In aid of mnda motor neurone disease association

East Sussex Branch

# Spring 2025 newsletter

## Drug closer to approval

**after Prescribe Life campaign success**

A breakthrough drug, proven to substantially slow progression of MND in those who have the SOD1 genetic change, is a step closer to being approved following a successful MND Association campaign.

The National Institute for Health and Care Excellence (NICE) has today (18 November) announced it has changed its mind about how it will assess tofersen, making it more likely it will eventually be approved.

The move comes a month after the MND Association launched its Prescribe Life campaign, alongside people affected by the disease, and working closely with the UK MND Research Institute and the UK MND Clinical Studies Group.

Over 15,000 people signed the charity's petition urging NICE to evaluate tofersen using its Highly Specialised Technology (HST) route, which the charity said gave the drug the best chance of being greenlit as a treatment for SOD1 MND in the future.

Eleanor Dalley, 49, from Barnet is taking Tofersen through the early access programme and has been a key member of the campaign team.

She said: "Today is really special for me – NICE has listened to the SOD1 MND community and heard us.

"By changing its original decision, NICE has taken another step down the road to securing this incredible drug, giving us time and hope, two things that often feel out of reach for people diagnosed with MND.

"I am so grateful to all the people who have felt driven to join the MND Association's campaign by what we saw as the injustice of NICE's original decision."

NICE's announcement on November 18 said that the 'topic routing was discussed at the NICE Prioritisation Board in October' and the 'board concluded that the topic was suitable for Highly Specialised Technology'.

Tanya Curry, CEO at the MND Association, said: "We are absolutely delighted NICE has decided to change its mind on this. Tofersen is the first proven effective treatment for MND for many years, and we are proud our campaign has helped our community get across how important it is that we give it the best possible chance of being approved.

"To be clear, there is still a long process to go through, and there is no guarantee that Tofersen will be approved at the end of the process. But it gives our community hope.

"While we disagreed with NICE's original decision, it deserves credit for being flexible enough to reconsider.

"We now need Biogen, the pharmaceutical company that manufactures Tofersen, to get the application process going again so we can move towards our ultimate goal - for people with SOD1 MND to access this life-changing treatment."

In trials, Tofersen has been shown to slow, and in some cases halt, the progression of MND in people with the SOD1 genetic variant, estimated to be around 60-100 people in the UK at any time.

The change in routing decision has now removed the logjam and while there is still a long way to go and there are no guarantees about the final outcome, the charity's hope is that Tofersen will now pass through the regulatory process.

**WE ARE ONLINE!**

**Visit the MND Association East Sussex branch website at www.mndaeastsussex.org.uk**

**You can also find us on Facebook @MNDAEastSussex and Twitter @MNDAEastSussex**


# 'Healthy fats' could protect against MND

## new research suggests

Enhancing levels of 'healthy fats' like omega-3s in the brain could be beneficial in motor neurone disease (MND), according to new research published in the journal, Nature Neuroscience.

"The potential impact of healthy fats, like polyunsaturated fats such as omega-3s, on the risk of developing MND and the length of survival has been of interest to researchers for some time, but crucially the understanding of their impact has been limited. This research takes our knowledge on a step.

"So would giving people with MND the same type of fatty acid increase their survival rate? We don't know yet. But it is an avenue worth exploring. The researchers must now look at which fatty acids should be tested further, in what quantities they could be effective and how they should be administered, before they carry out a clinical trial.

"We hope that further research and testing in humans will paint a clearer picture on the impact of diet on MND and other neurodegenerative diseases. In the meantime, we would advise anyone with MND to speak to their healthcare professionals before making any changes to their diet."

Previous studies have linked diets which contain high levels of omega-3 fatty acids, like those found in oily fish, nuts and seeds, with a lower risk of developing MND and longer survival in people with the disease.

A new study, led by the UK Dementia Research Institute (UK DRI) at University College London, and the UCL Institute of Healthy Ageing, found that increasing the levels of these healthy fats in the brain cells of fruit flies carrying a change in a gene called C9orf72, saw a 'dramatic' increase in their survival.

C9orf72 is the most common genetic cause of MND and frontotemporal dementia (FTD). Cells were also collected from people with these conditions and converted into brain cells in the lab. Healthy fats also increased the survival of these MND/FTD brain cells.

Scientists say the research, which was funded by Alzheimer's Research UK and the UK DRI, unlocks new understanding of the mechanisms underlying MND and FTD.




# Another comedy night success!

**Laughter was guaranteed!**

We have just held our second successful comedy night at The Chaseley Trust in Eastbourne.

Anthony is a great compere and comedian and introduced three very funny acts – Dan Evans, Ingrid Elise Dahle and Pierre Hollins.

Chaseley is a nursing home in Eastbourne, specialising in complex neurological conditions and over the years Chaseley has become home to several people living with MND when they could no longer cope with daily life in their own home.

They have a good size lounge with a bar which is ideal for our comedy nights and it's proved good to hold a join event and split the proceeds between our two charities.

Laughter is great medicine and it was good to see some of the Chaseley residents enjoying the evening too.

We will be putting on more nights at Chaseley so watch for further details of dates and artists.

Comedians performing at the last comedy night, clockwise from top left: Dan Evans, Antony Ayton, Pierre Hollins and Ingrid Elise.

# Have you joined our 100 Club?

**We would love to welcome you**

Do you know about our 100 Club? For each £24 a year you are allocated a number and at the end of the year if your number is drawn, you could win up to £100. If you are a tax payer, half of the £24 is eligible for Gift Aid increasing your contribution to branch funds.

Each year half of the amount raised is given out in prize money. You could be a winner too.

Just contact Denis for an application form by emailing hime at denischarles.bass@gmail.com

# Take on our swim 6km challenge in May

There are so many ways to raise money to help fight motor neurone disease (MND). One of these is our Swim 6km challenge which is returning in May!

Your efforts will raise essential funds to provide care and support for families affected by MND and to fund life-changing research aimed at finding a cure.

Join our #TeamMND Facebook group to set up your fundraiser, at this link: https://www.facebook.com/groups/swim6km

Once you've registered, we'll send you a #TeamMND t-shirt along with a swim cap to get you started!

For more fundraising ideas or to take part in an organised fundraising event, visit www.mndassociation.org/get-involved/fundraising

**If you have any comments, stories or articles for our quarterly newsletter, please email them to newsletter editor, Ellie Seymour, at hello@wordsbyellieseymour.com**

**Thanks for reading!**

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