

Chiltern Branch

Newsletter 2023

July

Upcoming Events

**Chenies Manor
Gardens
20 September 2023**

**Support Group –
18 Sept 2023
14.00 – 16.00
Cedar Barn,
Hazlemere,
HP15 7DW.**

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Welcome to our Summer Newsletter we hope you enjoy reading it and hearing what the Chiltern Branch Volunteers and supporters have been up to over the past three months since we last updated you.

Our new Chair!

On the very sad death of our Chair - Richard Coleman, Carmel Grant, Vice Chair and Association Visitor has taken on the role of Chair Chiltern Branch.

Carmel says "It was such a shock to all of us in the Chiltern Branch when Richard died so suddenly. Richard and I made a good double act – me being the Robin to his Batman and he is sorely missed.



I know many of you already through attendance at the Cedar Barn Meetings and our many fundraising events throughout the year. For those who don't know me, I've been a volunteer with the Association since 2019. As with many people who volunteer, I have personal experience of MND. My husband Martin died of the disease in 2014. As well as the Chair role, I will continue with my AV role as this is personally very important to me. The Committee, all volunteers and the MND Association have been so supportive of the transition and I know we will continue the good work that Richard started all those years ago.

One of Carmel's first tasks as Chair was to attend the MND Association Care Showcase in June at Boughton Hall Kettering. The event showcased the benefits and power of the Association's Support Grant Programme. The event was attended by people living with MND and their carers, volunteers, Health Care professionals and Association staff including the CEO Tanya Curry. The event was also attended by our Royal Patron, Princess Anne who took time to speak to all the table groups and hear stories about the impact of support grants.



If you have any questions for Carmel or suggestions on areas of focus for the Branch, please contact her via chiltern@mndassociation.org

Branch Recruit

First of all a big welcome to our new Association Visitor – Helen Gallop. Helen completed her training in the Spring and now is a fully fledged AV supporting her first family.

Helen lives in Marlow with her husband and two daughters. Helen Says “I’m a full time Mum actively involved in my daughters' schools. I am a school governor as well as regularly supporting in classes. I previously worked as a physiotherapist in the NHS for 10 years and specialised in working with people with neurological conditions – this included working with people with MND. Now my daughters are both at school, I want to take on a new role in which I could help and work with people.

Welcome again Helen and we look forward to working with you.

Introduction to Matthew – our Area Support Coordinator

Introduction to our new(ish) Area Support Co-ordinator Matthew Hollis. Matthew replaced Susannah who moved to a different area in January and he has been working with us since January.

Many of you have met him already at our monthly support meetings or one of our fundraising events where he seems to have taken on the role of chief washer upper! Matthew says “Hi, I’m Matthew and I’m the Area Support Co-ordinator (ASC) for the Thames Valley patch (Buckinghamshire, Oxfordshire and Berkshire). My role basically consists of looking after our volunteers and branches/groups in the area, supporting people living with MND, and linking in with health and social care professionals.

I’ve worked for the MND Association since 2013. Prior Before this I worked in conveyancing and I also have a degree in Environmental Planning and Management, but I joined the Association after my Mum died from MND in 2011 (I also lost my gran to MND in 2002 and my great gran in 1954). I started out in the Care Admin team before becoming the Communication Aids Co-ordinator in 2015, which I did for about 7 years. This involved looking after our equipment loan service, but I am most proud of the work I undertook to develop our voice banking information and services since those early days some eight years ago.

Following the pandemic I felt a strong urge to ‘get out there’ and get more connected with our volunteers and ultimately people with MND and their families, and I was lucky enough to secure the position of ASC.

Outside of work I am an amateur racing driver and I compete in the Citroen 2CV racing championship. I am also a keen traveller and have used this to do various awareness raising and fundraising activities, such as driving to the Arctic Circle and going from Lands End to John O’Groats without the use of a map. Getting in touch: Email:Matthew.hollis@mndassociation.org, Tel: 01604 800632

Volunteering

We would welcome applications for an Association Visitor in the North of Bucks or anyone who can offer ad hoc support for events, including baking cakes. If you would like to know more about volunteering with the MND Chiltern Branch – please contact our Area Support Co-ordinator Matthew Hollis on 01604 800 632 or matthew.hollis@mndassociation.org.

Fundraising

We continue to work hard to fundraise and meet our target of £30,000 for this year. Currently we are at £19,528.10.

We are so grateful to all those below and many others, for not only raising much needed funds to support local families, but also raising awareness of the disease which currently impacts more than 40 families locally.

A big thank you to all who have supported our fundraising efforts this year. In particular to:

- **Institute of Gas Engineers** Annual Conference at the Holiday Inn Bloomsbury who chose the Chiltern Branch as their nominated charity in honour of their long standing and hugely respected colleague – Chris Bielby.
- **The Rugby 7's** event at Aylesbury RFC in honour of Graham Bird who sadly died December 2022. The event was organised by James Bird – Graham's son, and attended by Debbie, Graham's widow and funds raised donated to the Branch. Several local school teams participated despite the heavy snow on the day.
- **The Great Missenden 41 Club** nominated us as their chosen charity for last year and raised £1500 handing over a cheque to Carmel and Vicki following dinner at The Gate pub in Bryant's Bottom. Thank you to all members of the 41 Club for their hospitality and generous donation.
- **Bledlow Manor Gardens** Thanks to Lord and Lady Carrington for allowing us to use their gardens for a fundraising day on Friday 16th June. We were so blessed with the weather and the gardens were in full bloom. The new indoor tearoom facility was also a blessing as it provided some much-needed relief from the heat! It was a very popular event raising over £2,200.



- **The White Lion Pub - Cryers Hill** – a big shout out to Sarah and the team at the pub for running the monthly quiz to support us. To date this year they have raised £1771.14. The only fly in the ointment is that your volunteer team appear to be stuck in either last or second from last place every time. But we're ever hopeful....! White Lion Quiz 1st Wednesday of the month.
- **Princes Risborough Golf Club**
It has always been a tradition at Princes Risborough Golf Club that the Men's and Ladies Captains select the charities that they wish their members to support during their Captaincy year. This year the Ladies Captain, Jill Peppett, chose the Motor Neurone Disease Association.

MNDA is important to Jill as a good friend of hers suffers from this dreadful disease. Her year as Captain started in November 2022 and to date the ladies have raised £2036. This has been through a Charity Quiz Night, an Eclectics competition, Captains Drive-In, various sales of kit, plants, and team events.

Jill says “We held a Race Night over the weekend which raised a further £850 with hopefully some more to come through the auction of a copy of the Charlie Mackesy picture of Kevin Sinfield carrying Rob Burrow over the finish line at the Leeds Marathon earlier this year.

We also have other events planned – a Charity Day, a Bingo Night, an Autumn Raffle to name a few. Our target is £4,000 by the end of October and we are very hopeful that we will achieve this. Our incoming Ladies Captain, Sue Pomeroy, is going to continue to have MNDA as the Ladies charity next year and she hopes to match the funds raised this year – or perhaps a little bit more. We appreciate the support we have had from the Chiltern MNDA group and David Alexander in particular. Thank you to everyone who is supporting our efforts.”

- **Our Head of Fundraising** – David Alexander has added a further £1000 through sales of donated items on EBAY. This brings his total raised since starting the challenge during lockdown to an impressive £15000! David says “If you are having a clear out and have something that you might ordinarily donate to a charity shop, you might want to consider contacting me and I will collect from you. I don’t take clothes or furniture. The trick is to establish the item’s provenance – if it has a good story I can turn it into cash. The advantage of EBAY is that when the item sells, it is paid for immediately. Each month I transfer the net proceeds to the Chiltern Branch of the MND Association. Please feel free to contact me with any donations at david.alexander@mndassociation.org or call me on 07931766888.

- **Charlies Challenge**

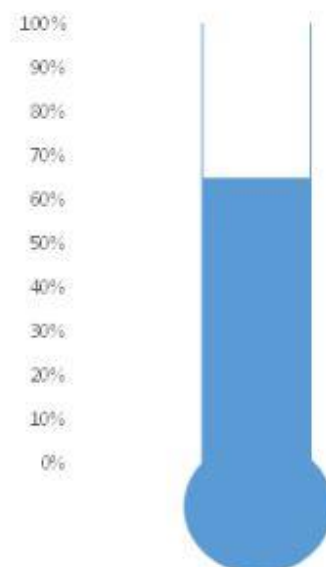
Our very own Charlie Mc Nicoll- Association Visitor, is taking on the awesome challenge of climbing Ben Nevis on 23rd August to raise money for MND Research. If you would like to support Charlie you can do so here:

<http://bit.ly/3K5dMOL>

The barometer shows our progress year to date. If you have any ideas on how we can hit our target in the next five months please let us know – all ideas and support welcome.

Month	income
Jan	5939.54
Feb	6318.78
Mar	1256.54
Apr	390.00
May	1862.75
Jun	3760.49
Jul	
Aug	
Sep	
Oct	
Nov	
Dec	
Total	19528.10
Target	30000.00

Achieved %	65%
Target %	100



The money we raise through fundraising is primarily used to provide financial support grants to people with MND and their families. This year to date the branch have awarded 14 grants with the Support Services team at the MND Association providing a further six grants. Please take the time to have a look at the attached chart which shows the types of grants we can provide and either talk to your Association Visitor if you have one or Chiltern Branch contact if you would like to know more or apply for a grant. The reason we work so hard on fundraising is so that we can provide these financial grants to local families so please don't be SHY!

On behalf of the Chiltern Branch of the MND Association, we thank all the above for not only raising much needed funds to support local families, but also for raising awareness of the disease that currently impacts 40 families in Buckinghamshire.

REMAP

We were very fortunate to have two Volunteers from REMAP attend our April support meeting to talk about the work they do. It was a very popular and well attended meeting and has led to a number of referrals for adaptations to support people with MND have a better quality of life. If you haven't heard of Remap –please click on the link to find out more and how they might be able to help you. <https://remap.cuk.uk>

Summer BBQ

The weather was kind to us on 11 July for our annual BBQ at Winchmore Hill Cricket Club and a good time was had by all. Thanks to David Alexander for being our chef and to Gaye and the team at the cricket club for putting on a lovely spread of salads and your hospitality in allowing us to use the facility.



David Bernstein

We were so very sorry to hear of the death of David Bernstein. David's wife Mae had MND and died in 2015. David was a stalwart supporter and fundraiser for the Chiltern Branch – joining us most recently at the White Lion Quiz in May 2023.

Cost of Living Grant

As you know the Branch is able provides financial support grants to cover for the cost of equipment or to assist in various ways in helping maintain quality of life. The Association recognises that with the current increases in energy costs and the cost of living in general, that some families may benefit from additional financial support. The Cost of Living grant is still in place for those who have not yet received one, so if you would like to make an application for this grant please contact your Association Visitor or email the Branch at chiltern@mndassociation.org.

Dates for the Diary

Support Meeting dates – no meeting in August, Mon 18 September, Mon 16 October, Mon 20 November and Mon 18 December 2023.

White Lion Pub Quiz dates

1st Wednesday of the Month. Contact Sarah if you would like to make up a table on 01494 713 900.

Chenies

We have again been able to have obtained permission to have an open visit at Chenies Manor Gardens on **Wednesday 20th September** between 2:00 and 5:00pm by kind permission of Mrs. Macleod Matthews. Refreshments will be available, with all proceeds going to the Branch. The Gardens include a sunken garden, herbaceous borders, topiary, a fountain court and a physic garden. Chenies propagate 1,500 plus dahlias each year and they are at their best in September. If you are able to help in any way on the day, we would be most grateful – our last visit was very successful with many people enjoying the gardens. Entry is £6 pp in advance (or £7 on the day) with no charge for children or people living with MND, nor for one carer accompanying them.

Ticket can be purchased in advance via Eventbrite at <https://cheniesmanorMND.eventbrite.com>



Local and national contacts

You can contact the Branch by email at chiltern@mndassociation.org or by phone on 07716 667582.

The National Office phone number is 01604 250505, and MND Connect, which is a helpline for those with MND, their families, carers and friends, as well as a source of information for Health and Social Care professionals is at mndconnect@mndassociation.org or by phone 0808 8026262.

***If you no longer wish to receive our Newsletters,
please either call us on 07716 667582 or
email us at chiltern@mndassociation.org***

MND Connect is available 9am to 5pm and
7pm to 10.30pm Mondays to Fridays.

0808 802 6262