

Cheshire Branch

Newsletter

ROUND UP

Welcome to our Summer issue which we hope heralds the beginning of plenty of sunshine and warm weather.

Inside you'll find news about some of the brilliant events that have taken place over the last few months (p2-4). We love sharing your stories, so keep them coming!

As our branch chair, Mike Coleman said:

"All funds raised helps us support local people who are facing this disease. We simply couldn't be there for those who need us without the generosity and support of everyone who arranges these events - and the friends and family who support them."

We also have exciting news about one of our very own committee members.

Rebecca Jackson is taking on her own fundraising challenge. She is one of a team of four planning to scale the heights of Kilimanjaro in September later this year. Read her story on page 5 and join us in wishing them all the best for this once-in-a-lifetime trip.

As always, please do get in-touch if you would like to see your news featured in the next issue.

Enjoy the summer!



Here comes summer!

Photo by Claire Smith on Unsplash.



Pictured: Rebecca in training for the trek

FUNDRAISING NEWS

Marathon effort for Cheshire branch

by Sarah Walker



Pictured: Emma during the challenging run.

Supporter Emma Hearse went the distance by completing the London marathon and raising an incredible £1,700.

It was the first marathon Emma had taken part in and she completed the 26.2 mile feat in a brilliant 4 hours 37 minutes. The 45-year-old wanted to do something to show her support for the Cheshire branch after her mum, Lorraine, was diagnosed with MND a year ago.

Emma, who lives in the capital with her two children Oliver and Abbie said: *"I am seeing first-hand how devastating and heart-breaking the disease is. Mum is being supported by the MND Association Cheshire branch, so I wanted to raise money for them to help fund their work."*

Emma added: *"The crowds were fantastic. I live in Greenwich where the marathon starts, and I ran past my daughter's school on route, so had lots of friends cheering me on."*

Coffee morning raises more than £500

by Sarah Walker

Naz Farid was inspired to organise the fundraising event after receiving support from the charity during her late husband Mo Youssefi's three year battle with the disease.

Naz was delighted to have collected such a fantastic total; *"Everyone was so generous and supportive. It was a brilliant morning and I'm so grateful to everyone who helped to make it such a success."*

The event included coffee, cakes and a raffle featuring a host of top prizes - including a personal training sessions and sports massages, generously donated by gymtec in Congleton where Naz works as a receptionist and the venue for the fundraiser.



Pictured: Naz (r) with Joel Millett from the MND Cheshire branch.



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Charity 80s night honours memory of much-loved granddad by Sarah Walker

Three granddaughters organised an 80s-themed charity night in memory of their granddad, Tom Bourne, who lived with motor neurone disease for 15 years - and raised an amazing £1,611.



Pictured: Steph Marvell (third from left) with guests at the party night.

Steph Marvell, along with sister Sophie Marvell and cousin Jessica Youle, organised the event at Crewe Alex football club in aid of the Cheshire branch of the MND Association and St Luke's Hospice.

It followed a similar night four years earlier for the same charities. It was such a success they decided the time was right to organise another, and were once again delighted with the support they received.

Around 140 people attended on the night, with funds raised through ticket sales and a raffle featuring a host of top prizes, including a bungee jump donated by Buy a Gift, a smartphone donated by Phoenix Cellular and a photo shoot with the Crewe Alex photographer.

A signed Frank Lampard football was also auctioned on eBay raising a further £203.

Guests got behind the eighties theme with fancy dress outfits featuring the likes of Zippy from Rainbow, Sloth from the Goonies and Del Boy from Only Fools and Horses.

Steph, who went as She-Ra, said: *"The night went really well, as soon as the raffle was over the dance floor was full for the rest of the night."*

"MND Cheshire Branch supported our granddad throughout the 15 years he fought MND, so we wanted to give something back to the charity that supported him and the family."

"We'd like to say a big thank you to everyone who contributed towards the night and helped to make it such a success."



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Race nights boost funds for Cheshire branch

by Sarah Walker



Two charity race nights raised funds for the Cheshire branch whilst giving supporters a great night out!

Ann Scales organised the first event in February at Lymm Golf Club, with help from her son and daughter-in-law. She wanted to do something to help because of the support her sister Margaret Chapman receives from the Cheshire branch.

The event raised more than £3,300 - a brilliant total which was split between the MNDA and two other charities.

Ann said: *"We were pleased to raise funds for the Cheshire branch to help those in our area who need the support."*

"It was our way of saying thank you for the work the MND Association does."

Meanwhile, a fantastic £3,700 was raised at a second race night held at Smallwood Village Hall in April, organised by Andy Westrup and his fiancée Nicola Shallcross. They were inspired by friend Michael Lowe, who is living with MND.

The sell-out night welcomed around 100 friends and family and included a pie and pea supper as well as the racing. Cheshire branch association visitor, Joel Millett, also said a few words about MND and why the support of those attending was so important.

Michael said: *"Not only was I incredibly grateful for all the hard work Andy and Nic put in to make the night a success, but I was incredibly touched to see the village hall at capacity with so many people that cared about my well-being and the fight against MND."*

"I must also thank the dozen or so that spent their evening cooking the food, comparing the races, selling the raffle tickets and running the tote."



Pictured: The packed race night at Smallwood Village Hall.



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COMMITTEE NEWS

Taking on the Kilimanjaro trek

by Sarah Walker

Our very own Rebecca Jackson is taking on the epic challenge of climbing Mount Kilimanjaro to raise funds for the branch - and we couldn't be more proud.

Rebecca, along with husband Dave, her brother Stephen Fox and his girlfriend Evie Gaynor, will travel to Africa in September to complete the trek up the highest mountain in the world, hoping to reach the summit at more than 19,000 feet.



Pictured: Rebecca (second from right) with the rest of the team in training for the trek

situations to themselves understood what they were going through," she said.

Rebecca, aged 30 and an operations manager at Cullen Wealth independent financial advisors, said: "Volunteering, and now this challenge, is my way of trying to give something back."

She said training - including gym work-outs, swimming and a weekend hikes of up to 18 miles - was going well, but there were other challenges they would have to overcome in order to succeed such as altitude sickness and mental fitness.

"We are all excited about the challenge and desperate to reach the summit. I believe the landscape is incredible, so we are all looking forward to the trek itself and hoping to raise a good amount of money to support the Cheshire branch's great work in the process."

If you would like to sponsor Rebecca and her team in their fantastic feat, visit <https://www.justgiving.com/fundraising/team4fox>.

They will be covering the cost of the trip themselves, and aiming to raise £1,000 in sponsorship for the MND Association in memory of Rebecca's step-dad and Stephen's dad Mike Fox, who was diagnosed in May 2016.

Rebecca, who began volunteering with the branch just before Mike's death in November 2017, said the support her mum and their family had received from the MNDA had really helped them through the ordeal.

"The MNDA Cheshire branch provided my Mum and Mike with the most amazing support. I think it was a comfort to see that they were not alone and others in similar



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AGM surprise

Last month, we held our branch Annual General Meeting at Abbeywood in Delamere.

As well as covering the usual formalities and an overview of activity during another busy year, we surprised our outgoing chair, Joel Millett, with an award presentation.

Our Cheshire branch patron, Lord Ashbrook, presented Joel with a certificate of thanks - along with some much-appreciated bottles of wine!

Thank you once again Joel!



Pictured: Joel (r) receiving his award from Lord Ashbrook.

CAMPAIGN NEWS

SCRAP 6 MONTHS

Petition closing

The [Scrap 6 Months petition](#) will close on 30 June. A small group of people representing the MND Association and Marie Curie will hand the petition in to 10 Downing Street on 3 July on behalf of all those who signed.

We would like to say a huge thank you to everyone who has signed so far. The Association as a whole has gathered over 13,000 signatures on the petition - the aim is to reach 17,000 in total. So if you can help to get us closer to that total, please act now!

Following the petition delivery, the Association will jointly host an event in Parliament with Marie Curie and the All-Party Parliamentary Group on Terminal Illness, for MPs to meet with people with MND, their carers and Association volunteers.

Since the Association launched the campaign, the Department for Work and Pensions (DWP) has published new guidance for clinicians supporting welfare benefits claims through the Special Rules for Terminal Illness (SRTI) fast track process. The Association contributed to the guidance review and it contains some important improvements, but the 6 months rule still applies, as this requirement remains in legislation.

We will continue to campaign to scrap 6 months and change this law across the UK, as Scotland did in 2018. The Scottish guidance on SRTI is due out soon and new powers are expected to come into effect from 2020.



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FINANCIAL STUFF

Summarised Accounts as at 30 April 2019			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	595	Financial Support	4,044
Restricted Donation	3,540	National Office	0
In Memoriam Donations	1,147	Info & Education	160
Corporate Donations	0	Admin Cost	1,244
Fund Raising	6,608	Publicity and Fundraising	370
Resale of Goods	1927	Purchase of goods for resale	
Sundry – Just Giving	0	CEO Appeal & MMU Research	0
Bank Interest	171	Total Expenditure	5,818
Gift Aid	0	Surplus for the year to date	8,170
Total Income	13,988	Total	13,988

Notable donations and fundraising events to April 2019:

- Liz Whalley, Newgate Kennels

In Memory:

- Joan Simpson (with permission of Hazel Francis)

DIARY DATES

22 June 10am-4pm	North regional conference	Radisson Blu Hotel, Manchester airport
1 July @ 2.30pm	Support meeting	Stamford Bridge Country Inn, CH3 8EL
5 August @ 2.30pm	Support meeting	Wilmslow Garden Centre, SK9 2JN
2 September @ 2.30pm	Support meeting	Abbeywood Garden Centre, CW8 2HW

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 emma@mndcheshire.org or on our website at www.mndcheshire.org.



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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

Paula Sutton is the Association's **Regional Care Development Adviser** and has detailed knowledge of the care and management of MND. She can be contacted on **07872 161024** or paula.sutton@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.

Printed by The NeuroMuscular Centre, Woodford Lane West, Winsford, CW7 4EH Tel: 01606 863464 www.nmcentre.com



This newsletter is funded by Hal Bailey In Memorium.

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