



MESSAGE FROM YOUR CHAIRMAN

It is May day. Last night we Stepped into Spring at Pannal Village Hall with an evening of entertainment from Christine Littlewood and Friends, a challenging quiz courtesy of our secretary Ruth, plus bar and fish and chip supper. It was a great evening with friends and supporters. Photographs to follow in the next edition! Here are my closing remarks, which are developed elsewhere in this edition.

Since our last 'do' here six months ago, a very significant and welcome development for us has been the lifting of the Covid restrictions. It has been hard during the pandemic to make sure no one should have to face living with MND on their own, including carers and families. Now our visitors can actually visit again. Very often people just want to talk, whether it is one to one or at events like coffee mornings.

We have also been supporting through donations to provide home equipment which improves the quality of life for everyone living with MND, often just by making life easier. We are very grateful for a significant number of donations received by the Branch in the last six months from individuals, voluntary organisations and charities.

We have all heard Stephen Hawking and Rob Burrow speaking through the medium of communication devices. A revolutionary ebook, which has been developed to allow people living with MND to bank their own voice as they read a story aloud has been launched and MND will provide funding for the use of the book in the UK.

'I Will Always Be Me' is a short story written from the perspective of someone living with MND as they explain their condition to families and friends in a shared experience. It takes less than half an hour to read. The recording of the reading is uploaded and transformed into a digital voice which can be banked and then used with communication devices when needed.

It is good to end on a positive note as we Step into Spring.

John Pike

WINNERS OF RECENT 100 CLUB DRAWS

At our Branch Meeting held in March we drew the final two winners for the current "Club" and they are. February – Orla Burn / March – Helen Clark



OUT WITH THE OLD AND IN WITH THE NEW

With apologies that we have not sent anything sooner we are delighted to send with this newsletter a form inviting you to join the new club. As we are already a bit behindhand we will make the draws for winners for April, May and June with the July draw at our branch committee meeting in the summer. We hope you will join in as this little fundraising activity gives you the chance to win your money back (plus more) whilst raising funds for our Branch.

As you will see on the accompanying form each number costs just £20 and you can subscribe by sending the form back with a cheque or by emailing Ruth with your "names" and paying by bank transfer.

FUNDRAISING UPDATE

Thanks to numerous people as we continue to receive money which enables us to continue to support people living with MND in our Branch area with equipment and other support.



As we noted in the last edition of Chatter we were astounded in January when £15,000 appeared in our bank account and our Chairman John Pike was delighted on 3rd March to be formally presented with the money by the Mayor of Harrogate Councillor Trevor Chapman.

Twice a year, the borough council's bereavement services raise money through the recycling of metals recovered from cremations with consent from the bereaved

families. The recycled metals include those used in the construction of the coffins and in orthopaedic implants such as hip, knee and replacement joints. Our Branch was the chosen charity for the previous six months.

Councillor Andy Paraskos, Harrogate Borough Council's cabinet member for environment, waste reduction and recycling, said: "I'd like to thank those families who, during a difficult time, have consented to us recycling metals recovered. By raising this money, everyone involved has done their bit to helping local charities such as MND Association.". Our Fundraising Officer from the Association Jenn Dodd who had found out about the scheme from a local contact who encouraged her to apply after being inspired by Rob Burrow's story. The application process was very straightforward and even better – we can apply again in two years time!

We were also delighted to receive a cheque for £500 from the Farnley Young Farmers Association. Jenn Dodd together with Branch Committee Member Veronica Ace attended their meeting where their Chairman James Driffield presented Jenn with the cheque. Jenn and Veronica gave a short presentation to the members of what MND is and how the work of the Association helps support those living with MND and also research - looking as ever for a cure.



We have also continued to receive various generous donations in memorium, and monies from the Local Lotto, if you would like to join in then please have a look at the website and buy some tickets!

<https://www.thelocalotter.co.uk/support/motor-neurone-disease-association>

MONIES FOR YOU!

Did you know there are lots of monies available for you!! More overleaf

MND Support Grant (Care) up to a maximum of £1500 per application. Predominantly equipment or adaptations requiring a professional assessment.

An MND Support Grant (Care) must be accompanied by an assessment from the relevant Health or Social Care Professional. The person receiving the grant will be informed who has provided the funding (Branch or Group/ Support Services /shared).

Examples of funding would be contributions towards: -

- Adaptations to property
- Stairlift rental/purchase
- Washer dryer toilet
- Respite care costs
- Riser recliner armchair

Included in support grant limit of up to £3000 in a rolling 12-month period.

Quality of Life (QOL) Grant up to a maximum of £500 per application. Serves to support both the person with MND and the family.

Does not require a professional assessment and enables the person with MND to purchase equipment, services or facilities which help maintain their independence, dignity, comfort and social connections. Can also be used to contribute to the cost of things which promote the well-being of the person with MND and immediate family.

Examples of funding would be contributions towards: -

- Adaptations to the home not requiring an assessment
- Support with essential garden and home maintenance
- Keeping connected e.g. tablets for accessing social media and video calls
- Hobbies and interests
- Special transport
- Accessible/adapted holiday venues

Included in the support grant limit of up to £3000 in a rolling 12-month period.

Carer's and Young Carer's Grant up to a maximum of £500 per application per rolling 12 months

Supports the main unpaid carer (aged 16+) for someone with MND to allow them to take a break from caring duties and/or promote the well-being of the carer or young carer.

Examples of funding would be contributions towards: -

- Hobbies and interests
- Keeping connected e.g. tablets for accessing social media and video calls
- Short breaks

Outside of £3000 support grant limit and can be applied for up to 12 months post bereavement.

Children and Young Person's Grant up to a maximum of £250 per person per rolling 12 months

Must be 18 or under and residing with a person living with MND or parent/guardian has MND.

Examples of funding would be contributions towards: -

- Driving lessons
- Hobbies and interests
- Keeping connected e.g. tablets for accessing social media and video calls
- Holiday/school trips

Outside of £3000 support grant limit and can be applied for up to 12 months post bereavement.

For more information do have a look at the relevant page of the national website

<https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/> where you can find all the forms and information about one off

Emergency Grants up to £250

MORE MONIES FOR YOU!

There are also the following places where you can get support

Cavendish Spencer Trust – provides help towards holidays for people with neurological or neuromuscular disorders with priority given to adults requiring mechanical respiratory support. For further info see www.cavendishspencertrust.com

Council Tax Reduction (Disability Reduction Scheme) – you may be able to get a reduction if someone in the property is “substantially and permanently disabled” and there is either an additional bathroom or kitchen used by / another room needed by or mainly used by / a space in the property for the use of a wheelchair indoors by a disabled person. Apply to your local council.

Electricity Supply Discount – varies between suppliers. You may be able to get a discount from your supplier if you are on a disability benefit and need to use essential medical equipment.

Water Supply Discount – Suppliers can offer capped water bills if you are on benefits, have a water meter and have a medical condition that means you use a lot of extra water (incontinence / washing sheets etc.)

Prescription Exemption – if you have “a continuing physical disability which means you cannot go out with the help of another person” you may be medically exempt from paying for prescriptions.

VAT relief / Reduced VAT for over 60s – People with a disability do not need to pay VAT on most equipment or adaptations made to equipment for their use. The supplier will ask you to sign a declaration form. Over 60 you can buy mobility aids for your home for a reduced VAT rate of 5%. See www.HMRC.gov.uk

Discounted Computers – visit www.getonlineathome.org for discounted prices from £99 for desktops for people on certain benefits (laptop and tablet computers also available)

INTRODUCING JULIE

Hi, I'm Julie Ferry. I have been a qualified nurse since 1984 and have worked predominantly in hospices across Yorkshire in many roles. Starting off at St Gemmas hospice in Leeds in 1992, where I met my first patient who had MND. I have always been interested in MND and was the link nurse when I was working as Macmillan nurse in Pontefract some years ago. I was CEO at Barnsley hospice until last year when I decided that I wanted to spend the last few years of my working life working directly with patients and what could be better than this role – Clinical nurse specialist working at St Michaels Hospice, Harrogate caring for patients living with MND.

I have two grown up boys, I just recently got married, so spend my weekends following my husband around the local clubs as he is a musician and I spend one day a week looking after my beautiful granddaughter.

I have this job for a year whilst Kate Adams has a career break, and I feel so privileged.

<https://saintmichaelsospice.org/how-we-help/mnd-clinical-nurse-specialist/>

A FEW SNIPPETS FROM THE NATIONAL WEBSITE

I Will Always be Me - This is a first of its kind e-book which banks people's voices as they read the story aloud. Written from the perspective of someone living with MND it explains to their loved ones about the condition and their experience with the disease. The short story, authored by New York Times bestseller, Jill Twiss, takes less than half an hour to read and is designed to be a shared experience for family and friends to be part of. Upon finishing the story, the recording is uploaded and transformed into a digital voice by [SpeakUnique](#) which can then be used with communication devices when needed. The Association will provide funding for people with MND living in England, Wales and Northern Ireland to take part, thanks to donations from [Dell Technologies](#) and [Intel](#). This free service also extends to people living with MND in Scotland, with funding provided by MND Scotland. The book is dedicated to the memory of Brian Moss, who died of MND in 2014. His son Stuart, Head of IT Innovation at Rolls Royce, was compelled to help better the lives of other people affected by MND and so, together with the Association created the NextGen Think Tank in 2019. Companies Dell Technologies and Intel were first to join this effort and other organisations soon followed. Over the past year, these companies came together to develop I Will Always Be Me to provide an alternative voice banking option. You can read more here <https://iwillalwaysbeme.com/>.

Scrap Six Months comes into Force - After years of campaigning, the Association is pleased to see that as of today the long-awaited changes to the Special Rules for Terminal Illness have been applied to Employment and Support Allowance (ESA) and Universal Credit (UC). The Association hopes that more people living with MND will now be able to get fast-tracked access to ESA and UC. This follows a Department for Work and Pensions' (DWP) review, which recommended the 'reasonable expectation of death within 6 months' rule be replaced with a 12-month end of life approach. The rule change is also being accompanied by a new form and guidance for clinicians. However the change still needs to be introduced for the remaining applicable benefits; Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Attendance Allowance (AA). The Association hopes this will happen as soon as possible as in the meantime this creates a situation where there are two different processes in place depending on which benefit is being applied for. In Northern Ireland, the changes are being implemented across all applicable benefits from today, 4th April.

Launch of a New Marathon - A new marathon to honour rugby league legend Rob Burrow MBE will launch next year, with the MND Association named as a charity partner. The Rob Burrow Leeds Marathon will take place on Sunday 14 May 2023 and will start and finish at the iconic Headingley Stadium, where Association patron Rob accomplished some of his greatest sporting achievements. A Family Fun Run will also take place on the same day. There will be 7,777 marathon places available, in honour of Rob's iconic shirt number at Leeds Rhinos. The event, organised by [Run For All](#), has been inspired by the epic challenges undertaken by Rob's former captain and friend, Kevin Sinfield OBE. Runners taking part will be encouraged to [#RunForRob](#) and raise money towards the fight against MND, with the MND Association and the Leeds Hospital Charity named as official charity partners. Rob Burrow MBE said: "It is wonderful to see the marathon return to the streets of Leeds and I know it will be a fantastic occasion. Any opportunity to raise awareness and funds to fight MND is wonderful and I know that so much money will be raised by those taking part for so many great causes that are personal to each runner. I am particularly pleased to see that the event combines the half marathon and a family fun run so that everyone, of all abilities, can get involved. Good luck to everyone who signs up and thank you for your support." Sally Light, Chief Executive of the MND Association said: "Like everyone who has followed Rob Burrow's journey with MND we are in awe of everything he's achieved. Being announced as a charity partner of the Rob Burrow Leeds Marathon is a huge honour and will help us maintain that important momentum towards effective treatments and ultimately a cure for MND. We want to thank everybody who will be lacing up their running shoes to take on this brilliant challenge in Rob's name."

JENN GETS MARRIED

Our Fundraising Officer Jenn got married in Ripon Cathedral in March and here she is looking absolutely stunning!



ROB BURROW GETS MBE

Patron of the MND Association and former rugby league player Rob Burrow was awarded his MBE at Windsor Castle on Tuesday 5 April. Fittingly, the Association's Royal Patron, HRH The Princess Royal presented Rob with the award. On the day, Rob was accompanied by his wife Lindsey and his parents. Rob was recognised in the Queen's New Year Honours list in 2021 for 'services to rugby and motor neurone disease (MND) awareness during Covid-19'. Commenting on this achievement, Rob shared: "I'm shocked to be accepting the MBE award. I'm so proud to receive this because of my rugby and the awareness for MND. This most importantly means that MND continues to be talked about and it remains in the public eye. I'm blown away by the response my diagnosis has had and I hope that the MND community know that it is all for them."



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 .

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

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QUICK NOTE FROM THE EDITOR

Just a reminder that we now produce three editions per year, the next one will be issued round about late September / October. If you have anything to share please do let me know.