motor neurone disease association

Fightback

Norfolk, Norwich & Waveney Branch Newsletter
Issue 94 | July 2024

EDITOR'S NOTE

Hello readers! Following my first successful issue, I'm welcoming you to this year's second edition of *Fightback*, covering plenty of local and national news.

Our Annual General Meeting, which took place in April, is recounted on page 2, with many local fundraising events from pages 3-4. Elsewhere I've included details of coffee meets you can get involved in, updates on campaigns, national news, and research, and other useful information, which I hope produce an instructive and uplifting issue.

As we enjoy the warmer weather, make sure to look after yourselves and those around you. As always, if you have a story you would like to contribute, please send your written piece and any photos (with permission from the subjects) to emfawkesmnda@gmail.com. We look forward to hearing from you!
Emma Fawkes

Contents:

Norfolk, Norwich & Waveney Branch Website:
www.mndnorwichandwaveney.org.uk

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

Instagram: @MNDNorfolk

Sunday 28th April 2024

28 people attended our AGM and Open Meeting, which was chaired by Liz Cooper in Malcolm's absence. The business part of the meeting was short and was followed by a delicious lunch thanks to Kelda and her staff. As usual we had an excellent raffle!

Tanya Curry, Chief Executive Officer of the MND Association, joined us as our guest speaker. She spoke of the importance of working together towards the same vision - to make a difference to the MND community to get the best for people - and the steps that have already been taken towards this goal.

When Tanya started in the role she wanted to spend 6 months listening and observing, but from day one she has been going at 100 mph. She has rebuilt the senior team following a restructure and improved digital offers. The three priorities are:

1. Research

2. Services, support, partnerships: This replaces care. We always care but this is wider.

3. Influencing: Building relationships with NHS and NICE etc., and campaigning. We need to be in the conversations with these people, from the highest level nationally through to local level.

Advance Notice of Next Open Meeting

Date: Sunday 21st July

Time: 13:00 – 16:00

Location: Upton Village Hall, Cargate Lane, Upton, NR13 6AU. The venue is accessible with a large carpark.

The meeting will include a cold buffet lunch prepared by Kelda's Kitchen.

Local Fundraising Stories

Kingswood Festival Rugby Tournament | 7th & 14th April 2024

Malcolm was invited by Martin Watts, Minis chairman, to attend an MND awareness event at Holt Rugby Football Club, which focused on raising awareness around the many local and national sportspeople who have sadly been diagnosed with MND. Thanks to Nick, Anne, and Grace, as well as CSN Trish Moore, £167.13 was donated across the 2 days.

Meet the Farmer | 18th & 19th May 2024

In May we had a gazebo raising awareness and money for our branch at the Meet the Farmer event hosted by Wroxham Barns and Wroxham Bure Valley Rotary Club. Thanks to Trish, Grace, and Malcolm, as well as dogs Tully and Muffin, we've received a fantastic £1,000!

Christopher's Walk | May 2024

In May, Christopher Brock walked 77 miles from Ilkley to Windermere to support our branch in memory of his wife Ruth who passed away from MND 12 years ago. Another relative of Christopher's has more recently been diagnosed. His JustGiving page has raised £70 more than his £2,000 target, and can be found at this link: https://www.justgiving.com/page/christopher-brock-dalesway2024

Holly Cossey's Charity Ball | 15th June 2024

In June one of our supporters, Holley Cossey, held a charity ball at the Mercure Hotel in Norwich. The fabulous black-tie event included a three-course dinner and prosecco with a DJ, raffle, and auction.

Altogether, the event raised £6,000, with additional money on its way from the purchase of entry photographs. This will be split between the MND Association and our branch. We give our thanks to everyone involved in organising the event.

Walk by the sea to D’feet MND | 6th July 2024

A very cheerful and determined group gathered at the Alive Oasis Swimming Pool on Saturday 6th July for the Walk by the Sea to D'feet MND, to increase awareness of the disease. We are very grateful to all 52 walkers who braved the wind and rain on the way to Hunstanton, determined to carry on whatever the weather.

Although the forecast was for heavy rain all morning, it stopped as we gathered on the Prom at 10.30. Everyone remained dry, even allowing most to stop for coffee at Heacham, the half-way point.

No doubt several people would have been put off by the weather and certainly the town and Prom were pretty deserted, with very few visitors about to put money in our buckets - although quite a few rushed out from houses along the route with generous donations.

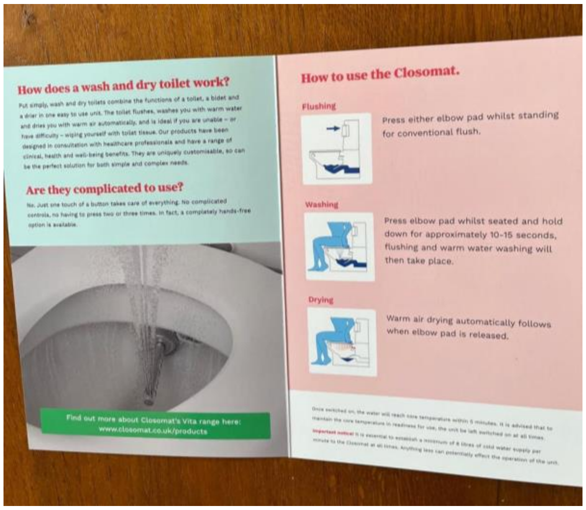
A total of £654.96 was raised for the Norfolk, Norwich & Waveney Branch of the MND Association, to help support people living in Norfolk with Motor Neurone Disease.

Any Other News

Closomat Toilet Available

We also have a Closomat Palma Vita toilet available. This was installed in December 2022 and used for less than a year. It comes with a full installation and user guide.

If you're interested or have any questions, feel free to contact jennyeason898@gmail.com.



How does a wash and dry toilet work?

Put simply, wash and dry toilets combine the functions of a toilet, a bidet and a drier in one easy to use unit. The toilet flushes, washes you with warm water and dries you with warm air automatically, and is ideal if you are unable – or have difficulty – wiping yourself with toilet tissue. Our products have been designed in consultation with healthcare professionals and have a range of clinical, health and well-being benefits. They are uniquely customisable, so can be the perfect solution for both simple and complex needs.

Are they complicated to use?

No. Just one touch of a button takes care of everything. No complicated controls, no having to press two or three times. In fact, a completely hands-free option is available.

Find out more about Closomat's Vita range here:
www.closomat.co.uk/products

How to use the Closomat.

Flushing

Press either elbow pad whilst standing for conventional flush.

Washing

Press elbow pad whilst seated and hold down for approximately 10-15 seconds, flushing and warm water washing will then take place.

Drying

Warm air drying automatically follows when elbow pad is released.

Once switched on, the water will reach core temperature within 5 minutes. It is advised that to maintain the core temperature in readiness for use, the unit be left switched on at all times.

Important notice! It is essential to establish a minimum of 8 litres of cold water supply per minute to the Closomat at all times. Anything less can potentially effect the operation of the unit.

Free Items and Items for Sale to People Living with MND

Please note that whilst we are able to offer a free advertising service, the Association requires us to advise that we cannot accept responsibility for the condition of the items advertised, and it is not endorsing or affiliated with any of the items being advertised. Arrangements for collection of free items or items for sale should be made directly between the buyer and seller. Where specialist equipment is concerned, you are strongly advised to seek advice from your

Branch Stories

Mark Oakley, Communications Officer for the MND Association, is seeking personal stories and experiences from current volunteers to help encourage new recruits.

Please note that these will be shared through the central social media accounts so anyone participating must be happy to be featured there.

Volunteers would need to include a photo, their name, role, branch/group, and a few sentences on why they volunteer for the Association and would encourage others to do the same. You can either email me at emfawkesmnda@gmail.com and I can pass your information on, or you can email Mark directly at mark.oakley@mndassociation.org. Happy writing!

Any Other News

MND Matters: The MND Association Podcast

The MND Matters podcast is a space for 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 of offering informal advice and support to their listeners whilst raising awareness of MND.

You can catch up with the most recent episode now or 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 another resource for anyone affected by 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. It's worth mentioning that some may find the content difficult and/or distressing.

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 access or register, 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 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 9:00 – 17:00 and 19:00 – 22:30. Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. You can also email the team at 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

Dates for Your Diary

2024 Coffee Mornings and Afternoons - Held on Wednesdays

July 10th for Online | 17th for Notcutts | 31st for Cherry Lane | 17th for Dobbies

August 14th for Online | 21st for Notcutts | 28th for Cherry Lane

September 11th for Online | 18th for Notcutts | 25th for Cherry Lane | 18th for Dobbies

October 9th for Online | 16th for Notcutts | 30th for Cherry Lane

November 13th for Online | 20th for Notcutts | 27th for Cherry Lane | 20th for Dobbies

Wymondham Rotary Satellite Group has made a donation to cover the costs of our coffee mornings for the next 12 months. We would like to record our appreciation of their generosity.

Hopefully we won't need to cancel any meetings due to unforeseen circumstances, but updates will appear on: https://www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch/

There's no need to let us know you are coming to the coffee mornings. For face-to-face meetings, please take a lateral flow test on the day to reduce the risk of spreading infection to people with MND. We'll replace this when you arrive so you're not out of pocket.

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 clarelowery93@gmail.com if you would like to receive the link. Newcomers are always welcome!

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 Garden Centre: Beccles Rd, Fritton, Gt 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.

Dobbies Garden Centre: Campbells Meadow, King's Lynn, PE30 4WQ **Time**: 14:30 – 16:30. These informal gatherings are hosted by Jane and others for people with MND, their carers, and friends.

Donations & Fundraising

received with thanks

Donations

Anonymous - £80.00
PEW - £40.00
VC - £40.00
EG - £19.52
PWF - £10.00
JMcM - £40.00
P & DG - £230.00
PT - £100.00
Collection Box - £49.00

Fundraising

Get Together IMO Debs - £82.33
Tesco Collection - £312.26
Cawston Quiz Night - £400.00
Wymondham U3A Quiz - £22.00
Holt Rugby RFC Collection - £167.13
Wymondham Rotary Satellite Group - £1,000.00
Martin Burnell Spreading Awareness - £400.00
Sarah Lusher London to Essex Ride - £545.00
King's Lynn Golf Club - £4,500.00
Wroxham Rotary Club - Meet the Farmer Event - £983.88
The Crown in Gayton Quiz Night - £60.00
Raffle at Eaton AGM - £115.00
Sale of Merchandise - £12.50

Donations in Memory of

JH imo her husband - £181.00
Rosedale Funerals - £560.00

Internal Transfers

Gift Aid - £36.75
Emergency Fund - £14.83
HMRC Charities - £22.50
Bank Interest - £432.74

Rob Burrow Leeds Marathon and Kevin Sinfield's Next Challenge | May 2024

On 12th May from 9:00, the second Rob Burrow Leeds Marathon in aid of various charities took place, with a 26.2 mile route from Headingley to Otley and back, and a similar half-marathon course of 13.1 miles. Alongside over 10,000 other participants, Rob's former teammate and Association patron Kevin Sinfield CBE was once again involved, helping raise an outstanding total of almost half a million pounds this time around.

Kevin is known for his completion of a series of challenges in support of the Association, and has recently announced he is completing his fifth on 1st December this year, which is a week-long event themed 'running home for Christmas.' He and his team are set to cover over 50km per day, in 7km hourly blocks which reference the number worn by Rob during his rugby career.

The run will progress across 7 regions in Great Britain and Northern Ireland, with the penultimate leg set to start at the Association's National Office in Northampton, and there will be chances for members of the MND community to take part at set points.

The route is published here, along with more information: https://www.mndassociation.org/media/latest-news/mnd-association-patron-kevin-sinfield-announces-challenge-number-five

Tofersen Update | May 2024

Tofersen, also known as QUALSODY ®, is a treatment which has been shown to slow the progression of MND in people with the SOD1 genetic variation. Around 1 in 50 people living with MND have this alteration, with an estimated 60 - 100 living in the UK.

Tofersen has recently been granted marketing authorisation by the European Commission, becoming the first approved treatment in the European Union for a therapy that targets a genetic cause of MND. In the UK, the National Institute for Health and Care Excellence (NICE) has previously confirmed its decision to appraise any submission for the drug through the Single Technology Appraisal (STA) rather than the Highly Specialised Technologies (HST) route, which goes against advice from organisations like the MND Association and leading MND clinical experts.

If appraised through the standard route, it's highly unlikely tofersen will reach a positive decision, meaning that while potentially available in Europe after having been approved under exceptional circumstances, it would be inaccessible to patients through the NHS. Usually treatments that target diseases affecting less than 1 in 50,000 people in England are appraised through the HST route, but the STA route is being applied as NICE does not view the variation as a clinically distinct disease.

Chief Executive of the Association Tanya Curry has spoken out against this, stating, "we remain committed to ensuring people with MND get access to proven, effective treatments and be a voice for our community in making the case for this decision to be reversed." You can read more at this link: https://www.mndassociation.org/media/latest-news/tofersen-given-green-light-european-commission

Rob Burrow | June 2024

It greatly saddened us to learn of the death of Association Patron, rugby league legend Rob Burrow CBE, on 2nd June this year. Rob was diagnosed with MND in 2019 and was very open in sharing his experience and journey with the disease, inspiring countless people within the MND community and beyond.

Following his diagnosis he dedicated himself to raising money and awareness with teammate Kevin Sinfield CBE. Thanks to Rob, at the time of his passing over £6 million had been raised for MND charities, and from 3rd June, work began on the Rob Burrow Centre for Motor Neurone Disease, a care centre for MND patients situated in the Leeds area. Rob was involved in the design and creation of this facility, and his family has requested that in lieu of flowers, members of the public can donate to the Leeds Hospital Charity appeal to help build the Centre.

His funeral will take place on 7th July, coinciding with Rob Burrow Day, and the route has been published so that the public can pay their respects. This can be found at the following article: https://www.bbc.co.uk/news/articles/c1348zmnepyo. Our thoughts remain with Rob's wife, children, and loved ones through this immensely difficult time, and we express our gratitude for his incredible legacy.

MIROCALS Trial Update | June 2024

The MIROCALS trial, which is investigating the effectiveness of the trial drug interleukin-2 (ILT-101) in people with MND, had promising preliminary results at the end of 2022. However, the final results still haven't been published.

In their reply to a letter the MND Association sent last month, the leading researchers informed that the paper is well-advanced, but haven't yet confirmed a publication date. The Association also wrote to ILTOO Pharma, the pharmaceutical company engaged by the MIROCALS Consortium, with a reply confirming the importance of the UK as a market for the drug if its effectiveness is proven, as well as revealing that it has begun engaging with regulatory bodies. ILTOO is also running a Managed Access Programme that could be a potential route for accessing the drug, and the Association has requested more information and clarification on this. We will also be working closely with healthcare and regulatory systems as well as the My Name'5 Doddie Foundation, MND Scotland, and the MND Community.

You can read in further detail here: https://www.mndassociation.org/media/latest-news/mirocals-trial-update

Campaigns Update

ACT TO ADAPT

Access to home adaptations for people with motor neurone disease

Act to Adapt

Our campaign on improving the housing adaptation processes for people affected by MND continues to reap rewards. Sue spoke with a Norwich City Councillor and learnt that the Council has formalised their response to our Act to Adapt Campaign. It is contained in within their Financial Assistance Policy for Independent Living.

In summary, Norwich City Council do fast track MND cases as part of their usual triage / prioritisation process. They also keep a register of accessible properties. In addition, they cover the first £6,500 of any adaptation so long as the proposed work meets the purposes for which a Disabled Facilities Grant (DFG) must be given and is necessary and appropriate. The DFG Calculated Contribution Grant of £6,500 is non-means tested and can only be awarded to people who are eligible for a DFG. It's almost guaranteed that people with MND are eligible for a DFG, albeit after the means test the DFG award itself may be £0.00. "*In short someone who needs an adaptation in Norwich will get at least £6.5k towards the cost of the works."*

General Election and Our MND Association Manifesto 2024

The 2024 general election took place on 4th July. It's a crucial time to ensure that the next parliament prioritises the needs of those affected by MND.

The MND Guarantee is a straightforward commitment candidates can make, promising to support people living with and affected by MND if they become your MP.

Sue Heal wrote to 54 prospective parliamentary candidates (PPC) across the 11 constituencies that cover Norfolk and Waveney. Thank you to everyone who wrote to their PCCs, the contact from constituents often works better! As of 4 July, Sue was aware of 13 PPCs who had pledged their support of whom three were elected; other returning MPs have given their support in the past and will hopefully continue to do so.

Sue will write to congratulate the successful candidates and will invite new MPs to meet with us to discuss how they can best use their position to support people living with and affected by MND. If you would be happy to join Sue in a meeting, please let her know at susan.heal@mndassociation.org.

Our manifesto includes 5 key asks of the new government to help transform the lives of people with MND:

1. Accessible homes: We need a major change in the way adaptations are provided in the home for people with MND. Too many are living in unsuitable and unsafe housing. We are asking local authorities to remove the red tape and fast track assessments for people with MND for these adaptations; as well as for the next government to consult on increasing the upper limit of a Disabled Facilities Grant.

2. Access to treatments: The next parliament will be a critical period for MND research, with unprecedented levels of research activity to develop new disease-modifying and life-extending drugs for MND. Now is the time for sustained investment and support to bring these drugs to those who need them.

3. Improved cost-of-living support: People with MND have been hit disproportionately hard by the cost-of-living crisis, especially regarding energy bills. We are asking the next government for targeted support to help people in the next parliament, and a sustainable, long-term solution to the energy crisis such as an energy social tariff.

4. Sustainable social care: We need the next government to provide a sustainable social care funding settlement with a clear plan to address workforce shortages to ensure the sector can fully support people with MND. Long-delayed measures to stop people incurring catastrophic care costs must now be introduced.

5. Support MND Carers: Unpaid carers are the backbone of support for people with MND. The financial support they receive does not reflect the contribution they make and too many are excluded from support at all. We are calling on the next government for a full review of the support currently available to unpaid carers.

Norfolk County Council Consultation

The consultation, asking for your views on Norfolk County Council's proposal to change the non-residential charging policy by reducing the Minimum Income Guarantee (MIG) in line with Government's rates, closed on 17th May. Thank you to everyone who took the time to fill in the online consultation questionnaire or who attended one of the drop-in sessions held across the county.

Following Sue's discussions with the Campaigns Team, Peter Lloyd, Senior Policy Adviser with the MND Association, submitted a well-argued paper reflecting our concerns and strongly disagreeing with Norfolk County Council's proposals. Sue was also able to attend one of the Council's drop-in sessions at The Forum, Norwich, where she again outlined our concerns in detail.

Branch Information

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 **30th September 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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