



EDITOR'S NOTES

Welcome to the October issue of FightBack which is full of local fundraising stories and events that have taken place over the last couple of months and coffee morning dates to look out for.

As the season changes and the autumnal colours create stunning landscapes around us, it is nice, occasionally, to pause and take note of our surroundings. I look forward to hot chocolate, candlelight and time with loved ones.

This will be the last issue I will edit as I am expecting my first baby early next year. So, I hope you all have a restful autumn and winter and that 2024 brings you joy, hope and peace.

If you have a story you would like to send into the newsletter, please send your written piece and any photos (with permission from the subjects) to NNWNewsletter@gmail.com.

Jenny Sampson



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Norfolk, Norwich & Waveney Branch

Website: www.mndnorwichandwaveney.org.uk

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

Instagram: @MNDNorfolk

NN&W Branch Open Meeting

Sunday 30 July 2023 Open Meeting

The July Open Meeting took place on Sunday the 30th at Upton village hall. The MND community came together to swap stories, catch up and enjoy a delicious lunch together in the pleasant village setting.



The meeting was well organised by the enthusiastic volunteers and attendees were treated to a wonderful lunch, kindly made and delivered by Kelda of Kelda's Kitchens, which featured home-made sandwiches, savoury delicacies, and sweet treats.

Not only was the afternoon an opportunity to catch-up, but it also allowed everyone the chance and space for our branch's community to be of a comfort to one another, reminding everyone of the support that is available amongst families and friends currently exposed to similar experiences that an MND diagnosis brings about.

After everyone had satisfied their appetites, our Campaigns Organiser; Sue Heal delivered a talk on numerous topics of current local relevance, including how to access support more easily from Norfolk County Council, as well as providing awareness on upcoming campaigns.

We wish to thank, once again, everyone who came to the open meeting, as well as Kelda for delivering the delightful food! It is always wonderful to see the support that exists amongst the MND community, and we look forward to seeing you all at our next Open Meeting!



Advance Notice of Open Meeting and AGM:

Date: Sunday 28 April 2024

Time: 1pm - 5pm

It will be held at St Andrew's Church Hall, Eaton

Rachael's Camino: August - November 2023

Steven Howe met his wife Rachael in 1979 at Norwich Cathedral when they were at the UEA. Sadly, Rachael passed away from MND at the end of 2022. To celebrate her life, Steven is following 'Rachael's Camino', which is Spanish for path or track.

Starting out on the 1st of August, Steven set out on foot from Norwich Cathedral to walk all the way to Santiago de Compostela in Spain. A journey that he and Rachael covered parts of together and will cover 1300 miles to end in mid-November.

Steven's fundraising goal is to raise 1p for each mile he covers, which he has already beaten.

Rachael took part in a variety of drug trials, even though she knew they would not help her, but would wish the work will continue to help others in the future.

The money raised will be shared with 80% going to research and 20% to the Suffolk MND Support Group.



Malcolm Chubbock, our Committee Chairman, was there to wish him well and see him start his epic and personal journey.

Follow his journey on Instagram [@rachaelscamino](https://www.instagram.com/rachaelscamino) or on his JustGiving page: https://www.justgiving.com/page/rachaelscamino?utm_source=copyLink&utm_medium=one_page&utm_content=page/rachaelscamino&utm_campaign=pfp-share&utm_term=45ec7f14fc344ae58464bdf86a6620db



Companion Dog Show: 15th July 2023

On Sunday the 15th of July; Worstead Ringcraft held their Kennel Club registered Companion Dog show at Worstead Village Hall in aid of Motor Neurone Disease.

There were 23 categories in Pedigree, Crossbreed and Novelty classes and the event raised £1,070.

The Norfolk, Norwich and Waveney Chairman; Malcolm Chubbock, is seen here with the Worstead Ringcraft secretary Sheila Clark at the cheque presentation.

Charity Bridge Drive: Tuesday 24th of October

The Rotary club of Norwich St Edmund are holding a charity bridge drive to raise money for the Norfolk, Norwich and Waveney branch of the MND Association.

It will be held at Bawburgh Village Hall, NR9 3LL at 10am. Tickets are £50 per pair which will include a morning coffee and a two-course lunch.

To book your tickets either email Sandra Pennell at: Sandra.pennell2@gmail.com or call her on 01953 609199 or 07768 030791.



Caister-on-Sea Cream Tea Fundraiser: 24th June 2023

In June, Ann Franklin held a cream tea fundraiser in her back garden to raise funds for her local branch of the MND Association. Fritton Village Hall were kind enough to lend her cutlery, crockery, tea urns and tables for the day which was lovely and sunny.

She had 2 sittings of 40 people, most people turned up and they all had a scone, butter, jam, and clotted cream each and copious amounts of tea. Many of Ann's friends had baked scones and other cakes to sell, which varied from Weetabix, carrot, vegan chocolate, lemon, and banana oat cookies.

A massive cupcake made in Motor Neurone Disease Association colours and a glistening chocolate cake were among the raffle prizes. There were also lots of donated items for sale too.

The staggering total raised from tickets and donations beforehand and the raffle and sales on the day was £2,290!

"I never imagined in my wildest dreams that we would raise so much money! Thank you to all the helpers that made this possible." - Ann Franklin



Ann Franklin, her husband, and son – Credit: Ann Franklin



Robin and Mike's Drive: 23rd Sept 2023

Over the weekend of the 23rd and 24th of September, Robin and Mike drove the 780 miles EWE course across the UK from East to West and back again to raise funds for the Norfolk, Norwich and Waveney Branch of the MND Association.

They drove Robin's 1936, Austin Opal 7, from Ness Point, Lowestoft to St David's Head in Wales, and back again. This was to be an estimated 12hours of driving each way.

Robin's father, David Baines, passed away in 2016, having only been diagnosed with MND a few months earlier. He was also a Rotarian and spent a lot of his time fundraising for local and international causes. He restored the Austin Opal 7 himself and drove it from John O'Groats to Land's End for charity.

Mike's son, Justin Hammond, battled MND for 2 years after his diagnosis and sadly passed away in January 2023, aged 50. Justin was a sales director with Princes Food Group and his colleagues raised £50,000 by walking from the office in Liverpool to Justin's home in Manchester.

Robin and Mike have raised over £6,000 so far in memory of David Baines and Justin Hammond. You can still donate to their Just Giving page here: https://www.justgiving.com/page/michael-hammond-1692633928350?utm_source=copyLink&utm_medium=one_page&utm_content=page/michael-hammond-1692633928350&utm_campaign=pfp-share&utm_term=90fdb770761245b08fe04260bac523a5

Dates for your Diary

Coffee Mornings 2023 - Held on Wednesdays

October 11th for Online | 18th at Notcutts | 25th at Cherry Lane

November 15th at Notcutts | 22nd for Online | 29th at Cherry Lane

December 13th for Online

January 10th for Online | 17th for Notcutts | 31st at Cherry Lane

February 14th for Online | 21st for Notcutts | 28th at Cherry Lane

March 13th for Online | 20th for Notcutts | 27th at Cherry Lane

April 10th for Online | 17th for Notcutts | 24th at Cherry Lane

May 8th for Online | 15th for Notcutts | 29th at Cherry Lane

Hopefully we will not need to cancel any meetings due to unforeseen circumstances; updates will appear on:

<https://www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch/>

There is no need to let us know you are coming to the coffee mornings.



Online Zoom Coffee Mornings:

Time: 11:30 – 13:00

These are friendly informal gatherings hosted by Malcolm, Sue, Clare and other volunteers, for people with MND, their carers, and friends. Drop in at any time and leave when you need to.

Email sueheal@btinternet.com if you would like to receive the link.

Locations:

Notcutts Garden Centre: Daniels Rd, Norwich, NR4 6QP **Time:** 11:00 – 13:00

These informal gatherings are hosted by Malcolm, Sue and others, for people with MND, their carers, and friends.

Cherry Lane - South View Nurseries: Beccles Road, Fritton, Great Yarmouth, NR31 9EU **Time:** 11:00 – 13:00

These informal gatherings are hosted by Judy and Colleen for people with MND, their carers, and friends.

Donations & Fundraising

Received with thanks.

Anonymous Donations - £92.50

Collection Boxes - £38.87

Upton Raffle - £78.00

Sale of merchandise at Upton - £88.19

Wroxham Bure Valley Rotary Club Event at Wroxham Barns - £750.00

Worstead Ringcraft Dog Show - £1,070.00

Wymondham Ukulele Group - £175.00

Donations in Memory of

Sheila Frances Mason - £88.00

Paul Anthony White - £25.00

Internal Transfers

EG donations - £19.52

Ann Franklin's Cream Tea - £1,780.35

Pier2Pier Walk - £6,017.30

Drive in memory of Justin Hammond - £50.00

Gift Aid - £152.50

MND Matters: The MND Association Podcast

Did you know that there is an MND Association podcast?

The MND Matters podcast, brought to you by the MND Association, is a place where people who are affected by MND to share their experiences and support one another.

Hosted by Chris, Helen, Nick and Steph, this podcast brings humour, emotion, and always honesty to its audience members.

They tackle a whole host of topics with the aim to offering informal advice and support to their listeners and raising awareness of MND.

You can catch up with the most recent episode now or go back and listen to previous episodes by following this link: <https://www.mndassociation.org/media/mnd-matters> or by searching for 'MND Matters' on your chosen podcast platform.



The MND Association Online Forum

The online forum is an ideal resource for anyone affected by or living with MND. It is hosted by the MND Association, but the content is created by a wide range of people with the aim of offering first-hand experiences and medical, emotional and practical support.

Anyone can access the forum to read the posts and gather information, but if you wish to post yourself, you will need to register.

To register, or access the forum, simply follow the link here: <https://www.mndassociation.org/support-and-information/our-services/online-forum>

MND Connect Helpline

The MND Connect team offer support and information on all aspects of motor neurone disease (MND), including practical management, symptom control, improving quality of life, clinical research and signposting to other organisations.

The MND Connect Helpline **0808 802 6262** 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. Or you can email the team on: mndconnect@mndassociation.org

To find out more information, follow the link to the webpage: <https://www.mndassociation.org/support-and-information/our-services/mnd-connect>

Read the latest from the Research Centre

All content compiled by Doctor Aidan Nicholson

Experimental Drug Candidate Targets Key Mechanisms in MND/FTD – July 2023

In early lab research, an experimental drug called ATH-1105 has shown promise in targeting key drivers of ALS/FTD reducing inflammation and neurodegeneration. In models, the drug has been shown to reduce neuronal damage highlighted by a reduction in a marker of neuronal damage called the neurofilament light chain. A key marker of this is a build-up of the protein TDP-43, which has been shown to be reduced in models using the drug. Although promising, the medication needs further research before being used in the wider MND population.

See more at: https://www.athira.com/wp-content/uploads/2023/07/AAIC2023_FTD_L5_6July2023.pdf?dm_i=40VQ,1KOBH,7D7IWZ,5WLW5,1



Genetic Testing Guidelines for MND in UK Have Changed – April 2023

In April 2023, the genetic testing guidelines for MND changed concerning who is eligible. The biggest change is that, before, genetic testing was restricted to people with family members also affected with MND or people whose symptoms started before they were 40. Now there is no limit on age or family history for routine genetic testing after a new study in September 2022 showed that, under the previous guidelines, hundreds of patients were missed and were not given specific genetic advice or gene therapy.

Although this is a step in the right direction, before this change, there have been significant delays with accessing genetic counselling, testing and their results and with this new influx of patients, these problems may worsen. The MND Association are currently looking at how they can assist with this issue.

See more at: <https://www.mndassociation.org/sites/default/files/2023-05/FAQs-Genetic-testing-April-2023.pdf>

MND Association Invests in MND-SMART clinical trial – June 2023

MND SMART is a multi-arm (more than one treatment tested at same time) trial which will initially test drugs already approved as treatments for other disorders in the UK.

Those participants will be compared with a single group receiving a placebo, meaning people in this trial are more likely to receive an active treatment rather than a placebo, as multiple treatments are being tested at the same time.

The first three drugs being tested can be seen with the below link, but new drugs will be selected based on a continuous review to provide people with better opportunities to obtain active treatments in medical trials.

See more at: https://www.mndassociation.org/research/clinical-trials/treatment-trials/mnd-smart?dm_i=40VQ,1KDQP,7D7IWZ,5V1NS,1

VISIT [HTTPS://MNDRESEARCH.BLOG/](https://mndresearch.blog/)

IF YOU WOULD LIKE TO FIND MORE INFORMATION ABOUT ANY OF THESE RESEARCH TOPICS

Rob Burrow: Living with MND at The National Television Awards

This year's National Television Awards took place on the 4th of September. A star-studded night of television personalities filled London's O2 arena to celebrate the best television programs from the last year.

The MND Association patron, Rob Burrow MBE, his wife Lindsey, and their children Macy and Maya travelled to be there at the live awards ceremony amongst a lot of famous faces.



The BBC documentary Rob Burrow: Living with MND was shortlisted in the Authored Documentary category. It was commissioned by BBC 2 from BBC Breakfast who have followed Rob's journey since his diagnosis in 2019.

Lewis Capaldi won the award, but the awareness raised of MND from announcements leading up to the awards across social media has been immense.

Back in 2021, his first documentary was also shortlisted at the NT Awards entitled; Rob Burrow: My Year with MND.

Sailing around Britain: Dr Andrew Hill-Smith

On the 30th of August, Dr Andrew Hill-Smith sailed back into Gosport in his little laser dinghy, HMS Betty, to finish the impressive 'Around Britain' sailing challenge.

Andrew had set himself the task of sailing, single-handedly, around the British coastline and hoped to raise £5,000 for the Motor Neurone Disease Association.

After retiring, Andrew took his small 14ft long boat, with no cabin, and set off from Gosport on the 10th of April.

He was determined to complete the voyage and managed to overcome the turbulent weather, and several capsizes to complete the 2,100-mile journey in only 20 weeks. Along the route, he had to sleep at the local yacht clubs, in stranger's homes and did some camping.



MND is a charity that is very close to Andrew's heart. He was inspired to take on this fundraising challenge to help find a cure for it in a tribute to his uncle, David Shawcross, and his friend, Guy Lidbetter, who both died of MND.

Andrew is only the third person ever to have completed the 'Around Britain' challenge in a Laser boat and has already beaten his £5,000 goal.

The Through the Roof cost-of-living campaign was launched on the 4th of September with new research that shows people living with MND are being disproportionately affected by the cost-of-living crisis.



THROUGH
THE ROOF

Findings, outlined in the new Through the Roof report, also highlight energy bills for households affected by MND are skyrocketing. Using and charging assistive equipment like electric wheelchairs and hoists are estimated to cost families, on average, £600 a year on top of their usual costs. Many people with MND rely on assistive equipment to keep them safe, well, and independent.

You can read the full report here: <https://www.mndassociation.org/get-involved/campaigning/take-action/through-the-roof>, and use the link on this page to contact your MP.

Whilst Sue Heal, Branch Campaigns Contact, has written to all ten Norfolk and Waveney MPs they are more likely to respond to their constituents. You can help by writing to your MP and asking them to support our call for more targeted energy support. It is helpful if you can personalise the email, perhaps by sharing your own experiences.

The campaign has been covered widely in the media, just one example can be found at <https://www.independent.co.uk/news/uk/mnd-government-england-winter-b2404216.html>.

Benefits, financial support and cost of living

If you have MND, Kennedy's disease or provide support as a carer, you may be facing unexpected costs. The MND Association has prepared a dedicate page on the website looking at benefits, financial support, and the cost of living.

<https://www.mndassociation.org/healthandsocialcare/benefits-financial-support-and-cost-living>

The MND Association is currently offering a one-off Cost-of-Living Support Fund up to the value of £350. This is to help people living with MND who may be struggling with household bills or food shopping costs. This fund is under continuous review.

You can find more details and the application form at:

<https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd>

In addition to this grant, the Association's Benefits Advice Service can offer guidance about benefits. The team of qualified advisers can provide support by phone, email, and web chat. You can find more details here: <https://www.mndassociation.org/support-and-information/our-services/benefits-advice> or alternatively phone 0808 801 0620 between 9am and 5pm Monday to Friday, excluding public holidays.

Support MND Carers

Sue has written to the district, borough and city councillors who sit on the Norfolk Health and Wellbeing Board to raise awareness of the needs of carers and to ask them three questions. Two councillors responded.

- What steps are taken locally to ensure that carers are identified, and their support needs are assessed?
- Do you work with local NHS bodies to ensure carers are identified and referred for a carer's assessment?
- Do you have an estimate of the proportion of carers in Norfolk who have been offered/received a carer's assessment?

She has also written to Cllr Alison Thomas, Cabinet Member for Adult Social Services and Debbie Bartlett, Interim Executive Director of Adult Social Services to share the MND Association's report *Understanding the experiences of unpaid carers of people living with MND*. In addition to asking the same questions she outlined the challenges presented when navigating the Norfolk County Council and asked them to focus on improving awareness, availability, and access to Carer's Assessments. On a more positive note, she was able to say that some people who had received a Carer's Assessment had found them very helpful.

Conversations Matter in Adult Social Care

Norfolk County Council (NCC) launched a consultation, *Conversations Matter*, inviting residents to be involved in shaping their adult social care strategy for the next 3 – 5 years. NCC described their vision for social care as 'promoting independence' and provided an online survey as well as print versions available in local libraries. The survey, which closed on 1 September, focused on three key themes:

- Keeping people well and independent in their homes
- Providing timely support for people to develop skills to live independently
- Living with complex needs

The MND Association submitted a paper, co-written by Peter from the Campaigns and Policy Team and Sue from the branch, which addressed these issues. It included the key messages agreed by the Association with the addition of issues and themes reflecting the experiences of social care raised in discussion with some of our branch members who are living with MND. Thank you to everyone who contributed their ideas. Thanks also to those who completed the survey independently.

Our submission has been acknowledged by Norfolk County Council and will be included in the consultation.

ACT TO ADAPT

We are pleased to report that on the 7th of September, the Department of Health and Social Care and the Department for Levelling Up, Housing and Communities, announced an additional £50 million for housing adaptations. The funding will be allocated to local authorities and will be delivered through the Disabled Facilities Grant.



You can read more at: <https://www.gov.uk/government/news/government-delivers-extra-50-million-home-adaptation-funding>

We will continue to work with our local councils to recommend they learn from existing good practice and make improvements to the support they provide by:

- Introducing a fast-track process for people with MND
- Removing financial assessments for Disabled Facilities Grants under £5,000 for people with MND
- Maintaining a register of accessible homes for people to move into



Trussell Trust Days of Action Campaign

In mid-September, hundreds of food banks within the Trussell Trust network came together for two Guarantee Our Essentials Days of Action, to raise awareness of the millions of people in the UK who are going without the essentials because Universal Credit is falling short.

The MND Association, together with many other charities and organisations, support this campaign and see links to our own work on the Cost-of-Living crisis.

There is an online petition to urge party leaders to commit to ensuring everyone can afford the essentials they need to get by.

Follow the link if you would like to support the campaign and find out more about the Trussell Trust. <https://action.trusselltrust.org/guarantee-our-essentials-petition-1?>

Upcoming Events:

Wymondham U3A coffee morning: Thursday 2 November 2023

You are invited to join the Wymondham U3A coffee morning on Thursday 2 November between 9am and 12 noon in Wymondham Central Hall, Back Lane, Wymondham, NR18 0QB.

There is paid parking in the car park behind Central Hall. It is a wheelchair accessible venue.

The Wymondham U3A support our Norfolk, Norwich & Waveney branch, and a team will once again be baking the cakes for us and organising a tombola! There is a small entry charge of £1 to cover tea/coffee.

The branch will have merchandise for sale – including Christmas cards, a sweepstake and possibly a quiz too. For more information or to donate prizes please contact Sue Heal on 01953 606569 or email sueheal@btinternet.com.

Sponsored Barefoot Walk

Simon Taylor, a bus driver from Caister, will be paying tribute to his beloved stepfather Les White by walking barefoot across Norfolk.

Les White sadly died a few years after receiving his MND diagnosis.

Simon is hoping to raise £500, so that, at the end of his walk, he can hand deliver it to the Norfolk, Norwich and Waveney branch of the MND Association.

"...the MND Association supported my mum and my stepfather with various bits of equipment, support, carers, nurses communication and were just fantastic," Mr Taylor said. "I just want to give something back."

To help him reach his fundraising goal, you can follow the link to his GoFundMe page:

<https://www.gofundme.com/f/raising-funds-in-loving-memory-of-les-for-mnd>

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Disclaimer: *The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.*

We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact Grace Fleming at mnda.norfolkwaveney@gmail.com or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ.

Please pass this newsletter on to people who may be interested.



Newsletter Editor: Thank you to all who have sent photos and stories for inclusion in our newsletter. The deadline for receipt of articles for the next edition is **19th of February 2024**.



If you would like to talk to someone about MND,
please contact our MND Connect team on **0808 802 6262** or email

mndconnect@mndassociation.org

Visit our online forum **<http://forum.mndassociation.org/>**

Website: **www.mndassociation.org**

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