

Cheshire Branch

Newsletter

ROUND UP

Welcome to our Spring issue, which includes a mix of news, information and even poetry!

To begin with, however, we thought you might enjoy some joyful spring pictures to brighten your day. After the last 12 months, we all need to look forward to some sunshine, don't you think?

And please do get in-touch if there is anything you would like us to include in the next issue.

Best wishes from, The Committee



POETRY CORNER

We are delighted to feature the following poem by Joan Nicholles.

Always keen to keep busy, Joan wrote this poem to inspire other plwMND and her family were so impressed that they encouraged her to share it with us.

Thank you, Joan, we are very pleased you did!



Two years (This is me!)

What is this life if full of woe
I've lost my ability to get up and go
I sit in my chair and watch and stare
As the people pass by without a care

I go out on my scooter that's bright and gleaming
And wave to the folks to share a greeting
We go down to the Rec and along the canal
When the weather is bright to boost my moral

The Middlewood Way is long and straight
But that suit me fine as there isn't a gate
We take a coffee and find a bench
Then sit and talk over the day's events

White Nancy stands high on Kerridge Hill
And I think back to the days when I climbed for the thrill
But then I think of what have I got now
My family, my friends and a man called Al

I'm feeling strong as I look out at the view
And look to the future like all of you
This MND I have is cruel
But I will fight and it will not rule

By: Joan Nicholles



FUNDRAISING NEWS

Chester city walls marathon

Fantastic fundraiser, Coyle Roberts, is embarking on another amazing challenge to raise vital funds for MNDA.



Coyle (c) with his daughters, Sam and Mel

Coyle and his 'Team MND' are planning to run a marathon around the beautiful and historic city walls of Chester.

Together with his two daughters (Sam and Mel), two son-in-laws (Jon and Paul) and some great friends, Coyle aims to raise awareness and funds for more scientific research into MND - a cause very close to their hearts.

"I don't think there is a better way to raise awareness for MND than to run a marathon within our stunning city, which has some amazing landmarks. The undulations of the wall, as well as the six set of steps and bridges are something not to be taken lightly," said Coyle

This is not the first time Coyle has set himself an ambitious fundraising goal. Two years ago, he cut hair for 24 hours in his City Road gents shop and - together with his team MND - raised an incredible grand total of £7,600.

"If this event is half as successful as the first one, no doubt we will be elated," added Coyle.

We wish Coyle and everyone involved the best of luck with the marathon run; a huge physical, mental and emotional challenge.

You can read their story and show your support by visiting <http://www.justgiving.com/fundraising/coyleroberts>



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FUNDRAISING APPEAL

Please help us fund a riser/recliner chair and support more plwMND



This month marks the launch of our new fundraising drive to raise the £1,200 needed to purchase a new riser/recliner chair.



To explain why these specialist chairs are so important, Jim Billingham kindly agreed to tell us his story.

“Like many in later years, I started to struggle getting up from an armchair, but factoring in my motor neurone disease it seemed wise to consider (sooner rather than later) how equipment might help.

“Our professional teams encourage us to pre-empt the need for equipment to make life as easy as possible. How wonderful then, that the MNDA - among other comprehensive support - should donate a very comfortable riser/recliner chair for me. Following just a casual enquiry from my AV (Joel Millett), the MNDA did not hesitate to arrange for a company to visit and measure me for a bespoke riser/recliner chair, perfectly accommodating my physical build and measurements.

“We are all shapes and sizes and, had I been extremely tall, the ‘chassis’ would have been built accordingly and

even supplied with additional motors to support its extended length. As it was, I needed a slightly slimmer chair than standard and the MNDA kindly arranged for a rental chair to fill the gap while this was manufactured. This has now been delivered and allows me to take a restorative daytime nap, read fully supported, or just simply relax and watch TV.

“So, I would like to say a huge thank you for this comfortable addition to our sitting room. Being able to choose the upholstery was a bonus - something which adds an extra personal touch. It is, like much that the MNDA contributes, very much appreciated.”

Please consider making a donation to support this important appeal - and asking your friends and family to get involved too. Together, we can make a difference.

You can donate via the dedicated JustGiving page, which has been set up by our branch fundraising co-ordinator, Nicola: <https://www.justgiving.com/fundraising/Nicola-Gough10>



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RESEARCH NEWS

by Richard Webb

research

On 1 February, the Cheshire Branch held an online social meeting for members and invited Dr Brian Dickie, director of research development at the MNDA, to speak about the latest developments. Some points of general interest were raised and are reported below.

Dr Dickie talked of progress on research. He explained that there are a number of factors that can affect people's susceptibility to MND such as genes and environment (which could be positive or negative) and age (more likely with age). The problem is in finding which effects were negative and which acted together, so that research can then focus on the way to beat these. International research is being driven by the discovery of genes affecting plwMND, with more being found all the time.

One project highlighted by Dr Dickie was Project MinE. This research initiative started as a collaboration between Holland, Belgium and the UK, but now covers around 21 countries all over the world. The DNA code of 15,000 plw MND and 7,500 who are not is being read and stored. Most of the work to date has been on protein coding genes which make up about 2% DNA.

More recently - and much closer to home - is the new research project due to begin shortly at the University of Liverpool. Led by Dr John Quinn - and part funded by the Cheshire branch - this initiative will look into retrotransposon genes, also referred to as jumping genes. These have been introduced into our DNA over many millennia, probably by viruses, and could have a long-term effect on DNA protein coding. Dr Quinn is working in conjunction with Kings College London, Sheffield, Utrecht and Murdoch (Perth WA) Universities.

In terms of treatment, the MNDA is hoping to secure £3 million in Government funding to trial a new drug which has shown some promise in Australia.

Interestingly, in a separate Local Delivery Team meeting - also held in February - Sally Light, chief executive of the MNDA, reported that the MNDA is currently funding more research than the Government. Both the MNDA and MND Scotland have put forward a strong case to the Government to put more money into research.

If you would like more information about content covered in either of these two recent meetings, please do get in-touch with our vice chair, Richard Webb on t: 07476 961260 or email richard.a.webb@outlook.com.



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SOCIAL MEDIA PLATFORMS

by Richard Webb

The MNDA held a webinar on social media on 11 February and invited Dean Donaldson of the West Sussex South branch to share his web expertise.

Following the meeting, three members of our committee - Becky, Nicky and I - discussed how we would use his insights to improve the social media presence of the branch and encourage greater participation.



One of the most important outcomes was to ensure we put all our events on the Facebook calendar, as well as our website and newsletter. This not only means featuring social and support meetings, but also highlighting fundraising events before they actually take place. In this way, we hope to boost awareness and funds raised.

So please do let us know as soon as you have organised a fundraising event and we will promote it through all our social media channels.

Other tips include adding hashtags to everything, considering Instagram to reach a younger audience and putting a video onto JustGiving which may have a greater impact than a photo. Certainly food for thought!

In the meantime, please do follow, share and hashtag our social media platforms:



<https://www.facebook.com/MNDaCheshire/>



@MNDa_Cheshire

GET IN TOUCH

As always, please do contact the committee if you have any news or events you would like to see featured in the newsletter and promoted through our social media channels.

Don't forget, this newsletter is also available by email by contacting emmaedwards500@btinternet.com or on our website at www.mndcheshire.org.



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FINANCIAL STUFF

Summarised Accounts as at 31 December 2020			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	2125	Financial Support	37,635
Restricted Donation	71,576	National Office	16,531
In Memoriam Donations	2,416	Info & Education	349
Corporate Donations	0	Admin Cost	1,062
Fund Raising	5,176	Publicity and Fundraising	69
Resale of Goods	1,328	Purchase of goods for resale	174
Sundry – Just Giving	0	CEO Appeal & MMU Research	0
Bank Interest	334	Total Expenditure	55,820
Gift Aid	1,498	Surplus for the year to date	28,633
Total Income	84,453	Total	84,453

Notable donations and fundraising events to 31 December 2020:

- Carol Mason
- Dianne Kinder

In Memory

- Michael Lowe
- L Silvester
- Keith Birkett

VIRTUAL DIARY DATES

12 April @ 2.30pm

Support meeting

Via Zoom: Contact Dianne Kinder for details

10 May @ 2.30pm

Support meeting

Via Zoom: Contact Dianne Kinder for details

7 June @ 2.30pm

Support meeting

Via Zoom: Contact Dianne Kinder for details



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Useful Contacts

MND Connect offers support, information and advice to people living with MND, health and social care professionals, staff and volunteers.

mndconnect
0808 8026262
mndconnect@mndassociation.org

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This newsletter was published by the Cheshire branch of the MND Association. If you no longer wish to receive information from us, please contact emma@mndcheshire.org or a member of the committee listed.

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