



## EDITOR'S NOTES

Welcome to the July issue of FightBack which is jam-packed full of fundraising stories, interesting developments from the research centre and some campaign updates too.

It is another hot summer we are in and with the temperature set to rise further, we need to take extra care in the sun and look out for those who may need extra support.

Remember to look out for local events happening near you where you can meet up, have a coffee and a chat or take part in or support one of the many fundraising challenges.

Until the next Issue, stay safe, enjoy the weather, and take care of the people around you.

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](mailto:NNWNewsletter@gmail.com).

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## Norfolk, Norwich & Waveney Branch

**Website:** [www.mndnorwichandwaveney.org.uk](http://www.mndnorwichandwaveney.org.uk)

**Facebook:** @MNDANorwichWaveney

**Twitter:** @MNDANorWave

**Instagram:** @MNDNorfolk

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## NN&W Branch Open Meeting

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Sunday 23 April 2023

The AGM and Open Meeting was held on Sunday the 1<sup>st</sup> of April at St. Andrew's Church Hall, Eaton, Norwich, NR4 6NW.

It was a successful event that seemed to be well appreciated - a couple of people commented that it was a really good day, it was lovely to meet everyone in person.

The food was splendid, and the National Alert at 3pm didn't disturb the proceedings too much. We raised £69 from the sale of Association merchandise. We held the usual raffle, which raised £138 - there were a lot of prizes.



Sally Hughes, Assistant Director of Care at the Motor Neurone Disease Association, gave a presentation focusing on the five promises of the MND Association.

- **Promise 1: We won't rest until MND is treatable and ultimately curable.**
- **Promise 2: We won't rest until everyone gets the care they need when they need it.**
- **Promise 3: We won't rest until every day with MND counts.**
- **Promise 4: We won't rest until you are heard.**
- **Promise 5: We won't rest until no one faces MND alone.**



### Advance Notice of Open Meeting:

Date: Sunday 30 July 2023

Time: 12:30pm - 4pm

It will be held at Upton Village Hall, Cargate Ln, Norwich NR13 6AU



Sally Hughes also presented our Chair, Malcolm Chubcock, with a certificate and badge marking 25 years of volunteering with the Association.

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## Local Fundraising Stories

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### The Wymondham Ukulele Group: Friday 10<sup>th</sup> March 2023

On a snowy Friday in March, the Wymondham Ukulele group were playing to a very receptive audience on the 14th birthday of the Wymondham Dementia Support Group at Fairland Hall, Wymondham.

Despite the snow there were about 80 people in attendance. There was a lovely atmosphere and people happily joined in, singing along to a varied selection of songs, predominantly from the 50s, 60s and 70s. They raised £105.

The Wymondham Ukulele Group raise money throughout the year and donate it to a charity of their choosing - this year they are raising money for the Norfolk, Norwich and Waveney Branch. They have donated £408.51 so far.



### Quiz Night at Rossis: 9<sup>th</sup> December 2022

Mike George and staff at Rossis Leisure at North Walsham organised a quiz evening on 9 December 2022 with proceeds to MNDA.

Approximately 200 people attended and there was a prize for most outrageous Xmas jumper.

£433.50 was raised on the evening and approximately a further £250 through gift aid.

(Left) Pictured is Sophie Robson of Rossis and Malcolm Chubcock of Norfolk Norwich and Waveney MNDA.



### Blofield Football Club: Saturday 18<sup>th</sup> of March 2023

On Saturday 18 March, Malcolm Chubcock attended a presentation at Blofield football club where after the match Paul Gray presented him with £140 being the proceeds of the sale of a Norwich City FC shirt.

Also present in the photo is Paddy Murphy Blofield FC President.

Also not pictured Paul Roofe of Blofield gave Malcolm £165 cash proceeds of a collection on the match day.





Photo credit: Lisa North Photography

### Charity Concert: Saturday 13<sup>th</sup> of May 2023

The Charity Concert at St Johns Church in Harleston took place on Saturday 13<sup>th</sup> May in aid of Motor Neurone Disease. The well attended event was a huge success and an amazing £730 was raised for The MND Association. The concert saw a range of music from classical to musical theatre performed by a range of vocalists accompanied by Andrew Wheeler.

The charity concert was organised by Meryl Raines in memory of her Mum; Janet Keeble, who sadly lost her battle with MND nearly ten years ago this October. The event attracted approximately 80 people and was very well received. In fact, Meryl has had requests to hold similar events in the future!

### Pier2Pier Challenge - Sunday 28<sup>th</sup> May

The Pier2Pier challenge was to walk around the Norfolk coastal path from the Britannia pier in Great Yarmouth to Cromer Pier, which is around 32 miles, in one day. This task was undertaken by the Officeflow Ltd team, to raise funds and awareness for the Motor Neurone Disease Association.

The MND Association is a cause that is particularly close to their hearts with member of the team going through the challenges of this life changing disease with friends and immediate family members.

As the big day arrived, the weather was in their favour, and they set off on their fundraising trek. The team thoroughly enjoyed the challenge and were well supported both at the start and end of the challenge. To date they have raised an incredible £6,181, thoroughly smashing their initial target.



The team outside The Pier Tavern



### Retired Bowling Pins

JR's Indoor and Outdoor Play, Bowling and American Diner at North Walsham decided the time had come to change their tired bowling pins. They have 6 lanes each having 20 pins so they had 120 pins to dispose of.

Owner Bruce Rossi's, rather than throw them away, knowing the support given to Jake and his family, decided to offer them for sale with the proceeds going to the Norfolk, Norwich and Waveney Branch of the MND Association. A grand total of £550 was raised.

The photograph shows a presentation on the bowling alley with the Manager Ben Ludbzook and Malcolm.

## Dates for your Diary

### Coffee Mornings 2023 - Held on Wednesdays

**June** 14<sup>th</sup> for Online | 21<sup>st</sup> at Notcutts | 28<sup>th</sup> at Fritton Village Hall

**July** 12<sup>th</sup> for Online | 19<sup>th</sup> at Notcutts | 26<sup>th</sup> at Fritton Village Hall

**August** 16<sup>th</sup> at Notcutts | 23<sup>rd</sup> for Online | 30<sup>th</sup> at Fritton Village Hall

**September** 13<sup>th</sup> for Online | 20<sup>th</sup> at Notcutts | 27<sup>th</sup> at Fritton Village Hall

**October** 11<sup>th</sup> for Online | 18<sup>th</sup> at Notcutts | 25<sup>th</sup> at Fritton Village Hall

**November** 15<sup>th</sup> at Notcutts | 22<sup>nd</sup> for Online | 29<sup>th</sup> at Fritton Village Hall

**December** 13<sup>th</sup> for Online

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 Sue, 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](mailto: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.

**Fritton Village Hall:** Hill House, Beccles Rd, Fritton, Gt Yarmouth, NR31 9HB **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.

### Donations

Anonymous donation - £255.00  
Sprowston Manor Golf Club, 2022 Lady Captains choice for their fundraising- £700.00  
Sale of the late Ronald Huggins tools - £300.00  
Tesco Bucket Collection - £500.00  
Gordon Baker donations in lieu of birthday presents - £520.00  
Speakers donation at Acle Evening WI - £100.00  
Alison Nadakavukaran donation - £184.00  
Proceeds of Alison Nadakavukaran's Tropic Skin Care event - £66.00  
Collection Box - £54.46  
Goodies Farm Shop Collection Box - £128.21  
Sale of merchandise at AGM at Eaton - £69.00  
Raffle at AGM at Eaton - £138.00  
Ann Franklin donations in lieu of birthday presents - £100.00  
Lowestoft Swing Night - £1800.00

Cont.

Wymondham U3A Coronation Cake Raffle - £85.00  
P & D Goulder donation - £240.00  
Pamela Downs Charity Workout - £2956.52

### Donations in Memory of

Donations in memory of Brian Osborn - £542.75

### Internal Transfers

Gift Aid - £141.50  
Emergency Fund donations - £50.00

## Read the latest from the Research Centre

All content compiled by Doctor Aidan Nicholson

### £1 Million Awarded to Research into New Therapy for MND – Jan 2023

Medical research charity LifeArc, the MND Association and my Name's Doddie Foundation have jointly awarded £1 million to researchers at UCL to progress two new therapies for MND. The first project aims to develop a gene therapy for MND using a specific cell called antisense oligonucleotides (ASOs) which are designed to rescue a lost gene lost in the disease. It is hoped that by restoring the lost gene it can slow down, stop or reverse progression of MND.

The second project's aim is to restore lost muscle function and prevent further muscle wastage in MND patients. The pioneering strategy involves injecting light sensitive motor neurons from genetically modified stem cells into nerves that control muscles which in theory will restore the function of paralysed muscles in response to light pulses.

See more at: <https://www.lifearc.org/news/2023/1-million-awarded-to-develop-cutting-edge-therapies-for-motor-neuron-disease/>

### Mature Neurons Lab Grown for First Time – Jan 2023

Researchers in Northwestern University have created the first highly mature neurons from human stem cells. This is in comparison to previous lab grown stem cells which were immature and therefore had limited potential in their therapeutic use. In addition to being more mature, the neurons had greater signalling and branching ability allowing for more effective communication between neurons and were less clumped together making them easier to maintain. With future developments it is believed that these mature neurons can be transplanted into patients as therapy in neurodegenerative diseases such as MND but also Parkinson's disease, Alzheimer's disease, and multiple sclerosis (MS).

See more at: <https://news.northwestern.edu/stories/2023/01/mature-lab-grown-neurons-hold-promise-for-neurodegenerative-disease/>



### New Study Reveals Possible Link Between Cholesterol and Prognosis in MND – Jan 2023

According to a new population-based study in the Netherlands elevated levels of HDL or 'good' cholesterol is significantly associated with a poorer survival rate among people with MND. In contrast, people who survived to later stages of the disease had higher levels of total cholesterol and LDL ('the bad cholesterol').

However, this new study contrasts to previous findings where higher HDL levels were linked with lower risk of MND. The new research poses further questions into the correlation between fats and MND however it is believed to be important as blood concentrations of lipids seem to be dependent on disease severity which may be a potential biomarker in the future.

See more at: <https://alsnewstoday.com/news/lower-als-survival-ratel-linked-higher-good-cholesterol-levels/>

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

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

### Study Identifies Features that Make Motor Neurons Vulnerable to MND – Feb 2023

New research has identified specific features of motor neurons which make them more vulnerable to degeneration in MND. The study catalogued the various cell types within the human spinal cord and analysed their molecular profiles. In particular they looked at motor neurons (the cells that die in MND) which provide voluntary movement and motor control.

It provides this through one long extension called an axon (sometimes up to a meter long) which conducts signals from the spinal cord to the muscle fibre. The research team found that motor neurons are distinguished by a specific set of genes are linked to the long size of the axon and body of the motor neuron but are also linked to the onset of MND. By recognising this association, it creates a potential foothold for future gene therapies that utilises this new spinal cell atlas.

See more at: <https://www.ninds.nih.gov/news-events/press-releases/study-identifies-features-may-make-motor-neurons-vulnerable-als>

### Study Suggests Inflammatory Proteins in Innate Immune System May Lead to MND – Feb 2023

New researchers in America have identified proteins within the innate immune system that could be at the root of many neurodegenerative conditions. These findings came from experiments on mice and human nerve cells whereby inactivating a molecule in the brain linked to inflammation prevented neuronal damage and delayed MND progression in mice.

The specific molecule is called gasdermin E, expressed in the brain most highly in nerve cells. When a neuron detects a hazard gasdermin E amplified damage to the neurons. In neurons affected by MND high levels of gasdermin E was found and when reduced the damage the neuron faced was reduced. More research is required to see if gasdermin E can be targeted with drugs however it is an important first step in developing new treatments for MND.

See more at: [https://hms.harvard.edu/news/new-insights-als?dm\\_i=40VQ,1JO1G,7D7IWZ,5R880,1#.ZBF05eouTFA.twitter](https://hms.harvard.edu/news/new-insights-als?dm_i=40VQ,1JO1G,7D7IWZ,5R880,1#.ZBF05eouTFA.twitter)

### Scientists Discover How to Prevent Deaths of Nerve Cells in Common Forms of Genetic MND and Dementia – Mar 2023

A new study conducted by the University of Sheffield have shown a way to block the transport of mutant genetic material and its subsequent production of toxic proteins which lead to the death of nerve cells found in the most common genetic subtypes of MND and frontotemporal dementia. Additionally, it was shown by blocking the mutant genetic material it increases the survival of nerve cells shielding them from neurodegeneration.

The gene in question is called C90RF72 is caused by excessive stickiness of a cell transporter named SRSF1. Conventional medications or invasive therapies have been inefficient in disrupting the stickiness of the SRSF1 protein however this new study has found that a small peptide inside of a cell can stick to the protein and block the transport of the rogue genetic material. This peptide can be given either orally or in other non-invasive manners such as nasal spray which then enters the brain. This new concept of using peptides to block the effects of rogue genetic material may transform how some neurodegenerative conditions can be treated.

See more at: <https://www.sheffield.ac.uk/neuroscience-institute/news/scientists-discover-how-prevent-death-nerve-cells-most-common-genetic-forms-mnd-and-dementia>

## The Rob Burrow Leeds Marathon



On Sunday the 14<sup>th</sup> of May, over 10,000 people including 2,300 #TeamMND runners took part in the very first Rob Burrow Leeds Marathon. This event was created to raise awareness and support for families living with motor neurone disease.

The runners started the course at Headingley Stadium at 9am and travelled the 42.2km looped route visiting picturesque landmarks of Leeds, with the streets lined with crowds of supporters, to then finish back in the stadium.

Taking part alongside the thousands of runners were Rugby League legends and patrons of the MND Association Rob Burrow MBE and Kevin Sinfield OBE. Kevin ran the whole course with Rob in a specially adapted wheelchair with a small support team. The heart-warming moment of the race for a lot of people featured Kevin unbuckling Rob from the chair and carrying him over the finish line to celebrate.

The total fundraising for both the full and half marathon currently stands at a phenomenal £1.5million. The money raised will support the Rob Burrow Centre for Motor Neurone Disease Appeal and the MND Association.

## Keith Harris's Marathon Journey

Keith Harris took part in the Rob Burrow Leeds Marathon and completed it with a time of **4:39:15**.

Here is his report on the day's events:

In the wishes of Kevin Sinfield, it was a tough route and the warm weather also added to the challenge. The people of Leeds and surrounding villages were out in force to cheer us all on and show their support to their local heroes who have stolen the nation's hearts.

In the villages, the people were handing out jelly babies and chopped orange, a few garden hoses were being sprayed over heated runners as they went by. The MND staff on route and in the stadium greeted all MND runners so warmly.

A challenging and memorable day with a congratulatory fist bump and thank you from Kevin Sinfield at the end.

Keith had nothing but praise for the event, adding; "I don't think I could have asked for a better marathon where the local communities all got behind the cause". He has now raised over £2,000.





## Global MND Awareness Day - 21st June 2023

Over 400 people had invited their MP to our Global MND Awareness Day parliamentary drop-in event. Thank you to everyone who sent an invitation. The event provided MPs with an opportunity to talk with people affected by MND, staff and campaigners to learn more about MND, so they could advocate to ensure policy and legislation works for the MND community.

The event highlighted a range of important issues affecting the MND community including access to new medicines, housing adaptations, support for MND carers, the financial cost of having MND, and access to benefits.

Branch Campaigns Contact, Sue Heal, attended and had been asked to focus on the needs of carers and our Support MND Carers Campaign. Of the ten Norfolk and Waveney MPs that she contacted five agreed to attend if parliamentary business allowed.



For more information:

<https://ecampaigns.mndassociation.org/page/127785/action/1?ea.tracking.id=e-action%20share>

## Support our calls for the Government to Guarantee Our Essentials

The MND Association is backing the *Guarantee Our Essentials* campaign by the Trussell Trust and the Joseph Rowntree Foundation. This calls on the Government to ensure Universal Credit covers the cost of life's basics such as food and bills.

The coalition now has an action asking people to contact their MP asking them to support the campaign.

If you wish to show your support you can do so

here: <https://action.trusselltrust.org/nearly-3-million-emergency-food-parcels-guarantee-our-essentials?>

90% OF LOW-INCOME HOUSEHOLDS ON UNIVERSAL CREDIT ARE GOING WITHOUT THE ESSENTIALS.

IT DOESN'T ADD UP.

The Trussell Trust / JRF JOSEPH ROWNTREE FOUNDATION

## United to End MND – Our Institute is up and running!

“The new UK MND Research Institute, set up after the successful United 2 end MND campaign, is now operational. The Institute, which includes over 20 Universities and Centres, aims to accelerate the search for treatments and improve access to clinical trials. Scientists who are part of the Institute have been submitting applications for the £50 million funding that has been ring-fenced by the Government for MND.” These words were taken from the MND Research Monthly, April 2023.

Importantly, the scientific work of the Institute is well underway addressing every step of the drug development process. All of this aims to accelerate the search for treatments, as well as insure much improved access to clinical trials for more patients. You can read more about this exciting development at <https://united2endmnd.org/2023/04/13/institute-up-and-running/>.

The United to End MND coalition are continuing discussions with politicians and officials to ensure the remaining funds, promised by the Government for investment in targeted MND research, can be accessed without delay.

### Carers Week 5 – 11 June 2023

The theme for Carers Week 2023 was *Recognising and supporting carers in the community*. The aim was for everyone to recognise the huge contribution unpaid carers make to society. Jamie Waldron, our Social Media volunteer, used our social media to spread awareness of the need to recognise and support carers. Some of you may have shared your story on <https://www.carersweek.org> and said, **I CARE**.

On Wednesday 7 June, the seven national charities behind Carers Week – Age UK, Carers Trust, Carers UK, MND Association, Oxfam, Rethink Mental Illness and The Lewy Body Society – accompanied a group of carers to Westminster, where over 100 MPs heard directly from carers about the challenges they face and the support they need. These charities also sent a joint letter to the Prime Minister, Rishi Sunak MP, urging him to establish and personally sponsor a cross-departmental ministerial working group focused on unpaid carers. They believe a cross-Government ministerial focus would ensure that carers' needs are understood and being responded to at the highest level of Government, and better enable it to coordinate its support for unpaid carers.

**An assessment will help you find out about:**

- care services, benefits advice and local voluntary organisations
- planning for respite, urgent or emergency care
- assistance with travel
- how to maintain your own interests, studies or activities while caring
- suggestions for counselling or support groups.

**Motor Neurone Disease Association**  
Francis Crick House,  
6 Summerhouse Road,  
Moulton Park, Northampton NN3 6BJ. UK  
[www.mndassociation.org](http://www.mndassociation.org)  
[MNDAssociation.org/SupportMNDCarers](http://MNDAssociation.org/SupportMNDCarers)

**SUPPORT  
MND CARERS**

**Carers Identity Passports** were co-produced with local carers and staff in a project funded by NHS Norfolk and Waveney Integrated Health and Care System, run in partnership with Carers Voice and Caring Together. They help unpaid Carers of all ages get the recognition they need to help them to do their caring role.

The following organisations currently recognise the Carers Identity Passport;

East Coast Community Healthcare, James Paget University Hospital, Queen Elizabeth Hospital King's Lynn, Norfolk and Norwich University Hospitals, Norfolk and Suffolk Foundation Trust, and Norfolk Community Health & Care Trust. The new Carers Identity Passport will help to ensure carers are recognised and linked in with existing support available in hospitals.

Carers Voice is working to ensure that it is recognised more widely, for example in GP surgeries.

If you know of a patient, colleague, or family member who is an unpaid carer they can register for a passport using an online form <https://www.carersvoice.org/carers-identity-passport/>. Anyone who needs support to complete an online form can call 07932 095312.

## Branch Contact

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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](mailto: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 **30th of September 2023**.



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](mailto:mndconnect@mndassociation.org)**

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

Website: **[www.mndassociation.org](http://www.mndassociation.org)**

Registered Charity no. **294354**

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