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New collar for People with MND

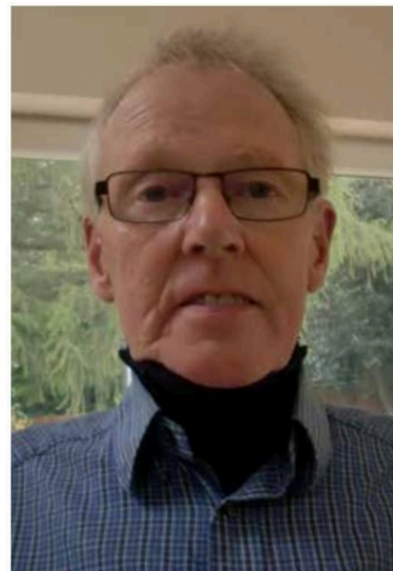
After years of research and development, a collar made specifically to help people with MND who are experiencing weakness in their neck has been launched.

For Philip Brindle, using the Head Up Collar has been life changing. Diagnosed with MND in 2015, Philip soon started experiencing weakness in his neck meaning that everyday tasks such as eating, reading a newspaper or using a computer became almost impossible.

“My head dropped forward which just meant that life became really difficult. I couldn’t even have a face-to-face conversation. It also affected my self-confidence, I just didn’t want to go anywhere.”

Philip first started using the collar during the trial phase and the effect it has had on his quality of life has been remarkable.

“Using the collar meant that I could keep driving for a while, as before all I could see were the pedals. I don’t drive anymore because my arms are too weak, but it gave me my independence which was wonderful. It also meant we could go on holiday and that I didn’t feel self-conscious. The collar is very comfortable, I would say that it feels like a scarf and it is also discreet. It can hardly be seen under clothing such as a shirt.



Philip Brindle, wearing the Head Up Collar

Professor Christopher McDermott, from the University of Sheffield, was one of the clinicians behind the collar’s development. He explains: “We started from scratch by working collaboratively with people living with MND to identify what the problems were with current neck collars and what features the ideal neck collar would have.

The design team listened to everything the user group suggested and went away to make prototypes.”

The collar was launched in April and is now available on the NHS or direct from www.talarmade.co.uk

Three Peaks Challenge

After a long, long journey up to Scotland on the Friday we settled down to a good night's sleep. Late May in Scotland turned out to be quite nice and at 3pm we were sat at the bottom of Ben Nevis in 27°C. The seven climbers set off with loads of water and sunscreen, but it was still a hot hard climb. After three hours they reached the top of Nevis and had probably the best view of all three mountains.



After coming down and eating we boarded the minibus and the back-up car and set off down to England to climb Scafell Pyke. We arrived in the early hours of the morning only 30 minutes behind our target schedule.

The team set off in the dark and started the long slog up the Pyke. The morning showed a fantastic sunrise and along with it a picking up of the wind. The back-up team then managed to get a bit of sleep after five hours of driving. After an hour and a half we all awoke worried whether the team on the hill were OK. The wind had picked up but it was still hot and sticky.

On the hill the team were making good progress and weren't far from the top of the hill, but the wind was blowing a gale and one of the team got a bit of vertigo doing a small climb. As a result the team had to find another way to the summit, which involved spending 11 hours on the mountain. This meant we weren't going to do it in under 24 hours, but the team made it back to the base, had a filling meal of chicken tikka masala and rice and boarded the transport for the trip into Wales.

This trip went very well and we made good time. As we turned off the A55 just past Conway we came across good ole Welsh weather; yep, the skies opened and the thunder and lightning started. We got to the Pig trail and the team set off. There was no need for sun cream or tons of water as enough of that was falling out of the sky, and we soon lost sight of them in the mist. The weather was wet-dry-wet-dry for the five hours that they took to climb and get back down. The weather at the top was zero visibility.

The whole team, tired and hungry finally made it to our accommodation at 11pm on Sunday. We hadn't done it in under 24 hours, but we had done it in under 30 hours and that alone was a great achievement. The next morning at about 6am an alarm went off and my eldest, Daniel, goes "Oops that's mine, sorry everyone!" I can't print the reply but let's just say he wasn't the flavour of the month.

So, who were the team? Well, firstly the drivers were me (Simon Crooke), Mick Huber and Malcolm Clifford (they were also the cooks.) The climbers were Daniel Crooke, David Crooke, Katie Marshall, Laura Whitwell, Martin Smith Leo Amies and Alex Clementson-Walker.

Money is still coming in but at the last count we were just over the £2k mark.

Well done to the whole team for a great effort and a great challenge.

Simon Crooke
Fundraising co-ordinator

Canoeing the river Nene

So, once this year's challenge had been done (see the Three Peaks on the opposite page), in the minibus on the way home chatter got to next year's challenge.

The overriding consensus was not to do another blooming walk, and whatever it was, to do something a bit nearer to home.

So, the next challenge is more local and it's not walking. It's not cycling either. It's canoeing and we are going to canoe the River Nene! Sounds easy doesn't it - a nice paddle down the river. Well it's 58 miles down the river, two nights camping and did I mention the 37 locks that we have to get out of and back into our canoes in order to get through.

This is going to be a fun wet challenge! It's £35 to enter, which covers hire of canoes, travel, camping and food. Oh, and when we get to the Dog in a Doublet pub at Whittlesey we are having a party and a BBQ. Family will be invited at a small cost per head.

Entries are open now. Spaces will be limited and I think they'll go quickly so sign up now! See the poster near the back of the newsletter for contact details.

Simon Crooke
Fundraising Co-ordinator

New General Data Protection Regulation (GDPR)

You may be aware that as part of a Data Protection exercise, we sent out letters to people who are interested in being contacted and have been receiving information from the Branch. We enclosed stamped addressed envelopes but so far only 30% have been returned to us.

May I remind those of you who were sent letters, that this will be the last you are legally allowed to receive from us if we don't have a reply giving permission to use your contact details.

I urge you to reply as soon as possible with your wishes, even if you would like to be removed from our Branch database; you may do so by using my contact details below. Please give your preferences of address, phone or email, or all three. I can email a copy of the original form if this helps.

Maire Collins: Secretary

52 Lambs Lane
Cottenham
Cambridge
CB24 8TA
Tel: 01954 200873
Email: mairecollins99@yahoo.co.uk

Strawberry Tea at the Old Post Office, Hail Weston – Sunday, June 24th

We were blessed with a weekend of glorious English Summer weather. Preparations started on Saturday, with the erection of the gazebo, kindly loaned again by Chris and Geoff Glover. David Griffiths arrived with his generous donation of strawberries, which were hulled and prepared for the next day.

Cynthia, Maire and Veronica arrived early on Sunday with the homemade scones and cakes, to set up the barn where the food would be served. Marion was also an early bird to set up her stall with branch cards.

Simon and John, Fred, Chris and Geoff were there to help with the preparation of the tables and chairs, and the raffle. Sue and John, our musical entertainers, also arrived early to set up their PA system.

On the afternoon, we were well supported by members and friends of the Cambridgeshire Branch of the MND Association, and villagers, family and friends, despite the televising of England playing in the World Cup in Russia.

The live music throughout the afternoon, supplied by John on the guitar and Sue accompanying him with her singing, added tremendously to the success of the day.

The raffle was a great money raiser, so thanks must go to the generous donations of prizes. The afternoon was judged to be a great success, with so many people supporting the cause.

At the final count, the record sum of £838.80 was raised, on the day. £350 will go towards the John Ross Tribute fund at David Niven House, and £488 to the Branch.

Thanks must go to all the Committee and friends who gave up their weekend to work so hard to ensure the day was a success.

Pam Wilkie



Cambridge Building Society and Cambridge News 2018 Cash for the Community Awards

In recent editions of the Cambridge News it has been announced that a share of £12,000 is on offer for 15 community groups/local charities thanks to the Cash for the Community campaign.

Many of you will remember we applied last year to be considered as one of the groups to receive funding under this scheme. We have once more put the branch forward and our entry has been accepted into the “draw”. The Cambridge Building Society Panel chooses the first 10 and the next top 10 will then go to a public vote to win the final 5 places.

The excellent news to tell you is the Cambridgeshire Branch has been voted as one of the top 10 favourites by The Cambridge Building Society staff and we go through to the final where we hope, with your help, we can win a share of the £12,000 donation.

The next 10 groups will be put to a public vote to confirm the final five.

The Cambridge Building Society says “social media will play a part in this campaign so follow @cambridgebs and @Cambslive on Twitter and ‘like’ both pages on Facebook at www.facebook.com/yourcambridge or www.facebook.com/cambridgeshirelive.

This is where we now need your help: the amount awarded to each group depends on the number of tokens collected. The first will appear in the Cambridge News on Tuesday 24th July. One token will be printed each day up to and including Friday 10th August 2018. Tokens must be cut out and placed in a sealed envelope, with the form that will be available, to detail how many tokens have been collected and which charity/group they are supporting.

Only original tokens will be counted. One online bonus token per person will be acceptable worth 5 tokens available on the News website.

Tokens must be received by midnight on Friday 17th August 2018 at the latest at one of the branches of The Cambridge Building Society or posted to: Cash for the Community, The Cambridge Building Society, PO Box 232, 51 Newmarket Road, Cambridge, CB5 8FF.

Tokens will be collated and verified by the Cambridge Building Society staff. Representatives of the 15 successful groups will be invited to a presentation evening where they will hear how much funding they will receive. The value of each token will be decided by The Cambridge Building Society Panel after the closing date has passed. The £12,000 will be divided by the total number of tokens submitted which will determine the face value of each token.

Full details of key dates are available at www.cambridgebs.co.uk/cash-for-the-community and at www.cambridge-news.co.uk.

It is fantastic the branch is part of this year’s “Cash for the Community” Awards with a chance to be the recipient of a portion of these funds. Contact me if you would like any further information.

YOUR HELP IS NEEDED – please collect the tokens from Tuesday 24th July and of course send them in!!

Cynthia George
Branch Chair
c.i.george@icloud.com
01954 202095/07515 534430

Easyfundraising.org

Easyfundraising.org is a great way to raise money just by shopping online. You don't pay anything extra. All you need to do is go to the easyfundraising website, click through to the retailer you want to buy from and make your purchase.

The price will be exactly the same and the retailer will give you a cash reward that you can turn into a donation. Easyfundraising collect this and send it on at no extra cost.

Visit easyfundraising.org and find out more.

Fun Run at Cottenham

The Fen Edge Community Association (FECA) hold an annual 'Fun Run' on the first May bank holiday with fundraising going to various charities in the village. This year due to MNDA Fundraisers within the village, the Cambridgeshire Branch was chosen and the certificates and medals were awarded by our Chair, Cynthia George, to those who came 1st, 2nd and 3rd in each category. The event includes stalls, refreshments, etc. and is an annual social event for everyone.

A marvellous amount of £1052.35 was raised at the event and the cheque was duly presented by Martyn Leeks to the Branch Chair, Cynthia George and the Secretary, Maire Collins at our recent Get-Together at Scotsdales Garden Centre in Gt Shelford.

We are very grateful to Martyn and all at FECA for the tremendous amount of work put in to raise funds for charities, especially ours, and we look forward to next year.

Maire Collins: Secretary



[Photo by Adrian Stephens]



[Photo by David Bradley]

Social Afternoon Get Togethers

Wednesday 16th May

Huntingdon MS Therapy Centre

We had a small but very sociable gathering for this afternoon. Everyone had time to exchange ideas and chat. The conversations are always on varied subjects and it's amazing what can be learned when chatting in small groups with interesting and lively topics part of the norm as well as the unexpected. This all makes for a homely and intimate time.

On hand of course is the usual cup of tea and variety of goodies to eat.

Always a good afternoon here with all those who come having a relaxed time.

Thursday 14th June 2018

David Rayner Building

A bright and cheerful occasion with many of you coming to catch-up with friends and hear what has been happening. Some of you arrive early to visit the garden centre beforehand with many enjoying the lovely food in the restaurant.

Parking is adjacent to the building with easy access through automatic doors into the air-conditioned building. The area is light and airy with room to move round the room to chat.

We were very pleased to welcome Martyn Leeks and Adrian Stephens from this year's Cottenham 7K Fun Run. Our branch had been nominated as their charity to receive the funds from this event. A cheque for £1,052.35 was presented to Maire Collins and Cynthia George – see separate report for full details.

Following this tea and coffee was brought round and the afternoon was then handed over to you to chat between yourselves with some of the branch committee on hand to mingle.

Cynthia George

Wednesday 11th July

Peterborough Salvation Army Centre

This is our venue for the northern part of the county with the Centre providing on-site parking and easy wheelchair access into the building.

On this afternoon we had our smallest attendance for a long time at any social afternoon get together. Saying this those of us who were there were able to have a good natter and laughs over a cup of tea.

These are excellent occasions to come and have a friendly chat and maybe talk through challenges or thoughts and issues that are of concern and find that someone else has found a solution or a way to deal with a particular issue.

We are at Peterborough again in November (14th) and hope that some more of you will be able to join us.

If you have any thoughts or comments on the format you would like for these afternoons then please let me know. These are your events so we would like you to have an input.

Cynthia George

Cambridgeshire branch contacts

Branch Chair and Branch Contact

Cynthia George 01954 202095/07515 534430
c.i.george@icloud.com

Branch Secretary

Maire Collins
Tel: 01954 200873
mairecollins99@yahoo.co.uk

Financial Support and Fundraising Coordinator

Simon Crooke 07551 575752
cambridge@mndassociation.org

Branch Newsletter Editor

Anthony Flynn
antonflynn@gmail.com



Regional Care Development Advisers

Liz Cooper 0345 375 1827

Lindsay Goward 0345 375 1829

eastangliarcda@mndassociation.org

MND Connect

0808 8026262
mndconnect@mndassociation.org
MND National office 01604 250505
enquiries@mndassociation.org
www.mndassociation.org

Registered Office:

Motor Neurone Disease Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG
Registered charity number 294354
Find out more about the Cambridgeshire
Branch visit
www.mndassociation.org/cambridgeshire

www.facebook.com/cambridgegshireMNDA

Future Get-Togethers... Dates of Get-Togethers in 2018

Wed 12 Sept
Thurs 11 October
Wed 14 November
Thurs 6 Dec

Huntingdon
Gt Shelford
Peterborough
Gt Shelford