

Cheshire Branch

Newsletter

ROUND UP

Welcome to our Autumn issue. In this edition, we are pleased to report the welcome return of our in-person support meetings and what to expect if you are thinking about joining us next month. There's also a gentle reminder that there is still time to get involved with a big fundraising walk at the end of September, as well as an article from Liz Ellis, newly appointed Trustee of the MNDa and one of our very own Cheshire members.

We are also delighted to feature newly-weds Mr and Mrs Burdett, who were finally able to celebrate their special day after lockdown restrictions were eased in July.

As always, please do get in-touch if there is anything you would like us to include in the next issue. We would love to hear from you.

Best wishes from, The Committee



Ian and Michelle on their wedding day



Offa's Dyke Walk - 26 September 2021

FUNDRAISING

Get involved!

As reported in our last issue, MND Cheshire is one of 12 branches taking on a section of the historic Offa's Dyke walk in a major fundraising event in September - and we need your help to make it a success.

If you are interested in taking part and/or would like any more information about the details of the walk - please do get in-touch with MND Cheshire branch:

- Nicky Gough (07895 540770 / nicolagough@virginmedia.com)
- Richard Webb (07476 961260 / richard.a.webb@outlook.com)

Or you can donate via JustGiving at: <https://www.justgiving.com/team/Offas-Dyke-Walk4MND>

A promotional poster for the Offa's Dyke Walk. The top half features a landscape photo of a path through a field under a blue sky. The MND logo is in the top left, and the RightMarket logo is in the top right. The date '26th September 2021' and the event title 'Offa's Dyke Walk' are prominently displayed in the center. The bottom half has an orange background with white text describing the walk and providing contact information. A Fundraising Regulator logo is in the bottom right corner.

mnda
motor neurone disease
association
cymdeithas
clefyd motor niwron

rightmarket

26th September 2021
Offa's Dyke Walk

Join our walk along this iconic path through some of the UK's most beautiful countryside. Walk as much or as little as you want & be a part of our event supporting people affected by MND. More details from your MND Branch.

Registered charity no. 294354
Created in RightMarket 16/4/2021 - 11:20:10

FR Registered with FUNDRAISING REGULATOR



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.

Wonderful wedding day

Ian and Michelle celebrated their special day with family and friends at the United Reform Church in Upton. Here, Michelle kindly shares their story.



Ian and Michelle with daughters, Sophie and Jessica

We always hoped to get married sooner but with work and two children - Sophie and my older daughter Jessica - we never seemed to have time.

Then in March 2018, Ian's speech became concerning. He was struggling to talk, his speech became slurred and he couldn't teach. After a lengthy series of tests and a referral to Dr Larner at The Walton Centre, Ian was given the devastating news that he had MND.

Soon after, we set about making plans to get married but then Covid hit and - like everyone else - our plans were put on hold. Then FINALLY, after just two and a half weeks of planning, on the 17 July 2021 Ian and I had the best wedding ever.

We were married in church and then went on to the Royal British Legion in Upton for lots of drinking and laughs - even the weather gave us a helping hand as it was glorious.

Even though we were only allowed 30 guests, we had the most amazing and memorable day with our wonderful family and friends. For us, it is a day that will forever be in our hearts.

We will never give up trying to find a cure for this cruel disease. We will continue to raise as much money and awareness as we can to keep fighting MND. And would like to thank all at the MND for helping Ian receive the essential equipment he needs to keep him safe and at home with us.

Ian and I met in July 2007 when he was in Chester recruiting for the army - he was a Gunner in 3RHA.

Although he had to go back to his base in Germany the following year, we managed to keep our relationship going and in 2008 when he was home on leave, Ian proposed to me in a beautiful Italian restaurant in Chester.

Ian eventually left the army and became a lifeguard and swimming teacher, helping many children to learn to swim, including our daughter Sophie.



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Welcome back!

By Joel Millett

We received a warm welcome from the staff at The Wilmslow Garden Centre when we returned for our September support meeting.



Coffee, cake and lively chat are all part of our regular support meetings

Our branch contact Dianne, said: *"It is always a pleasure to hold our support meetings here. The staff are so friendly and helpful and there is always a great selection of tea and cakes."*

There was a lot of catching up to do and a great deal of laughter. *"It's so lovely to be back and with everyone again,"* said Viv.

Gareth, who was attending his first support meeting, commented; *"It wasn't so daunting as I had already seen a few faces on the zoom support meetings. I have learnt so much from this afternoon, especially from Eric and Colin, and I'm already looking forward to next month's meeting."*

Also on hand were Association Visitors, Mike, Ros and Joel. Ros said: *"I always look forward to the monthly support meetings. They are so positive and uplifting and everyone always leaves on a high."*

Our patron, Lord Ashbrook, has mentioned the possibility of a visit to Arley Hall and a private tour of the famous gardens (wheelchair accessible). This may be in October but if not, then our next support meeting is pencilled in to take place at Abbeywood Estate on Monday 4 October.

Please check our website - www.mndcheshire.org - or contact Dianne for updates on upcoming support meeting dates and venues. And in the meantime, the next dates can be found on page 7.



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Newly appointed MNDa Trustee

Liz Ellis shares her story and reasons for becoming a Trustee of the MNDa.



I am honoured and privileged to have been elected as a Trustee of the MNDa and would like to thank everyone who voted for me.

My first experience of MND came in 1998 when my uncle was diagnosed. He was in his early seventies and I naively thought that the illness was age related. I know now, of course, that this is not the case.

We were all in shock when my son was diagnosed with the illness in 2018. He was 46 years old at the time. And I know that everyone reading this will, unfortunately, have some knowledge of the devastation caused by MND. In my son's case, his MND progressed rapidly and within less than a year he needed a tracheostomy to survive. This was his decision and, while not for everyone, I do believe that there must be an informed choice of all available options.

Prior to finally getting agreement for my son to have this procedure, we also experienced first-hand the difficulties of accessing essential healthcare equipment in a timely manner, despite being fortunate to have the help and support of many healthcare professionals. The local MND branch also provided us with support which was very much appreciated.

I know that the emotional and physical impact on families of people diagnosed with MND is unimaginable. To have to encounter complicated applications for resources at such a time is unacceptable and the processes need to change - and I want to help change them.

Awareness of the needs of people affected by MND is often poorly understood. It is not Complex Care as defined in the criteria for funding and accessing support. It is so much more. Training a healthcare assistant to support someone with invasive ventilation is a very lengthy process and outside most carers' experience, but it can be done.

All of these issues are the reasons why I wanted to become a Trustee. Awareness, research and potential cures are moving forward faster than ever before, and I am committed to supporting and helping in any way possible - both on a local level and as a Trustee.

My son now lives at home and has two carers, 24/7. He has, in the main, overcome the devastation of his illness and accepted his quality of life is different now. He is beginning to thrive and have fun. He makes the best use of technology; using a computer connected to his grid pad to hold conversations, email, text, telephone, use the internet, read, research. He can choose, either alone or with family and friends, to listen to music, watch documentaries and films, all of which he can control independently with the use of his computer and Alexa. I recall the delight and surprise when he first sent me a text. We plan to start having trips out once all the restrictions are lifted too.

My ambition is to contribute and support to the best of my ability.



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And finally...

Campaigning volunteers

Would you like to help us campaign on behalf of people affected by MND? We are looking for more members to become engaged with our campaigning work and help deliver important messages to decision makers on a local and regional level.

If you would like to work with us to help raise awareness and influence change, please get in-touch with our campaigns contact, Richard Webb, on t: 07476 961260 or email richard.a.webb@outlook.com.



MND Association podcast



Launched earlier this year, MND Matters is a new podcast from the MND Association. It covers a range of subjects and aims to provide a platform for people affected by MND to share their stories.

From Keven Sinfield talking about his friendship with Rob Burrow, to a personal experience of voice banking and insights into the latest clinical research - there is a growing list of topics to choose from.

You can view and listen to any of the episodes by using the links on the MND Association website here: <https://www.mndassociation.org/media/mnd-matters/>

Or search MND Matters in your chosen podcast provider.

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 July 2021			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	240	Financial Support	9,549
Restricted Donation	3,490	National Office	0
In Memoriam Donations	2,850	Info & Education	226
Corporate Donations	250	Admin Cost	532
Fund Raising	11,094	Publicity and Fundraising	0
Resale of Goods	331	Purchase of goods for resale	0
Sundry – Just Giving	781	CEO Appeal & MMU Research	0
Bank Interest	25	Total Expenditure	10,307
Gift Aid	205	Surplus for the year to date	8,969
Total Income	19,276	Total	19,276

Notable donations and fundraising events to 31 July 2021:

- Lord Ashbrook
- Margaret Chapman
- Rebecca Jackson
- Coyle Roberts
- Frodsham & Helsby Inner Wheel

Don't forget, all donations can be made via our dedicated JustGiving page: www.JustGiving.com/fundraising/mndacheshire

DIARY DATES

4 October @ 2.30pm Support meeting

TBC*: Contact Dianne Kinder for details

1 November @ 2.30pm Support meeting

TBC*: Contact Dianne Kinder for details

* Venue to be confirmed, according to current government guidelines.



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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

Branch Contacts

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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 emmaedwards500@btinternet.com or a member of the committee listed.

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