motor neurone disease association

Fightback

Norfolk, Norwich & Waveney Branch Newsletter
Issue 97 | August 2025

EDITOR'S NOTE

As Jeannette Walls said, "one benefit of summer was each day we had more light to read by." In this edition of Fightback, you can peruse local donations and fundraising efforts, alongside wider campaigns and research. You can also discover upcoming events, meetings for coffee or a walk with other members of our community, and lots of other useful resources and info all in one place.

As always, if you have a story you would like to contribute, or any resources to share, please send your written piece and any photos (with permission from the subjects) to emfawkesmnda@gmail.com. **Please bear in mind the deadline which can be found on the Branch Information page.** We look forward to hearing from you!

Emma Fawkes

Contents:

Norfolk, Norwich & Waveney Branch Website:
https://www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

AGM

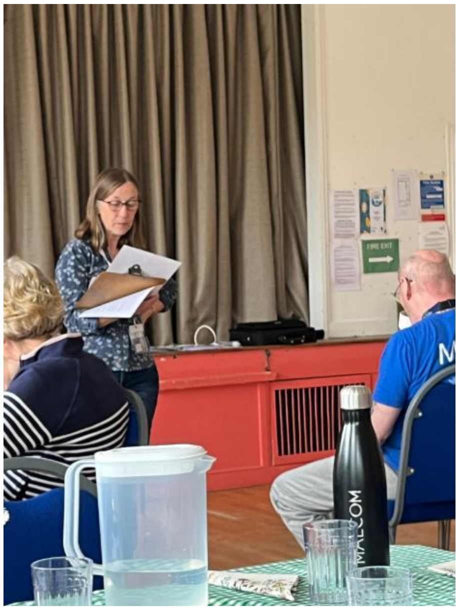
Sunday 27th April 2025

The AGM of the branch was held at St. Andrew's Church Hall, Eaton.

The day was filled with presentations, notably those by Liz Cooper in recognition of Malcolm Chubbock's 30 years as founder member, volunteer, and Chairman of the branch since 1995, and in recognition of Judy Burns-Thomson who was retiring as Branch Committee Member and Association Visitor.

Sue Heal also gave an excellent presentation describing the work she does as Campaigns Volunteer, as well as Ellie Miller who has been recently appointed to the role of Relationship Fundraiser East.

Thank you to everyone who attended and for all the valuable work being done by our amazing members and volunteers.



Advance Notice of Next Open Meeting

Date: Sunday 16th November 2025

Time: 12:00 am - 4:00 pm

Location: Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS

Ryston Park Golf Club Fundraiser | April 2025

Opposite, Jenny Mason and Elaine Lane receive a cheque on behalf of the Norfolk, Norwich and Waveney Branch of the Motor Neuron Disease Association, for the magnificent sum of £4,480 from Gary Rider and members of the Ryston Park Golf Club.

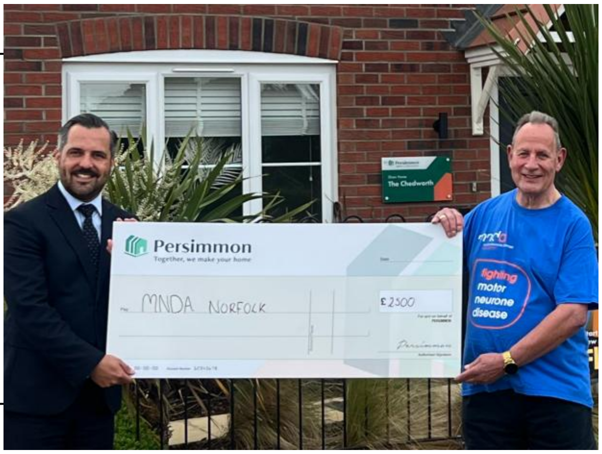
During his time as Captain for Ryston Park Golf Club, Gary Rider chose the Motor Neuron Disease Association (MND Association) as his nominated charity in memory of a family member, Derek Wright, who was sadly diagnosed with the disease and lost his fight earlier this year. Over the past year, members and friends of Ryston Park Golf Club have raised funds through a Charity Golf Day, a quiz night, and several other fundraising events. A cheque was recently presented to the Norfolk, Norwich and Waveney

Branch of the MND Association. Gary said: ‘The generosity and support shown by our members, friends, and local community has been truly overwhelming. Today, I'm proud to present this cheque as a symbol of our club's support for those affected by Motor Neurone Disease, and in memory of Derek. We hope this contribution will go towards vital research, support, and care for those battling this condition, and bring us all a step closer to a future without MND. Thank you to everyone who contributed, volunteered, donated, or simply showed up. This is your achievement too.’

The Norfolk, Norwich and Waveney Branch of the MND Association are immensely grateful for this donation and for the support of all the people involved. It will help the National Association to support the funding for research that leads to a better understanding of MND, potential treatments and ultimately, a cure. Locally, donations allow us to provide help with acquiring equipment, adaptations to the home and Quality of Life grants to people in this area who are living with MND, as well as their carers and families. Our volunteer Association Visitors who work closely with local NHS services can help them access vital information, practical solutions, and emotional support. We also arrange social events where people living with MND and their carers can meet in a friendly and informal setting. For more information please visit our website: www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch

Persimmon Homes Cheque Presentation | June 2025

Opposite, Jordan Knell, Sales Director of Persimmon Homes Ltd (East Anglia) presents a cheque to Malcolm at their Festival Park development at Easton near Norwich. This was for a generous donation of £2,500 from their Community Development Fund.



Upcoming Events / Donations

Autumn Fashion Show

Proceeds in aid of
Norfolk, Norwich & Waveney MNDA

Friday 3rd October 7:30pm

Fashion Courtesy of Doves of Dereham

Tickets:
£20 Complimentary glass of Prosecco
£10 "Partner & Pet Creche" to enjoy
a Complimentary beer in the Bar

StallsRaffle***

Contact: fashionshowmnda@gmail.com

Venue and Parking
Yaxham Village Hall
Norwich Road, Yaxham, NR19 1RG

Walk by the Sea to D'feet MND | 11th October 2025

Taking place in October is the annual Walk by the Sea to D'feet MND, and we hope you, your friends, and family can join to help raise awareness of MND and money for our branch.

The walk will begin at the South Prom Carpark near Alive Oasis (Beach Terrace Road, Hunstanton, PE36 5BQ) with registration from 9:30 am - 10:30 am, continue along the prom to Heacham, and back. This is total of four miles - two each way, but there are shorter options too.

Children and dogs on leads are welcome but unfortunately bikes aren't permitted on the prom. It's also a wheelchair-friendly route.

Collections will take place in Hunstanton and along the walk to raise funds for our branch. Help with collecting by non-walkers would be much appreciated. For more information, please contact either 07887 675458 or janelewis321@btinternet.com.

Donations & Fundraising

received with thanks

Donations
Unknown - £10
Mr & Mrs IK - £20
C & DT - £25
F.P. - £30
J.M. - £35
E.G. £29.28
J. McM - £60
P.E.W. - £50
P.T. - £200
S.B. - £80
D.G. - £230
Persimmon Homes – £2,500

Collection Tins
Station Bistro Wymondham - £6.09
Holt Shop - £54.82
Cringleford stores - £35.59
A.F. Collection at her Pilates - £70
Aylsham Tesco - £343.86
Wheatacre Hall Barns Farmshop - £362.80

Fundraising
Broadland Tangent Group of Ladies - £100
Raffle at AGM at Eaton - £177
Lyng and District Hall - £1,529.41
Ryston Park Golf Club - £4,480
Dereham Baptist Coffee Shop - £350
Lisa, Claire, and Emma's Bake-it - £1,495.90
Wymondham Ukulele Group - £764.10
Neatishead Big Breakfast – £758.37
Postwick Social Club Silent Disco - £480
T.A. Half-Marathon - £20
S.M. from Plant Sales - £200
S.B. - £200

Donations in Memory of
Joan Heal - £100
Sharon Gee - £90
Dilys Jones - £990
Carolyn Anne Wilde - £1,130
Greta Smith - £190
Derek Peter William Wright - £171

Miscellaneous
Emergency Fund - £588
Bank Interest - £826.61
Gift Aid - £274.03
Sale of Merchandise - £81.41
S.N. Sale of Ramps - £70

Sailing at Snettisham Beach

There is an opportunity for people living with MND to sail at Snettisham Beach Sailing Club on Friday afternoons, throughout the summer from 1:00 pm to about 4:30 pm. Ten people from the King's Lynn Coffee Group went to the Sailing Club, where three people went out sailing. Here are the details if you'd like to have a go!

They have adapted boats which are suitable for beginners who have never sailed before, or for more experienced sailors. They also have a team of trained volunteers and instructors to help. Adrian Tebbutt and the team of volunteers are very welcoming and helpful.

You will see that they are part of the Royal Yachting Association Sailability Scheme and hold the relevant safety qualifications. A good video shows you what it's like sailing on the lake. They also run a 'Sailability' training scheme, so you can arrange to go regularly and follow the syllabus for a sailing qualification.

A family member or carer is welcome to go along too. The address is 61-62 The Beach, Snettisham, King's Lynn, PE31 7RB, about midway between Hunstanton and King's Lynn. (For those who didn't come on Friday, the concrete road in to the sailing club needs to be taken very slowly as it's quite bumpy and you need your sat nav to find it!)

The Sailing Club is situated in a lovely part of Snettisham - by the sea, on the edge of the Wash. So it's definitely worth going to have a look on a Friday afternoon and enjoy the surroundings, whilst you consider the opportunity! I would still suggest that most people may prefer to go along to have a look at the access and facilities to see if it's suitable for you, before committing to sailing.

You can book a session for yourself; the cost is £12 for an hour for an individual booking. Click on the Accessible Sailing link on their website at https://www.snetbeach.co.uk/discover/about-accessible-sailing to bring up the relevant information and learn more about it. You would be helped on and off boats and accompanied by one of their volunteer sailors.

Don't forget that MND Association Quality of Life grants are available for this sort of leisure activity - but just apply two or three weeks before hand as they can't do grants retrospectively. You could apply for, say, £120 to cover ten sessions (providing you meet the criteria). The maximum total for all grants from the Association is £3,000 per 12 months - although the Cost of Living grants are additional to that £3,000. Information and application forms are on the national MND Association website.

Adrian Tebbutt from the Sailing Club has previously explained a few things which you may wish to be aware of :

A) Accessible sailing would be on the lake (although the Club also has sea sailing adjacent.)

B) Sessions would be held between 1:00 pm and 5:00 pm on Fridays – please book and pay by credit card on their website.

C) Individual or group sessions can be booked - £12 per hour for an individual, or £90 for a group two-hour session of six to ten people.

D) Typically it would be one person in a Hansa boat, with the instructor - although they have Wayfarers too, which can take two people plus instructor (so a person living with MND could be accompanied by a family member or carer if arranged in advance.)

E) A family member or carer is welcome to go along - there's a viewing area over the lake.

F)There's a cafe on site, open on Fridays after 4:00 pm.

G) There is a fairly steep slope down to the pontoon & lake, so manual wheelchairs would be attached to a winch, for safety, to go down the slope.

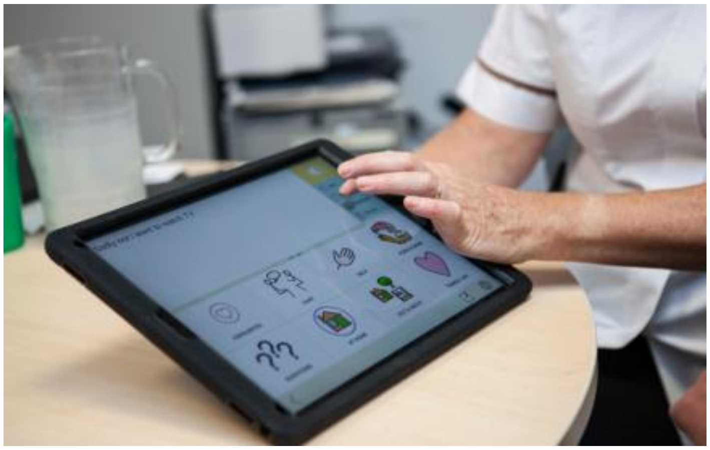
H) Where required, they have a hoist to lift people from the pontoon into the boat (max weight for hoist 119 kg.) There is other simple equipment to help transfer to the boat.

I) At present the toilet facilities are not fully accessible, so there would not be space to accommodate an electric wheelchair. One option discussed was to transfer from wheelchair to toilets using a walker, where appropriate.

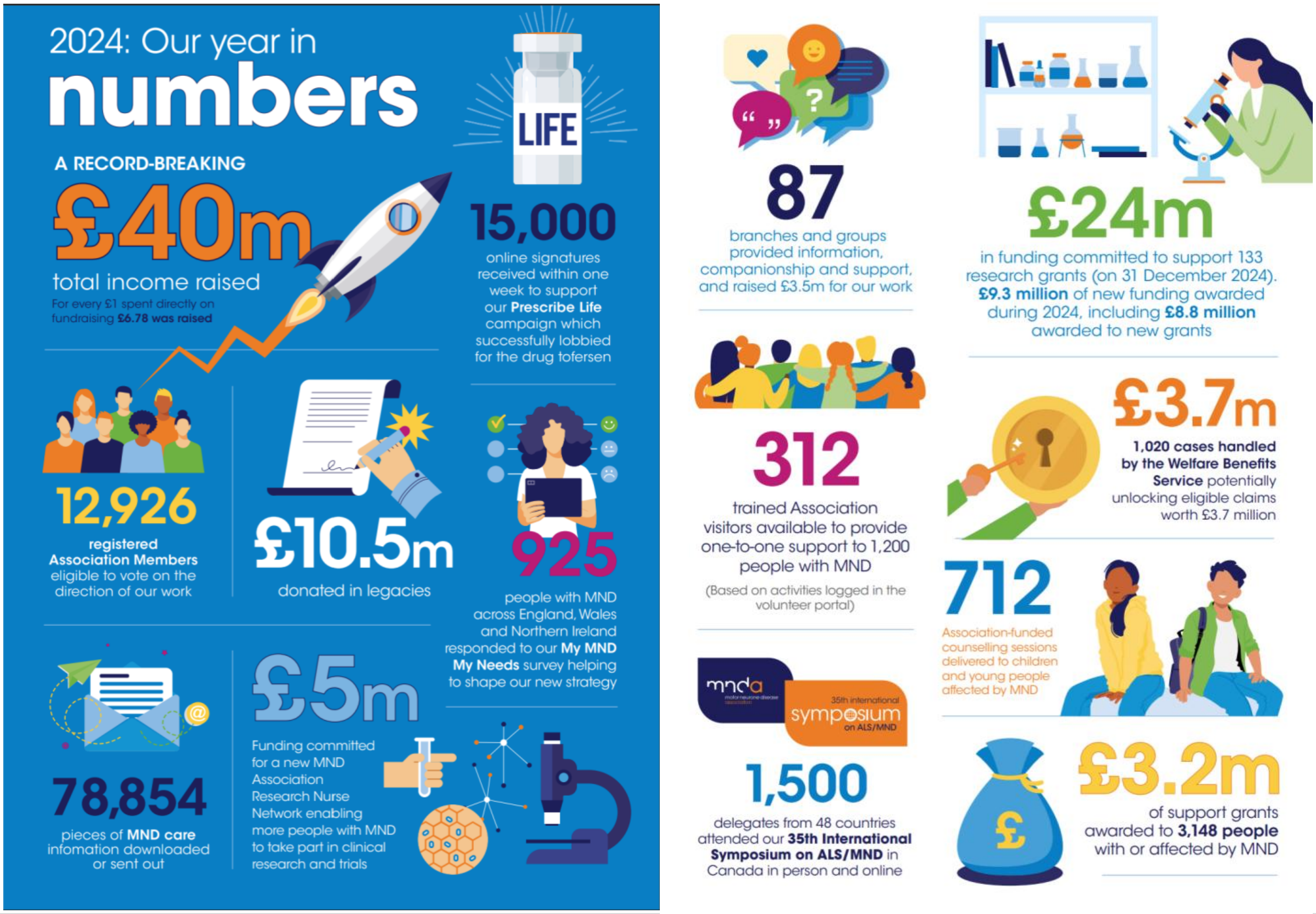
J) The Sailing Club would provide buoyancy aids and suitable clothing - you shouldn't get wet, unless it's raining!

Any Other News

Tech Skills for Life



If you struggle with or want to learn how to use technology and/or the internet, Tech Skills for Life could help you if you live in the West Norfolk, North Norfolk, King’s Lynn or Great Yarmouth areas. It’s a partnership led by Norfolk County Council, working with the NHS, volunteer groups, and local community organisations to help people use computers, smart phones, and tablets, and navigate the internet safely with skills and confidence, whether as a refresher or an introduction. There are free sessions with community tech coaches to do this, who can also help you access technology and mobile data and give advice about affordable broadband. To get in touch, please call 01485 536420 or 01493 448246; lines are open Monday-Friday from 9:00 am – 5:00 pm. A community tech coach will answer your call or you can leave a message. Alternatively you can complete an online form at https://www.norfolk.gov.uk/38923 where further information can also be found. Coaches normally meet clients in designated libraries but home visits may be possible. There is currently a high volume of requests; someone will be in touch as soon as possible.



2024: Our year in **numbers**

A RECORD-BREAKING **£40m** total income raised

For every £1 spent directly on fundraising **£6.78 was raised**

15,000 online signatures received within one week to support our **Prescribe Life** campaign which successfully lobbied for the drug tofersen

12,926 registered **Association Members** eligible to vote on the direction of our work

£10.5m donated in legacies

925 people with MND across England, Wales and Northern Ireland responded to our **My MND My Needs** survey helping to shape our new strategy

78,854 pieces of **MND care** infomation downloaded or sent out

£5m Funding committed for a new MND Association Research Nurse Network enabling more people with MND to take part in clinical research and trials

87 branches and groups provided information, companionship and support, and raised £3.5m for our work

312 trained Association visitors available to provide one-to-one support to 1,200 people with MND

(Based on activities logged in the volunteer portal)

1,500 delegates from 48 countries attended our **35th International Symposium on ALS/MND** in Canada in person and online

£24m in funding committed to support 133 research grants (on 31 December 2024). **£9.3 million** of new funding awarded during 2024, including **£8.8 million** awarded to new grants

£3.7m **1,020 cases handled by the Welfare Benefits Service** potentially unlocking eligible claims worth £3.7 million

712 Association-funded counselling sessions delivered to children and young people affected by MND

£3.2m of support grants awarded to **3,148 people** with or affected by MND

Any Other News

New Accessible Toilet in King’s Lynn Town Centre

West Norfolk Council has installed a changing places toilet next to the St James multi-storey car park in King’s Lynn, funded by the borough council and Department for Housing, Communities, and Local Government. This will benefit people with disabilities whose needs can’t be met by standard accessible toilets, including people with MND, in that it’s bigger, and includes an adjustable changing bench and a hoist. The Multi-User Community Hub that will be opening on New Conduit Street will include another changing places toilet when it launches.

The MND Association Online Forum

The online forum is a 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 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.

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 am – 4:00 pm. Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. They are also confidential. Alternatively, you can 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.

2024/2025 Coffee Mornings and Afternoons - Held on Wednesdays

August 20th for Notcutts | 27th for Cherry Lane

September 17th for Notcutts | 24th for Cherry Lane | 17th for The Range

October 15th for Notcutts | 29th for Cherry Lane

November 19th for Notcutts | 26th for Cherry Lane | 19th for the Range

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're 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.

Locations:

Notcutts Garden Centre: Daniels Rd, Norwich, NR4 6QP **Time**: 11:00 am – 1:00 pm. These informal gatherings are hosted by Malcolm, Sue, Clare, Anne, and others for people with MND, their carers, and friends.

Cherry Lane Garden Centre: Beccles Rd, Fritton, Gt Yarmouth, NR31 9EU **Time**: 11:00 am – 1:00 pm. These informal gatherings are hosted by Judy and Colleen for people with MND, their carers, and friends.

The Range: Unit C, Hardwick Retail Park, King's Lynn, PE30 4NA **Time**: 2:00 pm – 4:00 pm. These informal gatherings are hosted by Jane and others for people with MND, their carers, and friends.

Online Support Groups:

The Association runs a variety of online support groups for wider geographical areas including the southeast region. Follow the link as dates can be subject to change: https://www.mndassociation.org/online-support-groups. We would like to highlight the Continuing Healthcare support meetings which can be found under the 'Open Across England' tab.

Coffee and Walks for Bereaved Family and Friends

Informal meetups for walks and coffee are taking place bimonthly at 10:30 am in The Restaurant in the Courtyard in Sandringham, PE35 6EN. The remaining dates for the year are 11th October and 13th December

For more information, please email Jane Lewis at janelewis321@btinternet.com or phone 07887 675458.

All-Party Parliamentary Group (APPG) on MND

The group last met on 1st April, shortly after the last issue of Fightback was published. For the first time since the pandemic the meeting was held in person and online. Sue Heal, as the Branch Campaigns Contact, was able to attend online. The group received the results of the APPG on MND Priorities Survey, which was launched with the MND Association to better understand the challenges facing the MND community. The top three things mentioned were:

- Research and finding a cure (56% of respondents)
- Provision of care (20% of respondents)
- Financial support + cost of living (19% of respondents)

As a consequence, the meeting focused on research. Dr Mike Rogers, Director of Research and Innovation at the Association, outlined the challenges around developing new treatments for neurodegenerative diseases. He stressed the need for more involvement of industry and more Government funding. He then described the journey from research lab to NHS prescription, which is quoted in full to provide context for the next article looking at the Prescribe Life campaign.

- Starts with identification of potential therapeutics in the laboratory, this process takes about 10 years before the drugs move to clinical trials
- Clinical trials have four phases
- Around 70% of drugs get through Phase 1
- Phase 2 is a two-step process looking at how much of a drug should be given and how well it works. This is the most difficult phase to pass, with only 30-40% of drugs progressing through this stage
- Phase 3 tests a drug in large groups (hundreds of people) to evaluate efficacy before engagement with regulators
- Phase 4 involves monitoring in the broader population (thousands of people) after regulatory approval. Drugs are still monitored for safety throughout and beyond this phase and drugs are sometimes taken off the market after this point

Dr Nick Cole, Head of Research at the Association, provided an update on tofersen, which is brought further up to date in the next article.

This was followed by a question-and-answer session with the Expert Panel on MND Research. Lord Bellingham, Branch Patron, then asked some searching questions about appraisal of new drugs and collaboration with organisations supporting those with other neurological diseases such as Parkinson’s. After the meeting he met with Niall Murphy, Senior Public Affairs Adviser – Westminster with the MND Association to request Parliamentary Questions to the relevant Minister on this issue. We are grateful to Lord Bellingham for his support.

The next meeting of the APPG on MND is in November, watch out for the call to invite your MP to attend.

Campaigns Update

Prescribe Life Campaign

The MND Association's Prescribe Life campaign launched last year with the aim of making tofersen available to all who need it. Tofersen is a precision medicine targeted at people living with motor neurone disease (MND) carrying the SOD-1 gene mutation. This is a small group estimated at 2% of the MND population, or 60-100 people in the UK.

On 28th July, tofersen was granted marketing authorisation by the Medicines and Healthcare products Regulatory Agency (MHRA) for the treatment of SOD1 MND, bringing it into line with the US and Europe.

Now that it has been licensed for use in the UK, Biogen – the company responsible for the development of tofersen, has confirmed that it will now submit the drug to NICE (National Institute for Health and Care Excellence) to determine if it will be made available on the NHS.

Thanks to the success of Prescribe Life campaign's first win, tofersen will be assessed via the Highly Specialised Technologies route. The Association and other experts believe this gives it the best chance of being accepted for use on the NHS, though there is no guarantee.

In the meantime, the manufacturer has made tofersen available to patients free of charge through an Early Access Programme, as long as the NHS provides the staff time and resources. This means around 40 people are being given it each month via a lumbar puncture. However, some people – around 20 – are missing out because their local services do not have the capacity to administer it.

On 17th July, Seckin McGuirk, the face of our campaign, and others were in Westminster to hand in the petition with 21,859 signatures for our Prescribe Life campaign. The clear message was "people with SOD1 MND don't have time to wait, and the Government must act." That morning the group were outside Parliament with a life-sized ice sculpture of Seckin. As the ice melted, it was a powerful reminder that time is melting away for people like her who can't access tofersen.

Richard Baker MP and Frank McNally MP came to show their support, and Frank McNally raised the issue in the House of Commons that afternoon.

You can join our campaign at: https://act.mndassociation.org/join-our-campaign-help-people-living-sod1-mnd-access-life-changing-treatment.

Global MND Awareness Day

The Association held a Parliamentary drop-in at Westminster on 19th June sponsored by Jo Platt MP, to mark Global MND Awareness Day. MPs were invited to attend and hear first-hand from the MND community, including several people living with MND, about the challenges and issues they face.

Twenty-five MPs attended the event, including the UK Government Minister for Social Security and Disability, Sir Stephen Timms MP. They heard speeches from people affected by MND, one on her experiences of being an unpaid carer and the other concerning access to genetic testing and clinical trials. Discussions with MPs also addressed the urgent need for access to tofersen for those with SOD1 MND, as well as genetic testing and the significant financial pressures faced by people living with MND.

NHS Funded Continuing Healthcare (CHC)

Sue is an active member of the Association's CHC Action Group that meets regularly to work on a co-produced CHC Action Plan. One tangible outcome of the Plan is the webpage with up to date information and links to support: https://www.mndassociation.org/professionals/management-of-mnd/nhs-continuing-healthcare-chc.

Our online peer support group for people living with and affected by MND, Association volunteers, and Health and Social Care Professionals wanting to understand more about CHC funding processes, continues to run successfully and is well-attended. It takes place every six weeks on Mondays from 11am, with meetings planned for 1st September, 13th October, and 24th November 2025. To receive the link and further information contact chc@mndassociation.org.

The summer edition of Thumbprint, the magazine giving news from the MND Association Community to our members, featured an article on our pilot project that launched on 1st April. The pilot involves direct referrals to be made to Beacon via our MND Connect Helpline. Beacon experts can provide 90 minutes of free, personalised advocacy support for all aspects of CHC. The pilot is being evaluated regularly, and we have seen an increase in uptake of the support offered since its inception – including direct contact from people living with and affected by MND.

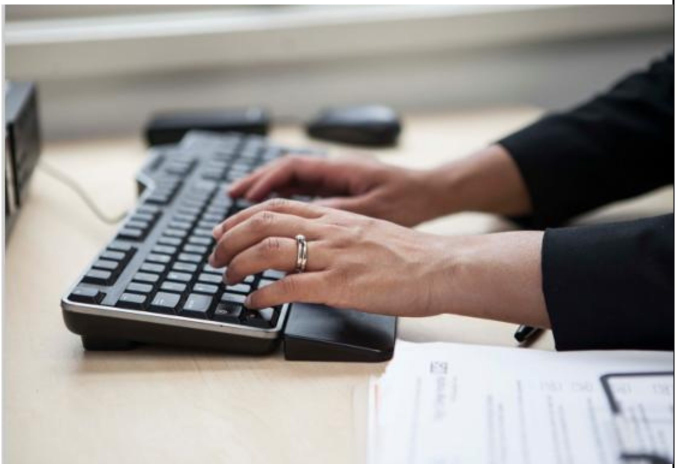
To access the MND Connect Helpline call 0808 802 6262 or email mndconnect@mndassociation.org. You can find the Beacon website at https://beaconchc.co.uk.

Campaigns Update

Neurological Nurse Specialist for the Wider Norwich Area

In May, we received confirmation of the outcome of the prioritisation process and unfortunately additional funds could not be secured for a neurological nurse specialist for the wider Norwich area. This is not the end of the story; the Associate Director of Commissioning has recently started a programme of work regarding standardisation of community health services and will be reviewing community neurology as one of the priorities. We will keep in touch and hope that one day there will be a successful outcome.

Meanwhile, as always, if you are a person with MND living in the Norfolk and Waveney areas and are in need of support, please contact your team for assistance. Where possible Helen will always endeavour to see people at home in the Norwich area.



Kyle's Story

Kyle was diagnosed with MND on 17th January 2025. His story was reported on the BBC in February: https://www.bbc.co.uk/news/articles/cyv41644j6go. Now aged 14, he is being treated in the Children's Hospital for Wales where he has been since last December. He is unable to return home because the family home cannot be adapted for the care he now requires. A petition has been set up to urge the local authorities to prioritise finding a suitable temporary home adapted to accommodate his disabilities whilst his parents try to sell their home. If you would like to sign the petition the link is: https://www.change.org/p/help-kyle-find-temporary-accessible-housing.

Could you be our next Campaigns Volunteer?

Do you enjoy writing, talking to people, and sharing stories? Our Campaigns Volunteer role could suit you – there is certainly room for extra support in this role across Norfolk! There is a lot you can get involved in from sharing campaigns on social media, contacting your local councillors or MP to improve services, or working with the Association's Campaigns Team to identify key issues to support vital campaigns. You'll have access to training and support and opportunities to connect with other volunteers. If you are interested email the campaigns team at campaigns@mndassociation.org or contact sue at susan.heal@mndassociation.org for an informal chat.

Branch Information

Branch Contact

Malcolm Chubbock
01603 960206
malchubbock@hotmail.co.uk
Norfolk, Norwich and Waveney Branch,
c/o MND Association, Francis Crick House, 6
Summerhouse Road, Moulton Park,
Northampton, NN3 6BJ

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 grace.fleming@mndassociation.org.

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 2025**.

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**

Registered Charity no. **294354**

Registered Address: **Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR**

MND Association National Office: **01604 250505**