

Cheshire Branch

Newsletter

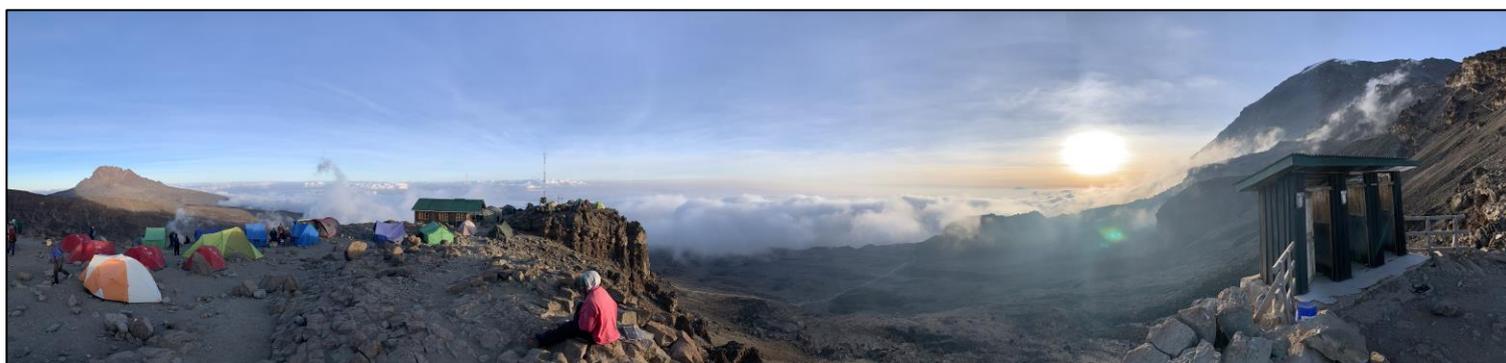
ROUND UP

Welcome to our Spring issue.

Spring may not have exactly “sprung” yet, but we are determined to bring you some warmth and sunshine. And where better to find it than in Africa, where our very own Becca completed an amazing week long trek to the summit of Kilimanjaro and raised an incredible amount of money for the MND Cheshire branch in the process.

Read her story on page 2 and enjoy the panoramic view from base camp below.

Inside, you'll also find the latest campaign news, fundraising ideas and research updates, as well as all the usual dates for your diary and useful contacts.



As always, please do get in-touch if you would like to see your news featured in the next issue and let us know about any fundraising events.

And if you have any ideas or suggestions for information you would like to see included in the newsletter - or how we can improve it - we would love to hear from you.

Best wishes, the Committee



FUNDRAISING NEWS

Top of the world!

by Becca Jackson



Becca and team at the park gate, with their guide.

Rebecca, along with husband Dave, her brother Stephen Fox and his girlfriend Evie Gaynor raised an incredible £3,767 in their epic mountain trek to the summit of Kilimanjaro.

Climbing Kilimanjaro was an amazing experience. It was both a physical and mental challenge, but I would highly recommend it to anyone who is vaguely considering it. Even when we were cold, tired or low on energy, the cause and the money we had raised always pulled us through. And some of the landscapes were breathtaking.

Of course, we were very sensible in our approach and literally did everything our guides told us; if they said eat - we ate, if they said sleep - we slept, and we made sure we drank at least 4 litres of water each day. The team of guides and porters who climbed with us were the most wonderful people and always had an encouraging smile, even on the tough days.

The trek took 7 days in total, 5.5 days up and 1.5 down - you make a much more direct route down! The first 4 days were all about acclimatisation, slowly making our way towards base camp at 4,600m. We set off for base camp on day 5, where we rested, before setting off for the summit at 11.30pm.

We reached Stella Point, which is at the top of the ridge at 5,756m, at 6.15am - just as the sun was rising. The views were incredible and a much needed morale boost. It took another 1.5 hours to reach the summit and we all found that part extremely emotional. Arriving at the famous summit sign was amazing. We couldn't believe we had done it!

Climbing Kilimanjaro was honestly one of the most challenging but rewarding and amazing experiences. We were so lucky to be able to do it. We received such incredible support from our friends, colleagues and family and were able to raise an awesome £3,767 for MND Cheshire branch.



Finally reaching the summit!



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

New fundraising events guide



The brand new MND Association Events guide is now available to download [here](#) or via the website (www.mndassociation.org/get-involved/fundraising or you can request a copy by telephoning 0808 8026262.

It is full of information about the many different ways you can get involved with fundraising, whether it's the challenge of an organised sporting event or doing your own thing in your own time. Check it out if you need some inspiration!



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RESEARCH NEWS



MND-SMART is led by a team of researchers based in Edinburgh and will simultaneously test whether two existing treatments for other conditions could have some benefit for people living with MND.

Funding is provided by Euan MacDonal Centre, substantial private donations, MND Scotland and My Name's 5 Daddie Foundation and we're pleased a number of Association-funded care centres will be involved in recruiting people with MND to take part.

There are more trials in the pipeline than ever before – the Association is currently involved in two trials, MIROCALS and TUDCA, across a number of our care centres.

The Association is working with neurologists on two additional trials through an international consortium called TRICALS that we hope will start in 2020 and work in a similar way to MND-SMART. If you would like more information about MND SMART, visit the “get involved in research” page at www.mndassociation.org/research

Research updates

All the latest research news can be found on the MND Association website at: www.mndassociation.org/research



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COMMITTEE NEWS

VOLUNTEERING OPPORTUNITY



We urgently require a branch secretary for the Cheshire branch.

This is a volunteer position. Duties involve arranging committee meetings 3 or 4 times a year and sending welcome letters to newly diagnosed members.

Full details about the role can be found in the volunteering section of www.mndaassociation.org/get-involved/volunteering or if you are reading the newsletter online you can click through [here](#).

If you would like to get involved, please contact:
Mike Coleman (Chairman)
Mobile 07895684529
E-Mail mikec.mndcheshire@gmail.com

Out of office

In other committee news, our wonderful publicity officer, Sarah Walker, is currently on maternity leave.

So, if you have any news or fundraising photos you would like to see featured in the newsletter, please get in touch with Emma, editor of the newsletter: Email: emma@mndcheshire.org.



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CAMPAIGN NEWS

by Richard Webb

The logo for the 'Scrap 6 months' campaign. It features the word 'SCRAP' in blue, '6' in orange, and 'MONTHS' in blue. The 'O' in 'MONTHS' has a small orange circle inside it.

The “Scrap 6 months” campaign was thought to be going through Parliament successfully after Mike Coleman and I, with many other representatives of the Association nation-wide, had been to Parliament last July.

Unfortunately, the election came before the Bill was passed and one of the two prime-movers, Madeleine Moon (Labour Bridgend), lost her seat.

Consequently, the campaign has had to be resurrected and, in fact, a MNDA delegation recently went to the DWP headquarters in London recently to explain why this rule is desperately in need of amending.

For anyone who does not know about this campaign it is to get the rule on fast-tracking applications for PIP etc, changed. At the moment, in order to fast track - and thus avoid the need to fill in a complex 35+ page form - you need to obtain a DS1500 form. This basically requires a terminal illness and a reasonable chance of death within 6 months, a very difficult criterion to judge, especially with something as complex as MND.

The logo for the 'Act to Adapt' campaign. It features three interlocking puzzle pieces: two blue and one orange. To the right of the puzzle pieces, the words 'ACT TO' are stacked above 'ADAPT' in a bold, blue, sans-serif font.

The “Act to Adapt” campaign has started for campaign contacts and follows the release of the report late last year. The sub-heading of the report, “Securing safe and accessible homes for people with MND – home adaptations and the Disabled Facilities Grant”, explains a lot of the intentions of this campaign.

The need to get home improvements carried out expeditiously and correctly for people living with MND has been identified as a problem throughout the country. Different local authorities (LAs) apply the rules in different ways, which means that some do not means test work below £5,000, whereas others means test all work. Some councils have created top-up grants for works costing more than the £30,000 limit in England, or raised the limit itself.

This campaign is still very much in its early days and an advisory group is being set up with a mixture of campaign contacts and full-time staff. When I am in a position to give more details on this, I will let you know. In the meantime, if any of you have had difficulties in applying for Disabled Facility Grants or getting work carried out when you needed it, please let me know.



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FINANCIAL STUFF

Summarised Accounts as at 31 December 2019			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	2,019	Financial Support	19,737
Restricted Donation	14,796	National Office	342
In Memoriam Donations	4,632	Info & Education	1,469
Corporate Donations	2,795	Admin Cost	2,844
Fund Raising	9,771	Publicity and Fundraising	370
Resale of Goods	1,927	Purchase of goods for resale	261
Sundry – Just Giving	0	CEO Appeal & MMU Research	10,000
Bank Interest	536	Total Expenditure	35,023
Gift Aid	172	Surplus for the year to date	1,625
Total Income	36,648	Total	36,648

Notable donations and fundraisers:

- James Brunt
- Trustees D G Lowe
- Marks & Spencer Nantwich
- Viridor Waste
- Lady Bibby
- J E Bailey
- Rebecca Jackson

In Memory:

Tim Hill

DIARY DATES

6 April @ 2.30pm	Support meeting	Abbeywood Garden Centre, CW8 2HW
4 May @ 2.30pm	AGM	Abbeywood Garden Centre, CW8 2HW
1 June @ 2.30pm	Support meeting	Wilmslow Garden Centre, SK9 2JN

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

Branch Contacts

Chair	Mike Coleman	07895 684529	mikec.mndcheshire@gmail.com
Vice Chair	Richard Webb	07476 961260	richard.a.webb@outlook.com
Secretary	Position vacant		
Treasurer	John Kinder	01260 291232	john@mndcheshire.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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