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40TH  
YEAR



The Cambridgeshire branch of the MND Association presents a multi-faith commemorative service and reception at Peterborough Cathedral to celebrate forty years of the Association on Saturday 5<sup>th</sup> October 2019. The service starts at 4pm.



The service is free but there is a small charge of £10 per head for the reception, which includes a buffet and hot drinks. All tickets must be booked in advance and booking forms are available from:

[cambridge@mndassociation.org](mailto:cambridge@mndassociation.org)

\* Please note the corrected date for this service on Saturday 5<sup>th</sup> October 2019.



## **CAMBRIDGESHIRE BRANCH ANNUAL GENERAL MEETING REPORT: 27 March, 2019**

The Cambridgeshire Branch AGM was held on 27 March, 2019 at the Village Hall in Hemingford Abbots and was attended by 37 people.

**Welcome:** Cynthia George (Branch Chair) welcomed Dr Kirsten Kelly who would be presenting a talk after lunch. Kirsten is Research Programmes and Partnership Manager at the MND Association.

She also welcomed everyone else to the AGM and thanked the Village Hall Committee for allowing the use of the Village Hall. She hoped it would be an interesting day and that everyone would enjoy the presentation by Dr Kelly, and the delicious buffet lunch provided by Christine and Andrew Norton and their daughter Jane Copeman.

**Apologies** were received from: 4 Committee members, 2 AV, 6 NO staff, 31 members and friends.

**Matters arising from AGM Minutes for 2018:** There were no issues arising and the Minutes were formally adopted.

**Chair's report:** Cynthia George's report on the year 2018 is as follows: The branch has continued on a successful note in helping, promoting and campaigning in the hope we can see a world free from MND in the near future.

Diagnosis can be a painful, difficult, traumatic and frightening experience and one we all hope will never come. The Cambridgeshire Branch is here to try and help in some small way to be there for you. This is the same for the Cambridgeshire MND Care Centre, the Peterborough MND Clinic and the MND Association initially through the Connect line. This extends to the whole family, spouse, partner, young adults and carers.

Research is a top priority for the Association in the hope that shortly a cure will be found. Lots of work continues in the background which many of us will not be aware of and would probably go above our heads. Dr Kirsten Kelly's talk later will enlighten us on many aspects of what is happening on this front.

Cynthia passed on the following information about the branch:

We were founded in 1987 – 32 years ago. We cover the whole of Cambridgeshire and can offer support to those living just over the county boundaries.

We have 10 committee members and 6 AVs/CSN.

All are volunteers, some undertaking a dual role.

We represent the MND Association at a local level and focus on:

providing support to those living with MND and their families/carers by way of monthly social afternoon gatherings;

fundraising;

raising awareness;

campaigning.

The Branch Committee Members, Association Visitors and Care Service Navigator are all volunteers and devote many hours of their time to MND. Without a team such as this we wouldn't be able to work as well as we do. We may not always be able to achieve everything our members would like us to but we try to do our best.

Here is a short resumé of the names and the job roles of your Branch Committee members, Association Visitors and Care Service Navigator:

**Maire Collins: Branch Secretary:** Our Secretary for many years, in fact 14. She continues to perform this role efficiently and effectively and has what seems like unlimited knowledge of how the branch should operate. Maire undertakes a dual role as she also helps with fundraising. A huge thank you to Maire for her sterling work.

**Melanie White: Branch Treasurer:** Mel has to work within the criteria set down by the Association which is not always an easy task and I am sure her workload has vastly increased since she first became our Treasurer 15 years ago. She carries out the work efficiently in spite of her family and working commitments. Thanks to Mel for keeping our finances in order.

**John Morren: Vice Chair:** My thanks to him for serving as Vice-Chair and the support he gives as a committee member.

**Simon Crooke: Fundraising and Financial Support Co-Ordinator:** Simon continues to give 101% and is always willing to help. He is a great asset.

**Anthony Flynn: Newsletter Editor:** Our branch newsletter is always very well produced by Anthony and my thanks to him for creating a professional image for this.

**David Griffiths: Webmaster:** Our Cambridgeshire Branch website ([www.mndassociation.org/cambridgeshire](http://www.mndassociation.org/cambridgeshire)) is kept updated on a regular basis by David. He has faced a number of challenges this year on this front and has not always been able to keep the site as updated as he would like but I think he is now able to access the site and post updates. We also have a Facebook page.

**Veronica Angus, Chris Glover and Pam Wilkie:** These three ladies are very loyal committee members always willing to help out and provide a great deal of knowledge and support at our committee meetings, at our social afternoon Get-Togethers and in general. Their committee work is often in the background and goes unnoticed so a special thank you to all three.

As you may have seen in the latest branch newsletter, from the end of December Chris Glover felt she needed to reign back on the time she devoted to volunteering and decided to step down as a committee member after over 17 years volunteering with the Association. I am sure this was not an easy decision for Chris. I take this opportunity to thank Chris personally, and on your behalf as well, for the many years she has been a committee member and the work this entailed over such a long period.

**The AVs/CSN covering Cambridgeshire are:** Carol Deytrik-White, Chris Glover, Sue Hallifax, Brenda Parkes, Fred Smith and Pam Wilkie. Due to personal family reasons, Carol decided she could no longer continue as an AV. I would like to thank her for the time she was able to give in this role. Thanks to them all for their efforts in helping and assisting many of you. The AV role I feel is a vital one. My aim is that we all work as a team.

We are of course supported by MNDA staff. Especially allocated to the Eastern area, are the Regional Care Development Advisors, Liz Cooper and Lindsay Goward; our Volunteering Development Co-Ordinator, Neil Penson, and Regional Fundraiser, Roger Widdecombe.

**Fundraising for our Branch,** led by Simon Crooke, takes up an enormous amount of time but can be very rewarding. Many of you fundraise for us which I hope you realise is much appreciated. Without your help we would not be able to support requests from those living with MND and their families to help with items not supplied or readily available from statutory services, additional equipment or in many other ways.

We were lucky enough to be selected as one of the charities/organisations under the Cambridge Building Society "Cash for the Community" scheme. The branch came 8th out of 15 and received a cheque for £737. Tokens were printed in the Cambridge News and the amount allocated depended on the number of tokens received. Again a big thank you to those who took the time and effort to send in the tokens – without your help we would not have received this money. This is a local community scheme which stipulates any funds must to be used in the local area.

Simon has also been successful in applying for funds from a Peterborough firm, Perkins, to help towards the cost of transport for you our members. Any schemes such as these are an ideal way of obtaining funds for this branch

which all go towards helping you, our members and family.

Our regular monthly social afternoons have been a success again this year. The Cambridge venue at The Scotsdales Garden Centre site in Great Shelford continued to be the most popular. We also meet at the Huntingdon MS Therapy Centre and Peterborough Salvation Army Centre.

At Cambridge we had a doctor come and give a talk about his research project on Mitochondria in MND; a representative from Techcess on helping people to communicate and computer access. We were also pleased to welcome from National Office: Richard Coleman, Chair of the Board of Trustees, and Suzanne Ostler, Communications Manager. The year ended with our usual Christmas party afternoon.

We hope these social afternoons provide an opportunity for you to meet others in a similar situation, share ideas and thoughts and generally enjoy a relaxing afternoon.

**MNDA Charter:** In September, Cambridgeshire County Council became the second Cambridgeshire council to sign the MNDA Charter as Peterborough City Council had already done so. Thanks must go to Fred Smith, one of our Association Visitors, for his persistence in getting CCC on board.

One little snippet of information - the MND Connect line received over 9,300 calls in 2018 from people living with, and affected by, MND, their carers and families, and health and social care professionals. Some of you will have used this helpline which is one of the great assets of the Association.

Finally, thank you all for listening and for your support over the last twelve months. With your help our media coverage is becoming more prominent and our campaigning continues to bring to the fore our hope for a WORLD FREE FROM MND in the not too distant future. I, and I am sure all of you, will continue the fight to achieve this.

**Presentation of accounts:** The statement was read by Maire Collins in the absence of our Treasurer, Melanie White:

Income for the last financial year was a spectacular £21,243.73, with expenditure amounting to £21,218.63.

**Income** is a great deal lower than the previous year because in 2017 we received a very large donation from the Peterborough Mayoral Charity of £15,545.38.

**Expenditure** on 'Care and Support' was 55% of the overall total spend and included payments for such things as:

Young Persons Grants

Carers Grants

Alternative therapies

Equipment such as closomats, stairlifts, hoists and house adaptations.

**Restricted fund** balances total £ 33,060.04 at end of year. Expenditure from the restricted funds was £ 3,786.75 and is included in the above total expenditure.

**Our year-end balance** in our Branch General Fund is £6,950.52. We are once again fortunate to have good reserves in our Restricted Fund balances to assist with the payment of Funding Requests. Without the generous fundraising donations that we receive and the restricted funds, it is quite clear that we would struggle to cope with the financial requests.

**Election of Branch Committee:** As Chris Glover had resigned from the Committee at the end of December 2018 and all the other committee members were happy to stand again an *en bloc* vote would be appropriate if everyone agreed. Therefore:

**The current Officers and their responsibilities are as follows:**

Cynthia George Chair and Branch Contact

John Morren Vice-Chair

Maire Collins Secretary

Melanie White Treasurer

Current Committee members and their responsibilities:

Veronica Angus Support  
Simon Crooke Fundraising Coordinator and  
Financial Support Coordinator  
Anthony Flynn Newsletter Editor  
David Griffiths Webmaster  
Pam Wilkie AV and Support

**Long Service Awards:** Cynthia explained that this year's Long Service Awards for Melanie White and Simon Crooke for fifteen and five years respectively would be presented on a suitable occasion as they were unable to be present today.

**Fundraising report:** Simon Crooke was unable to attend the AGM this year therefore David Griffiths read out Simon's prepared report which is as follows:

Fundraising for the branch has been very successful and we are very lucky to have a great group of people from all over the county who raise funds for us. Here is a snippet of the main ones.

**The Garden Party** held in Pam Wilkie's garden was a great success and attended by over 50 people. The weather was fantastic and we were all entertained by the lovely singing and guitar playing of our own Sue Hallifax and John Hirst.

**Railway Station Collections:** We again collected at the main stations during our June awareness month and we found travellers were very generous.

**Peterborough and District Farm Machinery Preservation Society** held a ploughing day using vintage machinery and raised £1060 for us.

**NISA stores:** We also thank both of the stores at Whittlesey, and Gunthorpe, Peterborough, who have fundraised for us this year.

**National Three Peaks Challenge:** This was the main challenge in 2018 and there was a great team of walkers taking on the challenge. It was unfortunate that we failed to finish in under the 24hr time limit by a couple of hours

but it was a great achievement by all and special thanks go to Mick Huber and Malcolm Clifford for driving the support minibus for us.

**Donations:** The branch was also lucky to receive donations from Persimmon Homes towards our Peterborough Cathedral Concert, and Perkins Engines for help towards our taxi fund.

We would like to thank everyone for all the other donations and fundraising events that have been held over the year. Every penny counts and every penny raised helps us to help people and families dealing with this devastating disease.

#### **Cottenham Fundraising Group**

Andrew Norton and his dedicated ladies in the group were very active in the period before Christmas. His wife Christine had produced nearly 300 packs of 5 Christmas cards which were very popular at £1 a pack. All the packs were sold and in addition, so were the little Christmas knitted tree decorations and favours.

Overall the amount raised was around £1800. For many years the group has been able to sell cards and favours in Addenbrookes Outpatients Dept but this has now ended as Addenbrookes Charitable Trust has withdrawn the space. We are trying to find a space elsewhere in the south of the county, so if anyone can help us with suggestions, please contact Andrew on 01954 251353 or 07811 389342, email [andrew.j.norton@pdmassociates.com](mailto:andrew.j.norton@pdmassociates.com).

Thanks again to the Cottenham Fundraising Group for their ongoing fundraising efforts.

**Forthcoming events:** If you are planning a fundraising event please let us know by emailing [cambridge@mndassociation.org](mailto:cambridge@mndassociation.org). We are always willing to help if possible and can give advice on getting your event publicised and noticed. If you wish your raised money to come to the branch then please put this on any social media fundraising pages.

**Any other business:** Cynthia George read out a message from Liz and Lindsay, our RCDA's: "We are really grateful for all the hours the Committee, AVs and CSNs put into their work for the Association. We recognise how seriously you all take your roles and know that you put lots of time and effort in to your respective duties. It really benefits people affected by MND and, as RCDA's we appreciate the support from the Branch and Care volunteer team."

Val Kay thanked the Cambridgeshire Branch for all they do for plwMND and their families in the county. She highlighted the number of hours of time given to support, help and advice which was very much appreciated.

#### **Presentation by Dr Kirsten Kelly, Research Programmes and Partnership Manager at the MND Association.**

Kirsten gave a presentation entitled "Research, Past, Present and Future". She began by telling us that Jean-Martin Charcot was the first person to diagnose the disease (between 1865 and 1869) when he discovered that ALS/MND was a distinct disease. He first used the name Sclerose Laterale Amyotrophique in 1874. Despite our greater understanding of this disease, his original descriptions of the associated clinical and pathological findings of ALS have remained virtually the same.

Kirsten talked about the MND genes and the research undertaken under the auspices of the MND Association. As at 2019, of the 30 genes causing MND, 10% are familial and 90% sporadic. The Association was formed in 1979 and the first research project undertaken in 1980 with the first research paper entered in the Journal of Neurology in 1983. In 1996 the Research team headed by Brian Dickie had awarded 8 grants and at the same time the first and only drug, Riluzole, was available in the UK. Currently there are 90 projects and grants being undertaken by MNDA, broken down into Project grants (Biomedical and Healthcare), PhD studentships, Clinical Research Fellowships,

Non Clinical Fellowships and other small grants, and the Association also works with the Marie Curie Partnership. A Research Information Sheet is available on the MNDA website.

All this and much more was illustrated by Kirsten in a series of slides showing very clearly what was being undertaken. She also talked about the MND register.

Finally she talked about Gene Therapy including the first faulty gene SOD1.

This presentation was very clear and we all appreciated the information we were given.

**Maire Collins: Branch Secretary**

### **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](http://easyfundraising.org) and find out more.

### **Are you fundraising for MND?**

If you or a friend are thinking of fundraising to help the MNDA to help others, then please let your local branch know.

We as a branch can assist with giving a short speech or getting you promotional posters and flyers. We can also help to get you T-shirts for your helpers and to also point you in the direction of your press offices.

To contact us: either email Simon Crooke on: [cambridge@mndassociation.org](mailto:cambridge@mndassociation.org) or the branch secretary on: [secretarycambsmnda@gmail.com](mailto:secretarycambsmnda@gmail.com)

**MND Association 40th Anniversary  
“Thank you” Garden Party for  
Volunteers  
Friday, 21st June 2019**

Today it was the Summer Solstice, the Global MND Awareness Day and a much appreciated “Thank you” for Volunteers of the Association Day!

As a volunteer of about 14 years, I was delighted to be able to accompany Cynthia George, Branch Chair, to this very special occasion which was kindly hosted by the Duke of Buccleuch at Boughton House, Kettering. Brenda Parkes as an Association Visitor and Care Services Navigator, for Cambridgeshire, joined us.

We were given a very informative and easy to understand presentation by Professor Ammar Al-Chalabi from King’s College London. We are hoping that we may be able to show this talk to you all at a Get Together. The research into a cure for MND is progressing worldwide especially in the field of genetics.

We also heard from Dr Brian Dickie, Director of Research Development at the Association, about his research work and contacts throughout the world. Nick Goldup, Director of Care Improvement, told us how good it is that 22 special Care Centres have been established throughout the country and how keen he is to help patients to use new technologies and to improve care services in every way.

The Duke of Buccleuch has become enthusiastic about helping our Association through his support of the Scottish Dottie Foundation.

He personally guided us on a tour of his gardens, chatting to many of us. We were also pleased to be able to see several of the

main rooms of the House. The vistas over the parkland were beautiful.

Also at the day were Jane Hawking who was married to Professor Stephen Hawking for over 25 years, his daughter, Lucy Hawking and daughter-in-law, Katrina, who had flown in from America. They all actively support the work of the Association.

We were all very interested to hear stories from four of the original Founders of the Association when they all became acquainted in 1978 as they were unable to obtain information or any support. In those days no one seemed to know anything about the dreadful disease. One of the Founders said that he sincerely hopes that there will be no need for a 50th Anniversary because a cure will have been found.

**Veronica Angus  
Volunteer and Committee Member**



**Brenda Parkes, Cynthia George and Veronica Angus**

**Social Afternoon Get Togethers**  
**Wednesday 3rd April**  
**Peterborough Salvation Army Centre**

We had a small gathering at this venue. We had a pleasant afternoon with some of our committee members present to talk with our members. All in all a friendly afternoon for those who came along.

We had our usual cup of tea and nibbles to keep our strength up.

**Thursday 2nd May**  
**David Rayner Centre, Scotsdales**  
**Garden Centre, Cambridge**

You our members and friends turned out in force again at this excellent venue. There is always a lively and friendly atmosphere with much to talk about with each other – to me it seems to be more like “old” friends meeting up.

To keep the afternoon flowing we, your committee and Association Visitors come round with tea or coffee and offer support if needed. Sometimes I feel there is so much chatter we fade into the background, this is good and I personally feel we have achieved our aim in getting you all together to exchange ideas and support to each other.

**Wednesday 5th June 2019**  
**Ely Community Centre/Larkfield**  
**Resource Centre**

Our first afternoon at this new location slightly more towards the east of our county.

We welcomed quite a number of our members where we had a lively afternoon with lots of conversation going on round the table. An imitate atmosphere where everyone was able to talk to each other.

It is hoped when we return in November even more of you our members will come along.

**Cynthia George**



## Care Award for Chris Glover

I attended a recent awards ceremony hosted by the Carer's Trust (Cambridgeshire, Peterborough and Norfolk) after having nominated one of our fabulous association visitor's, Chris Glover. Chris has volunteered for the Association for nearly 20 years in various capacities, Association Visitor, committee member and Association Visitor Co-ordinator.

Chris was shortlisted for the category, 'Outstanding Contribution to Carer's Award' and she won! Chris has been a huge support not only to numerous families affected by MND but also to myself as RCDA over the past 15 years.

Congratulations to Chris for winning this award.

**Liz Cooper**  
Regional Care Development Advisor for East Anglia



## 4-wheel walker and powered chair available

The Branch has very generously been asked to pass on 2 items that could be useful to any of our members.

1. A powered chair that can be dismantled to fit into the back of car.
2. A four-wheel walker with a seat and carrier bag, that can be folded up for transportation.

If these items can be of use to any of our members they can be viewed at the home of Pam Wilkie, who can be contacted on: 01480 581240 / 07876207655

Please note all items advertised are arranged privately and are not endorsed by the MND Association or the Cambridgeshire Branch and offered as private transactions.

## Farewell and Looking back

Way back I was a Speech and Language Therapist working at the Peterborough District Hospital (before the 'new' Peterborough City Hospital was built).

It was during those years that I first came across a patient diagnosed with MND at a time when very few people had heard of the disease. I realised that I must learn more about this cruel disease. I had by that time met Debra Garside who was then the Regional Care Adviser for MND in our area. She was extremely helpful, and it was her guidance which increased my interest in MND. When I retired at 65, Debra approached me and asked if I had any plans for my future and I was roped in!

This was at a time when the Cambridgeshire Branch of the MNDA had almost collapsed. There was no Chairman, and the Secretary was very ill and had to stand down for health reasons. The treasurer also resigned and within weeks the remainder of the Branch Committee members had also stood down.

With the help of Jools Cook from the MND National Office (who has sadly since died), we began to rebuild the Branch, with Jools as Acting Chair. We managed to put together a new Committee, and the Cambridgeshire Branch was reborn.

At about this time I was among the first few to train for the new volunteer role of Association Visitor (AV), a role which I hope to continue for some time yet.

Looking back to the development of our Branch, we were awarded an OSCARR two years running for the 'Most Improved Branch' which I was privileged to receive at the Association AGM, on one occasion from Lembit Opic who was President of the MNDA at the time.

Over the past 18 years it has been a privilege to know so many people affected by MND and I have been inspired by the strength which families have maintained in the face of this cruel disease, some for many years.

I feel now is the time for me to ease off a little and it is with some regret that I left the committee in December 2018. I will continue my role as an AV for as long as possible and look forward to seeing my committee friends and members of the Branch at Get-Togethers for as long as I can.

With my best wishes to you all,

**Chris Glover**



Pam Wilkie's  
**OPEN GARDEN  
AFTERNOON**

with  
**Strawberries & Cream**

Live Music & Raffle

**SUNDAY 21<sup>st</sup> July 2019**  
**2pm to 4:30pm**

**Entry £5 per person**

In aid of

**mnda**

motor neurone disease  
association

CAMBRIDGESHIRE BRANCH

Pam Wilkie  
The Old Post Office, 36 High Street  
Hail Weston, St Neots PE19 5JW



# Cambridgeshire branch contacts

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## Registered Office:

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Registered charity number 294354  
To find out more about the Cambridgeshire  
Branch visit  
www.mndassociation.org/cambridgeshire  
www.facebook.com/cambridgegshireMNDA

## Dates of Get-Togethers in 2019

Weds 11 <sup>th</sup> Sept	Hemingford Abbots
Thurs 3 <sup>rd</sup> Oct	Cambridge
Weds 6 <sup>th</sup> Nov	Ely
Thurs 5 <sup>th</sup> Dec	Cambridge