mnda
motor neurone disease
association

Cambridgeshire branch

NEWSLETTER

EDITION 1 2024

CONTENTS

CAMBRIDGESHIRE BRANCH ANNUAL GENERAL MEETING

The Cambridgeshire Branch Annual General Meeting was held on 3 April 2024 at Hemingford Abbots Village Hall. Attending were Tanya Curry, CEO at MNDA, and 40 members and friends including two other members of MNDA staff.

1 **Welcome**: Cynthia George, Chair, welcomed everyone, including Tanya Curry, our CEO of the MND Association, and thanked the Village Hall Management Committee for the use of its hall and facilities.

2 **Apologies**: were received from 28 members and friends.

3 The Minutes of the 2023 AGM were agreed as correct with no matters arising.

4 **Chair's Report**: It has been a privilege to lead the Cambridgeshire Branch for another twelve months. We have welcomed new faces into the MND family but very sadly some of our members have regrettably died. The diagnosis of MND can be a massive shock. Luckily in Cambridgeshire we have the MND Cambridge Care Centre and the Peterborough Clinic. Both these offer professional expert guidance and support.

The Cambridgeshire Branch Team, all volunteers, are always on hand to help you through your journey with MND. The majority have had first-hand experience of a close one who has been affected by MND and will be pleased to chat with you. The Association's Connect helpline is also on hand to give guidance and answer queries.

Our volunteers work extremely hard and give up much of their time helping members and promoting MND. We may not always be able to achieve 100% of what you our members would like but we will always try to do our best for all of you, we work as a team.

Cynthia introduced the Committee members, CSN and AVs to those attending.

All our volunteers are invaluable, but a special thank you to Simon Crooke who has returned as a volunteer, and is once again our Branch Fundraising Co-Ordinator. His enthusiasm and fantastic efforts in raising funds for the branch have been phenomenal.

I have been volunteering with the branch since 2008 and have been Chair from 2016, and feel lucky to be supported by such talent and thank all the team for their dedication and hard work.

At present some volunteering roles remain vacant. Can you help? If you feel you could, please have a chat with me or any of our committee members. Help in many ways is needed, as a committee member, on the secretarial and admin side, or compiling the newsletter to name a few. More Association Visitors who offer continuous support and advice are also required.

A full programme for 2024 is in place for our monthly social afternoon gatherings. These are relaxing, friendly and lively events, all are welcome to come along.

I finish with a massive thank you to everyone for your support. The branch will continue its efforts to campaign, fundraise and raise awareness of MND until we have a WORLD FREE FROM MND.

5 **Treasurer's Report**: Presentation and adoption of accounts: Brian Smith, gave his report as follows:

FINANCIAL REPORT FOR THE YEAR ENDING
31 DECEMBER 2023

2023 was a much better year. Income increased significantly with the return of our star fundraiser Simon Crooke. The Cambridgeshire Branch was able to increase Expenditure proportionally to care for people living with MND. Total income for 2023 was £48,498 and expenditure £53,427.

6 **Election of Branch Committee**: Cynthia George reminded delegates that only members may vote. The following were re-elected with an en bloc vote. Those standing for election:

Cynthia George: Chair and Branch Contact

Maire Collins: Secretary and Financial Support Co-Ordinator

Brian Smith: Treasurer

Current Committee members and their responsibilities:

Veronica Angus: Committee member
Simon Crooke: Fundraising Co-Ordinator and Facebook Editor
David Griffiths: Webmaster
John Morren: Committee member
Pam Wilkie: Committee member

7 **Fundraising** (Simon Crooke) A very successful year and a huge thank you to everyone who has fundraised for the branch. We have had golfers, bakers, quilters, runners, walkers; community cafes, and donations 'in memory of', art exhibitions, a concert; the branch has had bucket collections at train stations, stalls at Christmas Fairs and Shopping Centres and more. The amount raised has been phenomenal and it's a big thanks to our community in Cambridgeshire for all they do.

In 2024 we will have two Walk to D'feet events, Ely to Peterborough at the end of May, and our Grafham Walk in September as well as our skydiving day in August.

We won't stop until there is a cure.

8 **Any other business**: Long Service Award was presented by Tanya Curry, CEO, to Pam Wilkie; a 15 year award which has included a term as Branch Chair and AV as well as being a current branch committee member.

Liz Cooper, Area Support Co-0rdinator, thanked the Committee members, CSN and AVs for all the work they had put in over the last year. She was particularly pleased to see Simon Crooke back in England working hard on fundraising.

Roger Widdecombe, the Association Area Fundraiser covering East Anglia, thanked all the volunteers who help in any way with the branch, for the terrific amount of work they all do.

This concluded the formal part of the AGM.

Lunch break: An interval for lunch took place with time to socialise and meet new friends.

9 **Presentation** by Tanya Curry, CEO at MNDA

Tanya gave a talk about her first year as CEO which she had enjoyed very much. Because of Covid, the Association needed to update the way it works which takes time, and some discussions have been taking place with her new leadership team at headquarters about how to go forward in 2024.

Maire Collins, Cambridgeshire Branch Secretary.

Above is a short summary of the AGM, for a full copy of the minutes please email Branch Secretary at secretarycambsmnda@gmail.com

CAMBRIDGESHIRE BRANCH NEWSLETTER DESIGNER & EDITOR

We have recruited a new volunteer newsletter editor for the branch, Jo Berg, and welcome her to the Cambridgeshire Branch Team.

Firstly, a massive thank you to our previous editor, Anthony Flynn. His flair and innovation brought our Cambridgeshire newsletter into a new era. He dedicated a lot of time and effort to achieve a professional looking publication.

He became our editor many years ago before becoming a committee member from 2010. Regrettably for Cambridgeshire he moved away from the area several years ago but fortunately for us he continued to edit our newsletter until we were able to recruit a new volunteer.

This edition is Jo's first and we look forward to her contribution as a volunteer and becoming part of the Cambridgeshire Team.

A few words from Jo...

I am a graphic designer by trade, I graduated from De Montfort University and have recently taken early retirement as Creative Lead for the Premier Travel Group. Prior to working at Premier I worked freelance for many years and also have worked in design agencies throughout Cambridgeshire. Now retired I am re-learning to do pottery and I have also got my own small business making scented candles, which I started during lock down.

I am very keen to give something back to the MNDA as the help my mum received from the Association was fantastic, this is ideal opportunity for me to do so. I'm looking forward to getting involved with the Cambridgeshire branch and welcome any information and feedback for future editions of the newsletter.

FUNDRAISING

Hi everyone, I hope you are all enjoying the English summer. Fundraising has as normal been fast and furious so far this year with loads of our fundraisers doing a magnificent job

In my last post I told you about the lovely folk at Nellies Café in Sutton, well they have finished their fundraising for the branch and I was invited down to the café for the cheque presentation. Of course I had to sample the fine cakes and cups of tea that Nellies do. I was amazed when I was presented with a cheque for £1,000. A huge thanks to all at Nellies. Pic 1

Serpentine Green

We have had a stall at Serpentine Green again which raised funds and awareness of MND and the branch. We were also at the Coates village fete, similarly raising awareness and funds for the branch.

We have also helped out at Gog Magog Golf Club with the Captain's Day and the Charity Day. This is an ongoing fundraiser and I will update you with how this comes on.

Gog Magog Golf Club

Nellie's Café

Sarah Craddock and her team have raised funds for the branch by holding a fantastic cake stall. Due to bad weather the event they had planned was cancelled but they found a new home at a local football tournament.

Sarah and her team

Isla and her stall at Over Village Carnival

Ann Graham is another of our amazing fundraisers, she and her son Alistair are doing the tandem sky dive for us. Isla, Ann's daughter, held a stall at Over Village Carnival selling handmade crochet items. Thank you again Ann we really appreciate all you do for us.


St Neots Walk & Talk4Men

The St Neots Walk & Talk4Men invited me to their big cheque presentation. The event was saddened by the passing of John Woods who was with them when they did their virtual walk, Land's End to John O'Groats. The lads did a fantastic job and raised over £2900 for the branch.

Tracey Taylor and her great group of fundraisers have been doing some marvellous fundraising. This included a fun day cycling and rowing at Grafham Water. Tracey raises funds and awareness after losing her husband Lee to MND. Thanks to all of you.


Tracey's event at Grafham Water

Pam Wilkie held her annual Afternoon Strawberry Tea at her home at Hail Weston in July after a month's postponement because of Covid. It was a glorious summer's afternoon which encouraged many people to attend. Sue Hallifax and her partner John sang and played the guitar as background music which was much appreciated. Refreshments went beyond the strawberries, scones, jam and cream - Victoria sponge, chocolate gateau, not forgetting cups of tea or coffee and cold drinks, something for everyone to enjoy. There was a raffle with many prizes to be won. It was an early start and many thanks to Pam for opening her garden to fundraise for the branch and the volunteers for helping where needed.

Unfortunately we only managed to do three railway collections this year but as normal we were warmly welcomed at Peterborough, Huntingdon and St Neots by the staff and the customers who dug deep and helped us take just over £1,400.

As I sit here writing this we have had to cancel our Tandem Skydive day and I know this has been hard on our 18 volunteers who were due to jump but the English weather has stepped in and due to high winds the British Parachute Association had no choice. Safety comes first, always. So our new date is Sunday 08 September.

On Sunday 22 September we have our annual Grafham Water Walk to d'Feet starting at 10am, and again this year thanks to the kindness and generosity of Anglian water we have once more got free parking. Please let me know if you're attending so that I can get your free ticket. Entry is £10 per person but if you get sponsorship of £20 or more then you walk for free. This is a great day and many walkers walk in groups chatting and laughing.

Next year I am planning a really hard challenge we need 10+ people to make it viable. We are looking at doing what the SAS call the Fan Dance Pen Y Fan in Wales. It's a gruelling 24km march, the SAS candidates are allowed 4hrs 10mins but I'd like to think our brave volunteers could do it in 5hrs. If interested please email me on the normal email.

If you want to fundraise for the branch and need any help then again please email me I will do all I can to help you. If you have an idea for a challenge then again please contact me.

Thanks for reading and we wish you a great autumn and all the best for our fundraisers who without them we as a branch could not operate.

Simon

simon.crooke@mndassociation.org


Pam's Afternoon Strawberry Tea

SPOTLIGHT ON GIL BOYD
BEM (British Empire Medal)

I served with the Second Battalion The Parachute Regiment until November 1974 doing numerous tours in Northern Ireland.

After leaving the Paras I joined Cambridgeshire Constabulary, November 1974-2004, doing 30 years service in which time I served in Patrol, Traffic and 15 years as a Police Underwater Search Unit Supervisor.

On the disbandment of the Underwater Search Unit in 1988, my last 15 years I was responsible for setting up the Force Technical Support Unit, CID at HQ. This unit covered all aspects of CID Operations and provided support to all crime matters.

Due to its responsibilities, many innovative bespoke pieces of equipment were built especially for CID Operations, such as the first tracking device fitted into cycles to reduce theft in Cambridge City, which proved a very effective remedy to hundreds of cycle thefts in the early nineties with many organised City criminals brought to book!!

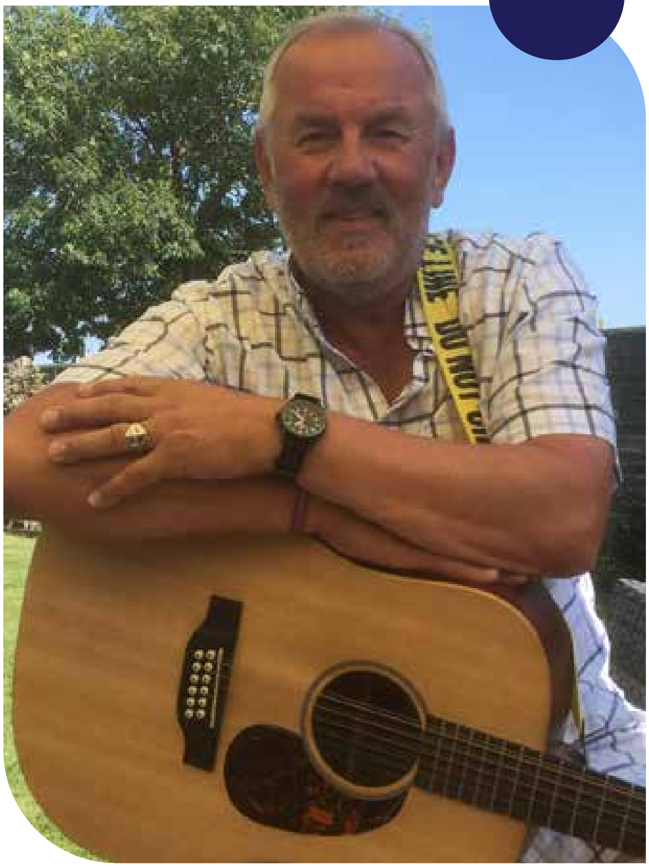
Following the Hungerford Massacre, where the use of Police Dogs was paramount at the time in searching for Michael Ryan, I developed W.O.L.V.E.S (Wireless Operational Link & Video Exploration System) which was in effect a miniaturised camera on a head harness of a Police dog and an integral microwave transmission system to transmit live images and sound from within a stronghold to outside officers safely.

This innovation won a Home Office Award for that presented by the then Home Secretary, Kenneth Clarke.

Many Forces and Military units around this country and the world use this system which has gone from leaps and bounds since those early days.

Following the IRA Breakout at Whitemoor Prison in Cambridgeshire in 1994, I developed a wrist worn miniature microwave receiver I called SKYNET, so that police officers on the ground could view the images directly from the Police Helicopters camera.

This invention won the BBC Television Tomorrow's World "Inventor of the Year Award" in 2000. SKYNET was used by many Police Forces and the Military.


Gil Boyd

Suffice it to say, I have invented many practical items including a torch that won an MOD contract after 4 years of exhaustive trials in the Gulf, receiving glowing reports after directly saving the lives of two Bomb Disposal personnel in Iraq through its performance in finding trip wires with the power of the bulb. It was issued to soldiers serving in both Iraq and Afghanistan on those dangerous EOD duties.

I was responsible for forming the Home Office Hostage Siege Technical Requirements Group in 1998, which I setup to develop technical solutions to meet the challenges of hostage taking in domestic sieges, and also aircraft hijack situations in the UK.

Many of the inventions I developed are still in use today.

STANDUP – 'Serious Traffic Accident Notification Directing Unsuspecting Public', is a standalone sign I designed. This was quickly deployed on the approach to road traffic collisions following the death of one of our Traffic Officers in Cambridgeshire, recognised as highly effective for road safety.

The VIPER UDV, Underdoor Viewer - I designed for Police and Military Rapid Intervention teams to see and hear what is going on in a room before entering by sliding under a door a thin 3.50mm blade.

Additional but very important ingredients that perhaps shed light on why I became an inventor:

I have always been innovative, which is probably reflected in dreaming up some of the daring stunts I carried out whilst serving in Cambridgeshire Police with a colleague, PC Bob Reynolds who sadly died whilst serving on the minors picket lines in Kent in 1985.

My son, Tom, who is now 44, served with my old unit the Second Battalion The Parachute Regiment, recently retired from the Army after 24 years. When he was born on 31st December 1979, he had a serious hernia of the stomach, and was rushed by a colleague in a traffic car from Cambridge to Great Ormond Street Children's Hospital where he remained for 6 months in Intensive Care.

They saved his life, and I promised to raise £100,000 pounds in 5 years for them. An equivalent of £1 million today. I had to use all my innovative ideas to come up with real fundraising ideas to achieve this which included:

1. Carrying out a DEATHSLIDE from the top of London Bridge into the Tower Thistle Hotel car park.
2. Carrying out a World Record of Parascending under 10 of London's Bridges on the Thames pulled by power boats and assisted by the Thames Division at Wapping, Met Police.
3. Carrying out a World Record of Abseiling the BT Telecom Tower in London as the world's highest building at the time.
4. Carrying out a World Record of the longest Deathslide across the Thames from the top of the London Weekend Television building on the south bank.
5. The last event was to thank all those Police and Military personnel who had assisted me to raise the £100,000 by having a special dinner at The Guildhall in London in 1986 where HRH The Princess Royal attended as the guest of honour.

Video footage and press releases are now retained on www.stunts4charity

The reason I mentioned the fundraising, is that it applied my mind to be able to accept that NOTHING was IMPOSSIBLE if you really applied yourself. This followed me through my career in the Police as someone who could develop and produce equipment from the various personal experiences I had encountered and the risks experienced by both Police and Military personnel along the way.

Sadly, I was seriously injured in a Police car collision in 1985 where a psychiatric patient I was escorting to Fulbourn Hospital in Cambridge grabbed the steering wheel of the police vehicle, crashing head on into a coach travelling in the opposite direction.

I retired on the 11th November 2004 after 30 years in the Police service and continued to develop equipment for the Police, Military and Prison Services.

My wife Theodora is an ex-Police woman who served in Cambridge where we met, 45 years ago, this year 2024.

I was a Patron of The Children's Hospice at Milton when it formed. I also started The Pidley Mountain Rescue Team Charity Club and was Chairman for 15 years. It was setup to buy a piece of equipment for a disabled person within Huntingdonshire and was the only registered charity in the UK where every single penny raised went to achieving that aim. The charity closed down after COVID.

I was diagnosed with Motor Neurone Disease in November 2022, which started from a "dropped foot" as I walked.

I host the Veterans MND zoom meeting once a month for those suffering from the disease who served in the Royal Navy/Royal Marines, Army and Royal Air Force, around the country.

I am so fortunate that my journey with the disease currently allows me to speak as my legs get weaker and I can no longer walk.

Gil

(aged 71)

The Branch would like to thank Gil for all he has done for us. His song living with MND has raised over £4k and we wish him and Theo all the best with their new life in Yorkshire.

TWO NEW VOLUNTEERS HAVE JOINED THE CAMBRIDGESHIRE TEAM

It is great to welcome to the Association Visitor/Care Services Navigator Cambridgeshire Team a new member, Gary Bennett. He has undertaken the MND Association's AV training for volunteers and is now fully on board. He joins our hardworking AVs, Jenni Barnett and Sue Hallifax, and Brenda Parkes, Care Services Navigator.

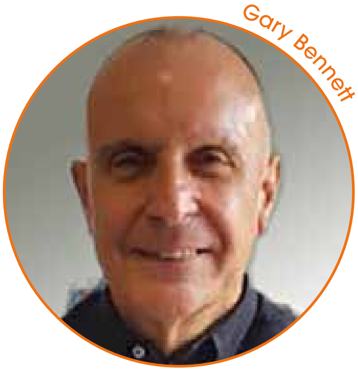
We also welcome Christina Watson to the team as a Support Volunteer for Carers. She has a particular interest in providing support for carers and bereaved carers.

GARY BENNETT

My working life and career has been in the field of administration and data management. Alongside this, I have actively engaged in voluntary work to support others in various ways. I have always held an interest in the field of health and social care and the voluntary roles I have undertaken include being a Samaritan, mental health advocate, a bereavement support worker and doing general casework.

I was motivated to join the MND Association as a Volunteer Association Visitor so that I could offer the use of my transferable skills to support those living with and affected by the demands and challenges that Motor Neurone Disease presents.

When not volunteering, I enjoy walking and trekking, yoga, meditation, reading, listening to music and life-long learning by doing courses.


Gary Bennett

CHRISTINA WATSON

My name is Christina Watson and I have joined the MND Association branch in Cambridgeshire as a Support Volunteer for Carers.

Born and educated in New Zealand, I came to England for six months in 1970 and have been here ever since. I have a background in social care and education - now retired and living in Cambridgeshire.

A dear friend was diagnosed with MND in 2023 - a huge shock for him, his family and friends. This triggered something within me to do something to help the Association which has an inspirational team of volunteers.

Having been a carer twice, I know only too well the devastation and turmoil of caring for a loved one with a terminal illness can be. The feeling of isolation thinking you are the only person who is going through this very difficult time.


Christina Watson

I am passionate about providing support where possible for carers who are affected by MND. Working alongside the Association Visitors and other volunteers within the Cambridgeshire Branch, I hope we can support you in any way we can.

The same applies for bereaved carers as well.

Please contact me if you wish to have a chat. I am not a therapist but I am more than happy to do what I can to help you through this difficult time.

Mobile: 07543 965640

Email: christina.watson@mndassociation.org

SOCIAL AFTERNOON GATHERINGS


Hemingford Abbotts
Aug 2024

For 2024 we have five venues where we meet-up for you our members to gather and have a relaxing time, see some "regulars" and also new faces. These are friendly relaxing occasions with the main aim being to provide an atmosphere where you feel "at home" and able to exchange ideas and thoughts.

We have already held afternoons at all five venues with the last one in August at Hemingford Abbots (at time of writing this report). It was fantastic to see many of you joining us on the 7th. We unfortunately said farewell to Gil and Theo Boyd who are moving to Yorkshire to be nearer family. Some of you will remember he entertained us at Hemingford last year playing his guitar and singing. We wish him and Theo all the best.

The online chats/meetings continue and are hosted by members of the Association staff. The link on the MND Association's webpage with details and information on who each group is aimed at supporting is on the link below or use the QR code:

https://www.mndassociation.org/online-support-groups

Those covering the South East Region from Isle of Wight and Jersey to East Anglia:

Recently Diagnosed Group

Peer to Peer Support Group

Online Group for Carers (daytime)

Open to across England, Wales and Northern Ireland:

Online Group for Carers (evening)

Veterans Support Group

PMA-PLS Support Group

Tracheostomy Support Group

Open across England:

Let's Talk Continuing Healthcare (CHC)

we need your help

The branch is regularly looking for volunteers. Can you help? Please get in touch to have an informal chat as we are sure we can match your skills to a volunteering role.

THE MND ASSOCIATION FINANCIAL SUPPORT GRANTS

Financial support grants are offered to anyone living with MND and their close family. All grants need to have an application form completed and supporting documentation provided as appropriate. Any grant funding needs to meet certain criteria and there is a maximum amount for each grant and in a rolling twelve month period.

MND Support (Care) Grant: This is available to anyone with MND. This grant may help towards home adaptations and equipment not available from statutory funding but is unlikely to be for the full cost. An assessment by a qualified health or social care professional needs to be undertaken and the application form signed by that person.

Quality of Life Grant: Applications may be considered to purchase equipment, services or facilities which help maintain independence, dignity, comfort and social connections or to promote the well being of the person with MND and immediate family.

Carer's and Young Carer's Grant: Supports the main unpaid carer (aged 16+) for someone with MND to allow them to take a break from caring duties and/or promote the well being of the carer or young carer and can be applied for up to twelve months post-bereavement.

Children and Young Person's Grant: Must be age 18 or under and reside with the person living with MND. A grant may be considered towards anything that helps the young person in their day-to-day life and can be applied for up to twelve months post-bereavement.

Cost of Living Support Fund: This one-off funding is currently available to a person living with MND who needs support towards household bills, food shopping, energy bills etc. This fund is under continuous review.

Grant application forms may be completed by any family member, Association Visitor, Health or Social Care professional on behalf of the person living with MND **except** the Support (Care) Grant which **must** be completed by a relevant Health or Social Care Professional.

For full details and application forms, please visit

www.mndassociation.org/financial-support-information-for-people-with-mnd

or contact

Maire Collins, Branch Financial Support Co-Ordinator,

secretarycambsmnda@gmail.com.

The forms have recently been updated and can be downloaded from the website or are available to receive, by email or post.

HOW TO DONATE to your local Cambridgeshire Branch

If you would like to help your local branch by making a donation there are various ways to do this:

CAMBRIDGESHIRE BRANCH JUSTGIVING PAGE

https://www.justgiving.com/team/TeamCambridgeshireMNDBranchx

TEXT TO DONATE

Text MND4CAMBS to 70085 to donate £5

Texts cost £5 plus one standard network rate message, to increase your donation add10/20/ etc

BACS PAYMENT

Account Name: MNDA-Cambridgeshire Branch

Sort Code: 30-96-09

Account No: 02968788

CHEQUE

Please make payable to MND Association Cambridgeshire Branch

For further details please contact

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brian.smith@mndassociation.org 07711 206452

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

All funds raised locally go directly towards helping our members and family living with MND

CURE FINDERS

What is Cure Finders?

Cure Finders is the community that believes MND can be beaten. It is the connection between you and MND research. For a monthly donation, you will get a behind-the-scenes look into and exclusive updates from the front line of research. You gain a deeper understanding of MND – and in return, 100% of your support will help fund vital research.

You'll get to know the researchers who are leading the way, gain a deeper understanding of their work – and become a vital part of the community that believes MND can be beaten.What do I get?

By becoming a Cure Finder, you will gain access to the Cure Finders Hub. Here, you can explore the labs and get to know the scientists on the front line of MND research, through articles and interviews. You will also receive research updates and news via quarterly emails. Becoming a Cure Finder is one of the best possible ways you can support MND research. Because every single pound you donate each month goes directly towards it. In return you'll get online access to behind-the-scenes updates from MND researchers.

You don't need to be an MND expert to help find a cure. You don't need to be a scientist. You just need to be you. Whatever your background, whatever your reasons for getting involved, you have something to offer in helping find a cure. Month by month you could help bring that cure closer, while giving families hope.

https://www.mndassociation.org/get-involved/cure-finders

"We're making progress - together, we will crack this"

Dr Nick Cole
MND Association
Head of Research

SKY DIVE CHALLENGE

So after failing to get this year's Sky Diving Challenge done on 25th August the majority of our brave jumpers did so on Sunday 8th September.

After a two hour delay due to heavy rain, it was a blessing to see the sun come out. Our brave jumpers were called up in groups of four to meet their tandom instructor. After being kitted up and a few tests they boarded the plane. They all jumped from a height of 13,200 feet, about 2.5 miles up. Free falling for about 15-20 seconds before the Parachute opened.

All of our fundraisers made it back to terra firma without injuries and everyone had a great time.

We have to say a huge thanks to all 19 jumpers for helping to raise in excess of £11k.

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2024 DATES FOR CAMBRIDGESHIRE SOCIAL AFTERNOON GET TOGETHERS

Wednesday 02 October	Histon & Impington Royal British Legion Hall
Wednesday 06 November	Hemingford Abbotts Village Hall
Thursday 05 December	Cambridge David Rayner Centre

These are social meet-ups for those living with MND, their partners and carers which provide an opportunity to chat and make new friends in a relaxed and friendly atmosphere. There is also the opportunity to meet the team who support the Cambridgeshire Branch - committee members, Association Visitors and general volunteers. All team members are volunteers.

CAMBRIDGESHIRE BRANCH CONTACTS

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To find out more about the Cambridgeshire branch visit
www.mndassociation.org/cambridgeshire

www.facebook.com/cambsmndbranch