



EDITOR'S INTRO

Hello, I'm Jenny Sampson, and I am your new Editor for FightBack, the Norfolk, Norwich and Waveney Branch Newsletter.

I am hoping to give you a newsletter full of local fundraising stories, dates for your diaries, highlights from the research centre and a brief overview of some of the national news from the previous four months.

I want to take this opportunity to thank Sue Heal who has handed over the reins to me & who has supported me in my new role; to Liz Cooper, area support coordinator, for giving me the opportunity and the NNW committee team for making me feel so welcome.

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

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Norfolk, Norwich & Waveney Branch

Website: www.mndnorwichandwaveney.org.uk

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

Instagram: @MNDNorfolk

NN&W Branch Open Meeting



13th November 2022

The November Open Meeting was held on Sunday the 13th of November 2022 at Wortwell Community Centre.

The afternoon involved a festive sit-down meal, a team quiz, and a raffle with lots of prizes! There was plenty of catching-up and conversation before the delicious Christmas meal was served. Our Christmas cards were on sale for people to send to their loved ones and we also had Association merchandise for sale.

A big thank-you to our supporters, organisers, and caterers for putting together such a fantastic afternoon!

We raised £370+ from the raffle and merchandise sales.



Advance Notice of AGM and Open Meeting:

Sunday 23 April 2023

12:30 – 16:00

It will be held at St Andrews Eaton Church Hall, Church Lane, Norwich, NR4 6NW.

We will be providing a hot lunch. The guest speaker will be Sally Hughes, Assistant Director of Care, Motor Neurone Disease Association.

Fundraising Football: 3rd October 2022

Fosters Solicitors and their partners from the Anglian Combination Football League and representatives of Blofield United FC got together to hand over a generous donation to our Chairman Malcolm Chubbock. The initial amount of £410 was raised at the league's annual charity match and later topped up to £500 by Fosters Solicitors.

Pictured making the presentation to Chairman; Malcolm Chubbock are Paddy Murphy (seated) and Martin Plumstead (far left) of Blofield United FC, Graham Jubb, Dale Brown and Chris McCullough of the Fosters Solicitors Anglian Combination and Fosters' Commercial Director, Will Hoy (second left).



Pat Goose's Christmas Fayre: 19th November 2022

After a 3-year absence due to Covid restrictions, Pat Goose opened the doors of Harleston Church Hall on Saturday 19 November for her Christmas Fair in aid of the MND Association.

There was a continuous flow of local friends and supporters enjoying the festive atmosphere. The event featured over 25 stalls including a tombola, raffle, and Father Christmas himself. Teas, coffees, and refreshments were provided throughout the day by a merry group of helpers too.

All of Pat's hard work in organising the event proved worthwhile as she was able to donate over £500 to our branch to be used in supporting local people suffering with MND.

Fakenham Christmas Tree Festival: 1st - 8th December 2022

The annual Fakenham Christmas Tree Festival took place in early December and featured over 60 decorated by 50 different charities.

Alongside the numerous colourful trees, there was a Christmas Market selling Christmas gifts, crafts and 'goodies' – including homemade Christmas cakes – and a stall full of books, a raffle and tombola.

The NN&W branch was represented with a strikingly beautiful tree decked out in navy blue and orange created by Louise!

Louise has been helping with the MND tree with the help of her in-laws for the last few years following the death of her husband, Ashley, to motor neurone disease in 2010.

Over £700 was raised during this event.



Edith Cavell Award – 17th Nov 2022

The NNUH Staff Awards night is an annual event that celebrates the outstanding work of individuals working across the NNUH hospitals.

The Edith Cavell Award for Outstanding Leadership is just one of the accolades that staff can be nominated for by their colleagues. *'This special award is given to the nurse who demonstrates outstanding leadership.'*

Having been nominated by one of her neurology colleagues as having "...transformed the care of patients with motor neurone disease in Norfolk", Helen Copsey; Multidisciplinary Team Care Network Coordinator in Neurology, was given this award at the 2022 event.



Helen Copsey (Left) receiving the Edith Cavell Award for Outstanding Leadership

The nomination highlighted that Helen deserved this award for many reasons including establishing monthly MDT meetings, which she also chairs, which brings together nursing, medical and therapy colleagues from palliative care, and also respiratory nutrition and dietetics.

Her colleague also stated: "She has gone beyond the coordinator role in Norwich CCG, where there is no Neurology community nurse, to undertake home visits to support people with MND...she has also played a crucial role in fostering research for patients with MND."

Helen is very worthy of this award and is insistent that it was a team effort stating, "I feel very humbled by it all. It is a real privilege to come alongside people facing the most awful time of their lives and I never cease to be amazed by the grace and courage that people show."

'Quiz with Ploughman's and Pud' – 29th October

Having advertised the event everywhere, this fun-filled quiz night was well attended by 76 people split up into teams all competing to be the champions.

This event was held at Cawston Village Hall and organised by Lynda Hind, with Quizmaster Yvonne and friends to help out. It was well supported with the all-important French sticks being donated by Aylsham Tesco and prizes donated by Cawston shop & Delicatessen and other local vendors.

Grace Fleming and her mum provided home baked puds and helped to serve the hungry competitors as they sought answers to the quiz, figured out the Dingbat sheet and even got creative with tinfoil for the Halloween challenge.

A fantastic £850 was raised for the NNW MND Association on the night.

Lynda would like to "...thank everyone who supported and helped with the Quiz Night in Cawston - it was a great success and I'm so pleased I didn't cancel!"

Quiz Night - 9th December

A quiz night was held at Rossis Leisure, North Walsham in aid of the Norfolk, Norwich & Waveney branch of the MND Association.

The event was very popular, with teams of 6 competing to get the most correct answers. An amazing £500 was raised on the night.

Tell us about your fundraising event and see it in the next issue of FightBack!

Dates for your Diary

Coffee Mornings 2023 - Held on Wednesdays

March 15th at Notcutts | 22nd for Online | 29th at Fritton Village Hall

April 12th for Online | 19th at Notcutts | 26th at Fritton Village Hall

May 17th at Notcutts | 24th for Online | 31st at Fritton Village Hall

June 14th for Online | 21st at Notcutts | 28th at Fritton Village Hall

July 12th for Online | 19th at Notcutts | 26th at Fritton Village Hall

August 16th at Notcutts | 23rd for Online | 30th at Fritton Village Hall

September 13th for Online | 20th at Notcutts | 27th at Fritton Village Hall

October 11th for Online | 18th at Notcutts | 25th at Fritton Village Hall

November 15th at Notcutts | 22nd for Online | 29th at Fritton Village Hall

December 13th for Online

Hopefully we will not need to cancel any meetings due to COVID-19 or other 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 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.

Martin Burnell Boot Sale - £30.00

RWE Generation UK Donation - £1,000.00

Norwich Pétanque Club Competition - £151.50

Collection Boxes - £112.18

Wymondham U3A Coffee Mornings & Sale of Merchandise - £431.75

K&S Lebell Donation from a friend - £20.00

Norfolk Quilters - £38.00

JE Sale of merchandise - £385.00

Sale of cards at Notcutts Coffee Morning - £73.00

P&D G Donation - £230.00

AW Tombola & Donations at Eaton Craft Fayre - £223.10

Norwich Cathedral Arms Donation - £600.00

PG Craft Fayre in Harleston - £506.00

N.I.A.M. Donation - £1,400.00

PT Donation - £100.00

Donations in Memory of
Bryan Eileen Chubbock - £60.00
Ray Cantwell - £157.00
Alan Peter Ward - £50.00
Frank Anthony Addy - £42.50
Mary Smith - £125.00
Geoff Buckingham - £10.00
Margaret Ann Simms - £195.00

Internal Transfers

Just Giving Emergency Fund - £135.00
Gift Aid - £130.00
EG Donation - £14.64
Eileen Chubbock Legacy in memory of
John Chubbock - £1,000.00
KH - Rob Burrows Marathon - £270.00

Read the latest from the Research Centre

All content compiled by Doctor Aidan Nicholson



Tofersen Found to Slow MND Progression in Published Paper – Sept 2022

Tofersen is a potential new treatment called an antisense oligonucleotide (AS) which targets a specific genetic mutation called SOD1 protein which is toxic to motor neurones and thus causes MND. A previous clinical trial trialling Tofersen showed some reduction in the SOD-1 gene and MND biomarkers.

However, there was no difference in the progression of MND (based upon the ALS functional rating scale) between the drug and placebo group. Based on the positive hints the trial continued for a longer period (an 'open label extension phase') in order to see if this had an effect on the progression of MND.

The new results are as summarised: SOD-1 protein levels are reduced with Tofersen treatment, biomarkers of nerve damage were reduced in the blood and probability of survival was increased in patients who took Tofersen from the start of the trial. This data has warranted a further trial called ATLAS which hopes to add to existing evidence that Tofersen can treat MND.

See more at: <https://mndresearch.blog/2022/06/10/valor-biogens-tofersen-trial-a-look-at-the-open-label-extension-data/>

New Study Suggests Changes are Needed in Genetic Testing Guidelines – Sept 2022

As more gene therapies such as Tofersen have been proven to have a beneficial effect in people with specific genes (in this case SOD1) conversation about genetic testing has grown louder. While this is a personal decision there is a louder voice that people once diagnosed with MND should have genetic testing to access potential treatments and participate in trials to produce more therapies.

Currently, only 7% of people with MND are offered genetic testing under current guidelines. Although beneficial in some ways, genetic testing can be an emotive and difficult subject requiring genetic counselling before the testing itself to make sure the person is completely informed and able to make a competent decision. With more therapies, further debates concerning the pros and cons of routine genetic testing will occur shaping future MND management.

See more at: <https://mndresearch.blog/2022/09/27/>

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

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

New Research Suggests a Link Between Rugby and MND – Oct 2022

A new paper has been published which has investigated the risk of developing neurodegenerative disease (e.g. MND) among former Scottish international rugby players. The research concluded that the former players had an increased risk of developing MND compared to the general population.

The findings focused on two main areas. The first being how long and the causes of death of rugby players and the general population, this showed rugby players living slightly longer and there being not much difference in cause of death. The second looked into the amount of people in both groups diagnosed with neurodegenerative conditions, this showed rugby players had a 2x increased risk of having dementia and 15x increase in MND.

Although this seems massive, there is a large margin for error in the research's estimates and by no means does this mean that if you are to play rugby professionally you will get MND as it is a very rare condition. One thing this research has done is raise important questions requiring further research with larger populations to uncover links between exercise, head trauma and MND hopefully uncovering potential causes of MND and ways to minimize the risk.

See more at: <https://mndresearch.blog/2022/10/04/new-research-is-there-a-link-between-rugby-and-mnd/>

A Protective Probiotic for MND has Been Found – Dec 2022

A probiotic bacteria called *Lacticaseibacillus rhamnosus* HA-114 has been shown to prevent neurodegeneration in an animal model (the *C.elegans* worm) used to study MND. The research team from Canada were testing whether the disruption of fat metabolism contributes to brain degeneration.

The fatty acids found in HA-114 are thought to help supplement a reduction in people with MND due to gene mutations affecting fat metabolism, restoring balance to energy metabolism, and reducing neurodegeneration. The researchers are currently repeating the same experiment but on mice this time hoping the effects are seen in a more complex animal model.

See more at: <https://medicalxpress.com/news/2022-12-probiotic-als.html>



The OptiCALS Trial Investigating Nutrition in MND – Nov 2022

This study is investigating if there is a connection between nutrition and quality of life/survival in people with MND. There has been some research that suggests personalised dietary targets can offer some survival benefit and it is hoped this research will help confirm this. OptiCALS is an online intervention for people with MND to help them track their calorie intake and set personalised calorie goals. First, using food only and if needed oral nutritional supplements participants will try to achieve their calorie target while recording their dietary intake within the online OptiCALS portal.

If you decide to take part, you will be randomised to either participate in the OptiCALS intervention or in the group receiving standard care alone. The trial has a 12-month follow-up period and recruitment is happening around the UK.

See more at: https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/opticals/?dm_i=40VQ,11FTJ,7D7IWZ,5L4Q7,1



Credit: <https://www.mynames5doddie.co.uk/who-we-are/>

Doddie Weir

Doddie Weir OBE was a larger-than-life rugby legend with his bright tartan suits and his good-humoured nature. At the age of 52, he sadly lost his battle with MND on November the 26th 2022.

Doddie Weir was first diagnosed with MND back in 2016; his immediate response was to fight back with good humour and fundraising.

With help from his wife, Kathy, they set up the [My Name's 5 Doddie Foundation](#) which aims to fund research and work towards its vision of a world free of MND. The 5 in the name matches the number on his Scotland shirt.

In 2019, he was awarded an OBE for his charity work and won the BBC Sports Personality of the Year Helen Rollason Award for outstanding achievement in the face of adversity.

The MND Association sent a message of condolence to Doddie's wife, his children, family and friends, and also to all at the My Name's 5 Doddie Foundation.

Kevin Sinfield's Ultra 7 in 7 Challenge

Kevin Sinfield OBE is the defence coach for the English national rugby team, as well as a former professional rugby league footballer. Inspired by his childhood friend and former rugby teammate Rob Burrow who is living with MND, Kevin has pushed himself to be 'a better friend' and raise awareness and money for MND charities.

Back in November 2022, Kevin Sinfield set himself another daunting challenge Ultra 7 in 7. Starting out in Edinburgh and running all the way to Manchester, he was aiming to complete 7 ultra-marathons in just 7 days. Kevin would cover more than 280km with an aim to finish at Old Trafford for the half time whistle at the Rugby League World Cup men's final on Saturday 19th of November.

A fundraising page was set up to collect donations with a goal of £777,777 as 7 was Rob Burrow's rugby shirt number. The money raised would be split across five charities: Motor Neurone Disease Association, Leeds Hospitals Charity, The Darby Rimmer MND Foundation, My Name's 5 Doddie Foundation and MND Scotland.

As Kevin and his crew ran the last mile right into Old Trafford stadium, he was greeted by thunderous applause from over 70,000 fans as well as BBC presenter Sally Nugent to cheer him over the finish line. The total at the end of day 7 was a whopping £1.3 million, three days later, it had risen to over £2 million and continues to rise.

Kevin was given an OBE for services to Rugby League and Charity Fundraising. To date, he has raised over £7 million. 'Kevin Sinfield: Going the Extra Mile' aired on BBC2 on February 3rd, catch up on iPlayer to see the journey in full.



Kevin Sinfield and his Ultra 7 in 7 crew. Credit:

<https://donate.giveasyoulive.com/fundraising/kevin-sinfield-ultra-7-in-7-challenge#:~:text=The%20plan%20for%20my%20third,and%20his%20playing%20number%207>

Support MND Carers

The findings of an MND Association report, '*Understanding the experiences of unpaid carers of people living with MND*', suggested that more than half of people who care for those with MND provide 75 hours of care every week. This prompted the Association to launch a campaign calling on the Government to improve the level of support for unpaid carers of people living with motor neurone disease.

Read the report at <https://www.mndassociation.org/app/uploads/2022/11/Carers-Report-External-version.pdf>.

The #SupportMNDCarers campaign was launched at the All-Party Parliamentary Group on MND meeting in November 2022. Alex Massey, the Association's Head of Campaigning, Policy and Public Affairs said: "Unpaid carers make an enormous and undervalued contribution to the UK's health and care systems. Our research found fewer than a quarter of carers of people with MND have ever had their support needs assessed, despite this being a legal right. We are calling on the Government to undertake a full review of carer's assessments immediately, and to work with local authorities and NHS bodies to understand why carers' support needs are not being met."

Please email your MP if you would like to raise awareness of this campaign:

<https://ecampaigns.mndassociation.org/page/117925/action/1>

If you are a carer and have not yet had an assessment, please be reassured that it is not judging your capability as a carer but allows you to discuss the help you may need.

For more information: <https://www.mndassociation.org/app/uploads/2022/06/4-Carers-assessment-2021.pdf>

You can apply for a Carer's Assessment in Norfolk: <https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/support-for-carers>, or Suffolk: <https://www.suffolk.gov.uk/care-and-support-for-adults/caring-for-someone/carers-assessments>.

The **Carer's Leave Bill**, a private members bill currently progressing through Parliament, meets one of the key recommendations in our report where we ask for improved employer support for carers. The bill passed its report stage.

Ahead of a debate on the 3rd of February, Sue Heal wrote to some of our local MPs seeking their support and sharing a briefing provided by the Association.

We are grateful to James Wild, MP for North West Norfolk for speaking in favour of the bill. He recognised the work of Carers UK, and other charities. It was good to read in Hansard that the Association received a mention. He said, "Sue Heal, a volunteer with the Norfolk, Norwich and Waveney branch of MNDA, with whom I have worked, emailed me this week to say:

"Recent research conducted by the MND Association found MND carers are physically and mentally exhausted, unable to access breaks and impacted financially. Many are also juggling caring with work and additional responsibilities."

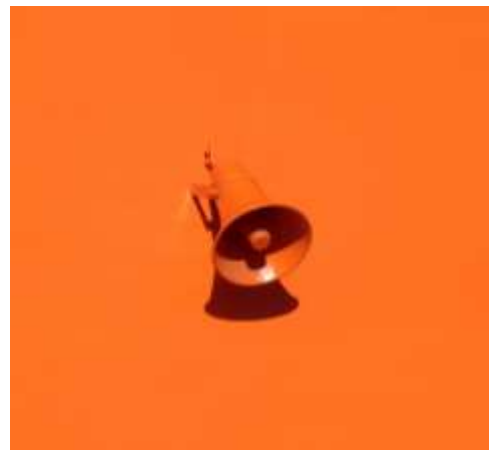
She asked me to support the Bill on behalf of MND sufferers and their carers and I am very pleased to do so today." Proof that it is worth writing to MPs!

NHS Continuing Healthcare for motor neurone disease

Readers may be aware from earlier editions of Fightback that the Association was working to improve awareness of NHS Continuing Healthcare (CHC) and the process for accessing care.

In October 2022, MND Matters podcast Episode 20 – NHS Continuing Healthcare gave some useful insight into the CHC process <https://www.mndassociation.org/media/mnd-matters/previous-episodes/>.

The Association recently released a new 7 minute animation. It is a concise and simple tool for understanding CHC and can be found at <https://www.youtube.com/watch?v=xn-qsKJcxo>. It starts by answering the question, 'What is NHS Continuing Healthcare (CHC)?'.



Cost Of Living Crisis

The ongoing #CostOfLivingCrisis is affecting people with MND. The Association needs to understand how it is impacting individuals before bringing the results to the attention of decision makers.

If you are living with MND we would appreciate it if you could take a couple of minutes to complete this survey: <https://www.mndassociation.org/get-involved/campaigning/take-action/cost-of-living-crisis/>

United to End MND

In November 2021, the #UnitedToEnd campaign secured a Government investment of £50 million to be targeted to MND research over the next five years. Since then work has continued behind the scenes to ensure the money can be accessed quickly and efficiently.

On 2 February, a Roundtable with Health and Social Care Secretary Steve Barclay, involving leading representatives from across the MND research community, people living with MND, and charities, Life Arc, MND Association, My Name's 5 Dottie Foundation and MND Scotland met to discuss the future of MND research. Dave Setters, who along with Lee Millard instigated the campaign, gave a powerful speech that you can read at <https://united2endmnd.org/2023/02/02/our-speech-today-at-steve-barclays-ministerial-mnd-roundtable/>.

After the meeting the United to End MND coalition released a statement which you can read in full at <https://www.mndassociation.org/statement-from-the-united-to-end-mnd-coalition/>. In it the coalition again stressed the importance of accessing "the Government money that has been ring-fenced for MND research as quickly and efficiently as possible, so that scientific discoveries can be translated into potential treatments and ultimately a cure". The coalition will continue their dialogue with the Government, the campaign continues!

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 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 **1st of June 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

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

Website: **www.mndassociation.org**

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