



# NEWSLETTER



# A community united

We're on a mission, and we need you to join us. Together we want to cover 5,000 miles, that's a mile for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot however far you can.

Our mission begins on 13th September 2020 and runs for five weeks until 18th October. Take part and cover as many miles as you can over the period, or on a single day or week. How far will you go?

# We need your support.

We expect to lose over £2 million this year due to the cancellation of community and sporting events as a result of the COVID-19 pandemic. But our fight against MND can't be delayed. People affected by the disease need our support now, they need their voices heard today. People facing MND in the future need our vital research to continue.

Every penny raised from Mission 5000 will bring us closer to achieving our ultimate mission; a world free from MND.

# How does it work?

1 Sign up and pledge your miles at www.mndassociation.org/mission5000.

2 Complete your miles by running, walking, cycling - whatever you choose.

3 Track your miles and submit your total.

4 Raise over £100 and we'll send you a limited edition Mission 5000 medal.

When you sign up and register, simply state whether you would like your donations to be for the Cambridgeshire Branch, National Office or split between both.

# Good luck!

# CAMBRIDGESHIRE BRANCH ANNUAL GENERAL MEETING 28 MARCH 2020 - POSTPONED

We were due to hold our Cambridgeshire Branch AGM on 28 March 2020 at Hemingford Abbots Village Hall, but this was postponed due to Coronavirus and the subsequent lockdown. In view of the uncertainty with Covid-19 and the continuing restrictions in place for social distancing, the limited number of people allowed in the hall, but more importantly our first priority to keep our members and other attending safe and well, the Branch Committee has decided not to hold an AGM this year. We have a date of Wednesday 21 April for our 2021 AGM when we hope we will see many of you coming along to support us unless we have to cancel again.

To keep you updated, the following is a short informal overview of what the branch has achieved during 2019 with your help, not just on the financial side, but as importantly, promoting and campaigning with the aim to create a world free from MND.

The accounts and balance sheet show a healthy position.

In the absence of the formal AGM the branch officers and committee members have all agreed to continue in their current roles. These are:

Chair	Cynthia George
Vice-Chair	John Morren
Honorary Secretary	Maire Collins
Honorary Treasurer	Melanie White
Fundraising & Financial	Simon Crooke
Support Co-Ordinator	
Newsletter Editor	Anthony Flynn
Webmaster	David Griffiths
General	Veronica Angus
General and AV	Pam Wilkie

The Association Visitors and Care Service Navigator covering Cambridgeshire are:

Chris Glover	Fred Smith
Sue Hallifax	Pam Wilkie
Brenda Parkes	

The branch committee and AVs/CSN are all volunteers here to support our members through their journey living with MND.

We were supported during 2019 by MNDA staff; especially allocated to the Eastern area, were the Regional Care Development Advisors, Liz Cooper and Lindsay Goward; our Volunteering Development Co-Ordinator, Neil Penson, and Regional Fundraiser, Roger Widdecombe. From 2020 there has been a restructuring of staff in the regions with some roles disappearing and others put in place.

Fundraising for our branch has been spearheaded by Simon Crooke with Andrew and Christine Norton and others involved in the Cottenham Fundraising Group continuing to raise funds for the branch along with many of our supporters. This enables us to help as many of you as possible in a variety of ways. For example, we may purchase or contribute towards the cost of specific equipment where it is not available locally from the NHS or other statutory services, additional equipment or in other ways.

# **Branch Volunteering Roles**

# Branch Fundraising Coordinator and Financial Support Coordinator

Simon Crooke who has been undertaking these roles will be stepping down from 7 September. He will be moving to Turkey but has said he will still maintain contact with the branch. We all wish him well and send our best wishes and hope he enjoys this new adventure.

This is very sad news for the Cambridgeshire Branch as Simon has been volunteering with us for six years. He has always been very enthusiastic and given 110%. His fundraising efforts have made a huge difference to our branch funds.

We are currently in the process of appointing a new Branch Fundraiser - more on this in our next newsletter.

# **Branch Financial Support Coordinator**

To cover this position for the immediate future Maire Collins our Branch Secretary has agreed to deal with any financial support requests. Therefore, from 7 September Maire will be the person to receive these applications.

# Cynthia George: Chair

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420.00

2,882.87

3,302.87

275.45

275.45

21,243.73

6,730.83

574.56

954.02

1,040.80

2,569.38

# MND ASSOCIATION

**Cambridgeshire Branch** Annual Return : Profit & Loss Account For the Year ending 31st December 2019

#### INCOME

	2019	2018
DONATIONS RECEIVED	£	£
General Donations	8,612.18	4,575.40
In Memorium Donations	6,491.24	2,478.65
Tribute Funds	495.00	5,847.33
Corporate Donations	30,389.70	2,324.03
Grants	-	-
Legacies	-	
Other	-	2,440.00
Total Donations Received	45,988.12	17,665.41

#### FUNDRAISING INCOME

Fundraising Activities- Branch Organised Fundraising Activities- Third Parties **Total Fundraising Income** 

13

# OTHER INCOME

**Bank Interest** Gift Aid Other **Total Other Income** 

#### TOTAL INCOME

Restricted Income included above

#### EXPENDITURE

CARE EXPENDITURE Financial Support	6,510.39	1,360.05
Equipment	340.00	595.99
AV expenses	2,466.58	1,618.25
Carer Support	-	180.00
Payments to DNH	10,953.26	7,944.43
Other	-	-
Total Care Expenditure	20,270.23	11,698.72

#### Meeting costs Printing, Postage & Stationery IT costs Information & Education Other **Total Branch Administration Costs**

#### **OTHER COSTS**

**Fundraising Costs** Other **Total Other Costs** 

#### OTHER TRANSFERS TO DAVID NIVEN HOUSE

Branch Annual Transfer Donations (Research) Purchases via MND (Sales) Ltd. Chief Exec's Appeal & other donations **Total Other Transfers to DNH** 

#### TOTAL EXPENDITURE

Restricted Expenditure included above

#### NET INCOME

**Movement in Restricted Funds** 

,677.58	
,699.43	
-	
300.00	
248.00	
,925.01	

779.63

10,257.71

11,037.34

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-
6,950.52

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	3,	78	6.	7	5

25.11
2,944.08

# MND ASSOCIATION

Cambridgeshire Branch Annual Return : Balance Sheet As at 31st December 2019

As at o 1st December 2010		
	2019	2018
	£	£
FIXED ASSETS (total NBV from Fixed Assets schedule)	-	-
CURRENT ASSETS		
Cash at Bank - (cashbook balance)	56,715.97	46,611.09
Cash floats held	350.00	350.00
Debtors (items owed to Branch at 31 Dec.)	-	-
Total Current Assets	57,065.97	46,961.09
CURRENT LIABILITIES		
Creditors (items owing by Branch at 31 Dec.)	332.41	6,950.52
NET CURRENT ASSETS/LIABILITIES	56,733.56	40,010.57
TOTAL NET ASSETS	56,733.56	40,010.57
La le		
GENERAL FUND		
Balance brought forward at 1 January	6,950.53	9,869.50
Surplus/(Deficit) for the year	(950.52)	(2,918.97)
General Fund Balance at 31 December	6,000.00	6,950.53
RESTRICTED FUNDS (See Separate Analysis)		
Balance brought forward at 1 January	33,060.04	30,115.96
Transfer from Income & Expenditure	17,673.52	2,944.08
Restricted Fund Balance at 31 December	50,733.56	33,060.04
TOTAL ACCUMULATED FUNDS	56,733.56	40,010.57

# Covid-19 (correct at time of going to print)

# Keeping safe and staying in touch

The pandemic has led to uncertain times for us all, but for those affected by MND there are likely to have been particular concerns. The MND Association has adapted its services at this time to ensure that people affected by MND continue to receive up to date information and support. This has included our amazing network of Branches and Care Support Volunteers reaching out to all people living with MND and keeping in touch where required. Branches have engaged in virtual platforms to continue their important committee work, and we are trialling virtual support meetings via platforms such as Zoom in some areas.

# On-line support meetings trial

Due to coronavirus restrictions, we have been unable to provide our usual services, including Get Togethers and regular home visits from our volunteers (although these can be agreed with you where necessary and safe). We are keen to trial an on-line support meeting in Cambridgeshire if there is an appetite for this. In some areas, this has proven to be very successful and after initial 'trial runs', several local on-line groups have formed across the country and some have continued to 'meet' on a regular (perhaps monthly) basis for a coffee and chat. Although these cannot replace the supportive 'Get Togethers' provided by local branches, these forums can provide a means of social contact and an opportunity to 'meet' and share ideas with others who are experiencing similar challenges. For those with speech and communication challenges, these 'meetings' can prove to be inclusive in terms of making use of the 'chat' function to contribute to chat and discussion.

If you think you might like to take part in a trial Zoom meeting in Cambridgeshire please either let your local Branch, Association Visitor or Care Service Navigator know or, please

e-mail me on liz.cooper@mndassociation.org

#### Keeping in contact

If you don't have regular contact with one of our volunteers but would like to, then please let me know and we can set this up for you. If you prefer you can always get in touch with one of our advisers on MND Connect:

MND Connect is available Monday to Friday between 9am - 5pm and 7pm - 10:30pm. Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills.

Call us: 0808 802 6262 Email us: mndconnect@mndassociation.org

# Planning ahead

In the meantime, we do encourage you to consider setting up on-line shopping services if you haven't already done so. Even if you don't require these at the present time, it could be that these services come into their own as winter approaches, and in the event of any future local lockdowns, especially if family and friends are unable to visit. If you are not technologically minded, you might want to consider asking family or friends to set this up for you while they can visit you at home.

It is also worth considering registering with your local Power Network, who will prioritise your need for support, especially if you rely on medical equipment and devices:

www.ukpowernetworks.co.uk/power-cut/priorityservices-register

# Up to date information on Coronavirus and MND

Please do keep safe. For up-to-date information about Coronavirus and MND please visit our website. You may find the link below useful:

www.mndassociation.org/about-mnd/coronavirusand-mnd

# Liz Cooper: Area Support Coordinator, East Anglia

AUTUMN 2020

# Long Service Awards

Maire Collins had requested the awards ready for the AGM 2020, but in light of having to cancel the AGM she has them on hold. Members discussed what to do about them and decided to wait until next year, 2021, before awarding them. The awards are as follows:

# 2019

10 years

Pam Wilkie should have received this award in 2019 but was accidentally missed off.

# 2020

Maire Collins: Branch Secretary		
15 years	Maire Collins (Feb)	
15 years	Veronica Angus (Aug)	
10 years	Anthony Flynn (Oct)	
5 years	John Morren (Mar)	

# A few words from Area Support Coordinator, East Anglia

Some of you will be aware that following a structural re-organisation, the Regional Care Development Adviser (RCDA) and Volunteer Development Coordinator roles were made redundant last December. From 1 January 2020 I have taken up a new position as Area Support Coordinator (ASC) in East Anglia. Sadly, my former job share, Lindsay Goward decided to leave and I am currently working full time in the role across East Anglia.



Having been RCDA for almost 16 years (albeit part time for the past 10 years), I feel grateful to be able to reconnect with branch and care support volunteers as

well as health and social care professionals in Cambridgeshire. It is a pleasure to work now with both care support volunteers and Cambridgeshire Branch personnel in steering the support we offer to people affected by MND in Cambridgeshire and beyond.

The change in role means I am now less involved in strategic influencing, planning and education with our health and social care colleagues and more involved with leading the provision of all Association volunteer services and support in East Anglia. Complex issues are referred on to our Service Development Manager, Scott Maloney. Where they relate to the provision of services (and can't be easily resolved), Scott will consider if there are systemic problems that need to be followed up, hopefully leading to the development of improved services.

Alongside the Branch we are making plans to develop services in Cambridgeshire (whilst taking into account the changes imposed upon us all in light of the Covid-19 pandemic). This includes recruiting volunteers in a variety of roles and considering how best to support people remotely during lockdown.

I have been overwhelmed by the commitment of our Association Visitors, Care Service Navigators and Branch Committee Members in adapting new and creative ways of working. We look forward to supporting you and working with you in the future.

If anybody is interested in finding out more about volunteering with the MND Association please either drop me a line or visit:

www.mndassociation.org/get-involved/volunteering/become-a-volunteer/

Liz Cooper – Area Support Coordinator East Anglia

# Joe Gilbert's Mum

My Mum was diagnosed in November 2018 with an expected life expectancy of 2 years. Covid-19 has thrown in some horrific complications, which has made the past few months really difficult when thinking about carers for my Mum, or just even being able to see her when time is so precious. It has also impacted my fundraising with event after event being cancelled or postponed. I had hoped to complete a few iconic events this year, but I have spent my time working from home at my dining room table. I have kept pushing on with my fundraising regardless and with over £4,500 raised so far, I am tantalisingly close to my target of £5,000. It would mean so much for my Mum to be able to see me hit my target.

I have a new challenge now that looks to be set in stone and not likely to be cancelled; it is the "Endurance Life, Coastal Trail Series -North Yorkshire Moors" - a 35 mile ultra marathon along the coast by Ravenscar. Anyone who knows that area, knows there are a lot of steep ups and downs as you go up to the moor tops and down to the coast. The route racks up a considerable amount of elevation, and I am training in Cambridgeshire, the flattest part of the country, and with the addition of a newly acquired lockdown belly! So this won't be easy, especially as I had switched out of my training routine. However, eager to complete an event and push on with my fundraising, I signed up to this race despite not being fully in the right shape. So, this is going to hurt, there is no other way to put it! But, I am hoping it can inspire enough people to help me hit my target of £5,000, which would be an incredible achievement in approximately a year and a half.

If you'd like to help me, I'd really appreciate it, and every little helps, even just £1. If everyone who reads this donates £1 I'll hit my target. You can donate at www.justgiving.com/fundraising/mndmum **Joe Gilbert** 



# **Feel Stuck Indoors?**

It is a feeling we have all had, especially during the current Covid-19 pandemic. But some of us have felt this way for some time. It can be a big expense for a lot of families who can't afford to purchase a wheelchair accessible vehicle.

Taxi fares tend to cost more for a wheelchair user and thanks to the work of your committee we have secured funding to help our members get out and about. This is with thanks to the National Lottery and we hope that this money can go a long way to helping with that.

Here are just some of the things it can be used for: trips to the doctor, hospital appointments, shopping trips, a meal out with family, an evening at the cinema or a show.

To find out if we can help you please fill in a branch funding request form, which you can find at www.mndassociation.org/ cambridgehsire and send to secretarycambsmnda@gmail.com. We hope this brings a lot of freedom to our members.

Simon Crooke: Fundraising Coordinator and Financial Support Coordinator

# **Cambridgeshire Branch Contacts**

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Registered charity number 294354 To find out more about the

www.mndassociation.org/cambridgeshire www.facebook.com/cambridegshireMNDA

Cambridgeshire Branch visit

Northampton

NN3 6BJ

#### **MND** Connect Dates of Get-Togethers in 2020 0808 8026262 All dates cancelled until further notice: mndconnect@mndassociation.org **MND** National Office Weds 16th Sept **Hemmingford Abbots** 01604 250505 Thurs 15th Oct Great Shelford, Cambridge enquiries@mndassociation.org www.mndassociation.org Weds 11th Nov Elv **Registered Office:** Thurs 3rd Dec Great Shelford, Cambridge Motor Neurone Disease Association Francis Crick House

Unsubscribe: If you prefer to receive Newsletters electronically or not at all, please contact: Mrs Maire Collins (contact details above)