Voice banking helps people with MND maintain identity and feel more comfortable communicating through a device.

CONTACT US
mndconnect@mndassociation.org
0808 802 6262

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BENEFITS AND NOTABLY THE ESA CAMPAIGN

The Association has recently successfully introduced a new Welfare Benefits Advice which has helped 700 people receive over £1m in unclaimed benefits. This has made a significant difference to those families, many of whom had concerns about financial security due a family member being diagnosed with MND.

In her blog on campaigning Sally Light, Chief Executive of the MND Association, notes that campaigning has also taken place for improvements in access to benefits and financial support more widely with active campaigns on Continuing Health Care (CHC) funding, Personal Independence Payment (PIP) and Employment Support Allowance (ESA). In respect of ESA the objective is to stop people living with MND having to go through reassessments in order to receive this benefit. From October 2017 no one with MND claiming Support Group ESA for the first time will have to have a reassessment. Unfortunately the new rules on ESA reassessment were not applied to people already claiming ESA and as things currently stand they will have to have one more paper-based reassessment before they are given exemption.

The Association notes that this situation is unacceptable and causes unnecessary anxiety and stress for those concerned and so we are working with the Department for Work and Pensions (DWP) to find a way to identify those people affected and exempt them from that final reassessment. As part of that work we would like to hear from anyone who is called for reassessment, please contact us on

campaigns@mndassociation.org. If you would like to read Sally's blog in full please follow this link <https://www.mndassociation.org/about-us/our-directors/chief-executive-blog/esa-campaign/>

BRANCH AGM HELD ON 25TH MARCH

Many thanks to all who turned out to support the Branch at our AGM where Sally Light was delighted to present long service awards and also to have the chance to meet various Branch members



Treasurer Geoff Catley receiving his 5 year long service award



BMC Member Paul Bradley receiving his 5 year award



AV Margaret Thompson being given her 20 year long service award



Chairman Peter Thompson being given his 20 year long service award



Chief Executive Sally Light with the Branch Management Committee

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

FISHING COMPETITION COMES BACK IN 2018

Once again Graham Walker is organising this fantastic fundraising event at Pool Bridge York www.poolbridge.co.uk on 7th July. This is a fully accessible site with good disabled access, parking, café, loos etc. There is even a campsite at the venue and anglers are encouraged to make a weekend of it!

Anne Walker Memorial Shield

Would you like to have a go at fishing and be coached by an experienced angler while raising money for charity?

This is a fishing match with a difference. You don't need to know anything about angling to participate and qualified angling instructors will be there to look after you and the fish you catch. All bait and quality tackle will be provided.

Last July this event raised almost £6,000, shared between local branches of MNDA. This year we are looking to beat that figure and what ever you raise will go to the branch of your choice. Participants will be featured on the match website and friends and family will be able to sponsor them online:

www.proangler.org

Saturday 7th July from 10:00am

Venue: Pool Bridge Farm, York (near the Designer Outlet)

The match will be fished from 11:00am to 3:00pm. Free barbecue at 4:00pm

Café, toilets, disabled facilities. Camping and caravanning facilities too.

To find out more, or to book your slot contact Graham Walker on 01904 607496



All proceeds will go to the
Motor Neurone Disease Association
www.mndassociation.org
Registered Charity Number 294354



There are three categories of entry:

The anglers - they have to be sponsored by at least £60 and they won't need any help or explanations excepting that some match rules will be ignored. It's a fundraising event, not a serious match

The novices - £60 again, but they will be borrowing tackle and have a mentor sitting alongside. If they don't fancy touching worms or wriggly fish then that's not a problem. I have to say that the welfare of the fish is paramount so the presence of that mentor will ensure that they won't come to any harm.

The mentors - will be getting sponsorship money but because they will be donating tackle and time (some are professional angling coaches), they are not subject to any minimum sponsorship. We're just glad they want to be involved.

Ideally each angler will raise money for their local MNDA Branch/Group. This can be easily done via Justgiving as long as the angler annotates their page stipulating which Branch should benefit. If anglers aren't interweb savvy then paper sponsor forms can be used and cash paid on the day. People who want to attend and fish should contact Graham direct. Either by phone 01904 607496 or via email: gbw@grahamwalker.org

DATES FOR YOUR DIARY

Everyone is cordially invited to the AGM of the West Yorkshire Branch on **Saturday 21st April 1pm for 2pm** start at All Christ Church, South Ossett, Vicar Lane, WF5 0BE Speaker: Dr Brian Dickie, Director of Research for the MND Association.

Tickets are selling well for "**Swing into Spring**" - our music and supper evening (with quizzes!) on **28th April**. Do get in touch and book yours soon!

After that the next **Social Lunches** will take place at The Old Spring Well, Skipton Road, on **16th May** and **18th July**. Just get in touch if you want to come along (Margaret or Libby).

Don't forget

Walk to D'Feet get together **27th June** and
Fishing competition **July 7th**

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 Crimble Hall on Leeds Road just outside Harrogate.



Registered Charity 294354

**YORKSHIRE
DALES
BRANCH**

**SWING INTO
SPRING**

**SATURDAY 28th April 2018
at 7.30 pm**

PANNAL VILLAGE HALL

featuring

HIGH JAZZ

Including Fish and Chip Supper
(cooked on site) plus Bar & Quiz

Tickets: £12.50

from Crimble Fresh / Pannal Post Office
or Tel 01423 870130