Cambridgeshire Branch

Autumn/Winter 2017





Highlights in this issue...

Fundraising
MNDA South and East Conference
Get Togethers
Poems

page 2 page 4 page 6 page 7

New booklet launched on 'Making the most of life with MND'

We are delighted to announce the launch of a new booklet, *Making the most of life* with MND.

This A5 booklet was developed in response to requests for information about maintaining interests when diagnosed with MND. People with MND wanted to know how to continue doing things they enjoy for as long as possible. The booklet explores ways to adapt to life with the condition, and includes guidance on how to find appropriate support, if needed.

Feature pages introduce people living with MND and their carers, who share their approaches to life, hobbies and experiences.

Lee Millard, who features on the front cover of the booklet riding his recumbent trike, offered his outlook on his featured page: "We live in the 21st Century and we can adapt in ways that were not possible 10 years ago. The future will bring more and more."

You can order a printed copy of the booklet from MND Connect helpline on o808 802 6262.



Fundraising report

Owen and Holly

Owen and Holly completed the Great North Run in 1 hour 57 minutes and have so far raised about £1000.



If you would like to sponsor them, their donation page is still open at http://uk.virginmoneygiving.com/RunningForMND

Royal Air Force College band

We were very pleased to receive a cheque from the Royal Air Force Wyton Area Voluntary Band. The money was raised at a concert held in February this year at Peterborough Cathedral featuring the band of the Royal Air Force College. The donation was given to the branch by

band member and Station Commander, Wing Commander Phil Owen. £1600 was raised overall, of which approximately £1100 will go to research with the balance going to support local people living with MND.



Littleport Community Choir

The Littleport community choir held an evening of music at St George's Church in Littleport. A great evening was had by everyone and a fantastic £502 was raised.



Maureen Beeby

Friends and family held a day of selling food cakes and bric-a-brac at Farcet Church on behalf of Maureen. The day was a great success and the group raised a fantastic £3,300 which is being divided 50/50 between the branch and research.

Simon Crooke

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

We again applied for funding under this scheme. Tokens are printed in the Cambridge News for a two-week period and have to be sent in to support that chosen person's charity. Sixteen charities/organisations were selected this year from applications received.



I am pleased to say that for the second year running we were successful in the first round of being included as one of the charities to receive funding.

At the beginning of September Maire Collins, our Branch Secretary, and I attended a reception to receive the cheque on behalf of the branch. The amount allocated to each of the chosen charities depended on the number of tokens submitted and ranged from £2,162 to £250. We came 6th and collected a cheque for £862. In first place was The Huntingdon Therapy Centre which received £2,162. Many of you will know this Centre from coming along to our Social Afternoon Get-Huntingdon Togethers.

Well done and thanks to those of you who took the time and trouble to send in tokens. We came higher up the "league table" and exceeded last year's figure so many thanks to all those who supported us in this way, which once again gives us more funds to enable the branch to help those of you in the area living with MND. **Cynthia George Branch Chair**

Special Day for Mindfulness Meditation Ely Cathedral Centre Sunday 19 November 2017

Carole Chiverton who is a Mindful Instructor hosted a special day at the Ely Cathedral Centre on Sunday, 19th November, to raise funds for the Cambridgeshire Branch of the Motor Neurone Disease Association. John Morren and I were happy to support this event which was held in a building with striking views of the Cathedral from every window.

Carole wanted to raise funds in memory of her friend Beth, and here are a few words written by her:

"My dear friend Beth died from MND this August, following a short illness. We met whilst both District Nursing in our twenties, and stayed friends. She was the kindest, most beautiful, thoughtful person and helped me generously when I was ill many years ago. When I heard of her diagnosis, I wanted to help, but her close loving family had got all that covered. I decided my efforts would be better directed towards raising money for the MND Association, something of which she heartily approved."

Carole had several enthusiastic friends helping her provide a raffle with many lovely prizes. Tea and coffee as well as platefuls of delicious cakes and scones were available throughout the day. People made friends and there was lots of chatter in the cafe area.

Upstairs in the quiet and comfortable lounge, Carole led sessions about Mindfulness; one in the morning and one in the afternoon, both of which were well attended. I joined the afternoon session and learnt:

"Mindfulness is a mental training that allows us to better pay attention to, and see clearly what is happening in the present moment. Whilst it cannot eliminate life's pressures or change events, it can be a good way to help people deal with them in a calmer manner that is beneficial to overall well-being."

I certainly benefited from relaxing quietly, listening to Carole, and I hope I will remember most of her teaching. Mainly, I am trying not to worry too much about the past, or the future, but to appreciate the present, and as she told us, when under pressure... "STOP, BREATHE AND BE".

A very big Thank You to Carole and her friends for the efforts they made for this special day, and for the generous proceeds which have been donated to the Branch.

Veronica Angus, Committee member and John Morren, Vice Chair

MND Association South and East Joint Regional Conference held at Ealing Sunday 24th September 2017

Fred Smith one of our Association Visitors attended the above conference and below is his resume of the day...

The day started with refreshments before we were welcomed by Alun Owen, Chair of the Board of Trustees. He outlined how the day would unfold and gave introductions to the delegates who would be speaking to us.

Nick Goldup, Director of Care Improvement, gave an interesting talk on the Work of the MND Association touching on some of the topics which would follow. He has only been in post six weeks but at the end of his speech received a warm response.

The next speaker was John Gillies-Wilkes, Regional Delivery Manager - East, who briefly outlined what was happening in branches and groups and regional fundraising. He introduced Maxine Dimmer, a Regional Fundraiser, who as a pabMND has raised thousands of pounds for the Association by organising Balls, running marathons, etc. Her talk was very interesting and it was clear that she has put her heart and soul into raising money for the MND Association.

Maddie Portwain was next to tell her story. Once again she has raised a huge amount for the Association. She and her friend (who was not present) have taken on many challenges, even letting the people sponsoring them dictate what challenges they should do, including

handling snakes, of which she is petrified, not even being able to put a real picture on the screen.

Mark Gately from North West Kent Branch is living with MND and has done a huge amount for his Branch and the Association during the last few years including getting his local council to adopt the MND Charter. Again this was a most satisfying talk and I think most people at the Conference would be impressed by the work put in by a plwMND.

After a short refreshment break there was a talk on Research by Dr. Brian Dickie, Director of Research at the Association, during which he outlined the current state of research and the amount of money being spent to try and beat MND. After completing his talk he introduced Dr Rickie Patani of UCL. Dr Patani runs a laboratory which carries out Modelling Human MND. With the aid of slides he showed us what is happening in his field and the battle to defeat MND. This was a very interesting talk and hopefully he and his team will learn what the causes of MND are.

During lunch there were a few exhibitors which allowed delegates to glean some more information of which I appreciated the explanation of Benefits.

The next set of presentations was introduced by Alice Fuller, Campaigns Manager-East, who spoke briefly about Care and Campaigning and Supporting people now and in the future. She then handed over to Alison Avis, Association Visitor- North Wilts. As can be imagined this talk was of great interest to me and I

learned a bit more about my role. Later I was able to have a face to face talk with Alison and this strengthened my thoughts on being an AV. Alun Owen was next to speak and he gave a really good talk on the MND Connect Helpline for which he volunteers during the evening hours. David Setters, Campaigns Contact, then concluded this session with more information on campaigning.

The Chairman for the day, Alun Owen, wound things up by thanking all who had attended the conference, especially those plwMND.

Before I went to the Conference I was a bit worried that it may be too corporate, however I was pleasantly surprised at how friendly the whole day was and I certainly recommend anyone to attend at least one of these events.

Fred Smith Association Visitor

Wheelchair in good condition needs a home

There is a standard modern wheel chair with head support which has only been lightly used and is in very good condition, in need of a good home. The chair is a basic design and folds into a car boot, but the present owner is now unable to make good use of it, and would like it to be of benefit to someone else living with MND. The chair is at present safely stored in a Sheltered Home in Hampton, Peterborough. There is no cost, but anyone interested would need to collect it from the present owner.

Please text or call Daniel Emery on 0771411060 or Chris Glover on 01733 380922 or 07504813461 if you are interested.

Social Afternoon Get Togethers

Wednesday 13th September Huntingdon MS Therapy Centre

For this afternoon we were joined by Wing Commander Bob Carr from SSAFA, the Armed Forces charity.

Bob has been involved with SSAFA (Soldiers, Sailors, Airmen and Families Association) for a number of years and has seen many changes. The charity was formed in 1885 and helps not only the more elderly service personnel but also the younger members. It operates on a branch/county basis and is run by volunteers – 6,500 throughout England – and has helped 14 million people. A large number of cases are for financial help and SSAFA is able to liaise with other organisations/charities when needed. They hold regular fundraising events to raise much needed funds.



Bob is a very engaging speaker, extremely knowledgeable and enthusiastic about his work for SSAFA and a delight to listen to. He answered the many varied questions which were put to him. It was a shame when I needed to bring his talk to an end.

It was pleasing to see a good number of members and family/carers that afternoon. This all made for a lively get together. We had our usual refreshments and cup of tea but these seemed insignificant compared to having our talk by Bob Carr.

Cynthia George Branch Chair

AGM 2018

The Cambridgeshire Branch AGM will take place on 21 March 2018 at Hemingford Abbots Village Hall. Our speaker will be Dr Rhys Roberts, Addenbrookes Hospital MND Care Centre Director.

You will receive your invitations in February so please keep the date free and come and join us.

Jenny Kiss'd Me

By Leigh Hunt

Jenny kiss'd me when we met,
Jumping from the chair she sat in;
Time, you thief, who love to get
Sweets into your list, put that in!
Say I'm weary, say I'm sad,
Say that health and wealth have miss'd me,
Say I'm growing old, but add,
Jenny kiss'd me.

Mathematics of Light

By David Morley

The wavelengths of daylight register on bright equipment:

flutterings across a spectrum from infra-red to ultraviolet.

Discover me at an ice age, at a midnight of colour,

in a place where rainbows unbind themselves completely.

But you stand in the noon. Shadows are inventing themselves

over your quickening retina; the day moves on to shade

when spires are like pen-strokes in the heat haze... It's

like Newton's gold trances as he skimmed slates on the sea,

like Einstein's chatter over tea, borealis, wispy cigarettes. It's

down to the human to live it, take it in. Keep my sunlight warm for me.

Cambridgeshire branch contacts

Branch Chair and Branch Contact

Cynthia George 01954 202095/07515 534430

c.i.george@ntlworld.com

Branch Secretary

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

Financial Support and Fundraising Coordinator

Simon Crooke 07551 575752 simoncrooke@aol.com

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

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

Huntingdon Wed 3 Jan **Gt Shelford** Thurs 15 Feb Peterborough Wed 11 Apr Wed 16 May Huntingdon Thurs 14 June **Gt Shelford** Wed 11 July Peterborough Wed 12 Sept Huntingdon Thurs 11 October **Gt Shelford** Wed 14 November Peterborough Thurs 6 Dec **Gt Shelford**