motor neurone disease association

www.mndsouthessex.org

South Essex Branch
SUMMER 25 NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist

Record Breaking Walk 2025

Walk to d'feet MND

Another successful **Walk to d'feet MND** for 2025!
Under brilliant sunshine we had over 110 walkers with their friends and families coming together for a great day, some sharing their stories and rearing to go. Special mention to Sean N. who despite living with MND, managed to complete the whole 10 miles and has currently raised £310 on his JustGiving page.
We collectively raised **£1296** in the collection buckets alone, it was a great achievement and the sea of blue t-shirts on Southend sea front helped raise awareness for our cause. All in all it was a great day!
It's now time to get your sponsorship monies and JustGiving contributions so that we can be certain of exceeding the target of over £250,000 raised through 20 years of local Walks to D'feet MND.
What an amazing amount of support for folks living with MND in South Essex!

Scan this QR code if you want to use our JustGiving page for your fundraising efforts.

Meet Up?

Meeting Dates

Drop in meetings 2-4pm

The hospices kindly let us use their lovely rooms for our get togethers. Chat and make friends. We will supply the food and drinks.

Friday 1st August- Fair Havens
Saturday 6th September- St Luke's
Friday 3rd October - Fair Havens
Saturday 1st November- St Luke's
Friday 5th December - Fair Havens
Please contact Pat for more information
patricia.ahlquist@mndassociation.org

Recently Diagnosed Group

3rd Friday of the month via Zoom 2pm.
Allows all affected people to ask any question and find out about available support.
18th July/ 15th August/ 19th September
17th October / 21st November / 19th December
Please contact Pat or MND Connect

South East Region Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.
30th July/ 27th August/ 24th September
29th October / 26th November / 31st December
Daytime: 1st Tuesday of the month via Zoom 11am
1st July / 5th August/ 2nd September/
7th October / 4th November / 2nd December
Please contact Pat or MND Connect

South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.
15th July/ 19th August/ 16th September
21st October / 18th November / 16th December
Please contact Pat or MND Connect

Veteran's Group

4th Wednesday of the month via Zoom 2.30pm.
23rd July/ 20th August/ 24th September
22ndOctober / 26th November / 24th December
Please contact Dawn Pond for details
dawn.pond@mndassociation.org

Other groups available on MNDA website.
Please scan above QR code.

To Come

PANTO

Rylan is back for this year's Cliffs Pavilion Panto.
We still have spaces to give away for the matinee show on 17th December and the free Buffet Lunch beforehand.
Please contact Debbie if interested
deborah.darke@mndassociation.org

QUIZ night

The 2025 Annual quiz night for MND is being held at the Canvey Island War Memorial Hall on Friday 17th October at 7pm
Please contact Rowan to register your team
rowan.harvey@mndassociation.org

Reseach Update

Tofersen EAP: Sign our petition to help people living with SOD1 MND access a life-changing treatment

As you may be aware, Tofersen has been made available to patients free of charge through an Early Access Programme (EAP).

For the 2% of people with MND whose disease is caused by a fault in the SOD1 gene, Tofersen offers a new hope of slower disease progression, and so more time to enjoy life with family and friends.

However, not all people with SOD1 MND have access to Tofersen. Some who desperately need this treatment are missing out as their local services do not have capacity to give it to them via the required monthly lumbar puncture – even though Tofersen the drug itself is available for free.

Please scan attached QR code to sign our petition addressed to Karin Smyth MP, Minister of State at the Department of Health and Social Care, urging her to intervene immediately.

MIROCALS trial of IL-2: Results have been published

MIROCALS
Modifying Immune Response & Outcomes in Amyotrophic Lateral Sclerosis

Full results from the MIROCALS trial, testing an existing drug called IL-2, have been published in the Lancet. Overall, the trial failed to meet it's primary aim of showing that IL-2 is an effective treatment for MND for the whole trial population. When the whole trial population was analysed, treatment with IL-2 showed a modest increase in survival (12%) for those on the treatment during the study, but this was found not to be statistically significant.

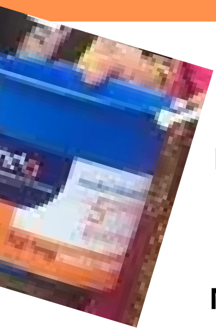
However, the researchers have suggested that it may be beneficial for a subgroup of people with MND. This subgroup was based on levels of a marker of disease activity called neurofilament. Those with low neurofilament levels, suggesting that they had slower disease progression, were found to be most likely to benefit from IL-2 treatment. The researchers found that those with low neurofilament and taking IL-2 were 18% more likely to be alive at the end of the trial compared to those with slow progression who were on placebo.

They also reported a 23% decrease in the rate of change in ALSFRS-R between those with low neurofilament and on IL-2 and those with low neurofilament on placebo. The researchers suggest that IL-2 is not an effective treatment for all people with MND, but that it may have a modest benefit for some people with MND who have slower disease progression, as measured by levels of neurofilament.

Some Amazing Fund Raising

London Marathon

Anna Hounsell raised **£4,596** for our branch on JustGiving in memory of her mother!



Snowdonia Hike

Michael Latham raised **£320**.

Iron Man

Mark Scruby raised **£545** by competing in the Copenhagen Iron Man.

Mark Wilson Pairs tournament 2025

Over the Early May Bank Holiday weekend, the **Mark Wilson Pairs Bowl tournament** filled all its entries with 128 pairs. The field, as usual, included a number of International players, as well as plenty of fancy dress enthusiasts, all of which created the usual laid back and fun atmosphere, with music playing throughout and plenty of sun (on the Saturday anyway!).
Over **£2,620** was raised for our branch, which is also a new high-water mark for the tournament!
The Trophy final saw a mouthwatering clash between the past 2 Mens National Singles champions from Devon and Kent and is now available on the Club's YouTube page.
The club looks forward to seeing everyone again in 2026!

Quiz Night

Hadleigh Tennis Club held a quiz night to raise money in memory of a founder member of the club. His wife Lynn was the Guest of Honour. They moved to Sussex from Hadleigh last year and he was diagnosed with MND soon after. Gill Gibson represented the branch at the quiz and joined a team including Lynn and some club members and only lost in a tie breaker in the end. They raised **£430** for our branch and one club member set up a regular donation to the National Association. Grateful thanks to the club and Lynn for a wonderful donation and a really fun evening.

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WHO'S WHO in your BRANCH

Stevan Wing: President
Philippe Udrzal: Chair/committee
Pat Ahlquist : Vice Chair/committee
Rowan Harvey : Treasurer/committee
Debbie Darke : Secretary/committee
Marianne Morgan: committee
Kevin Watts : X/committee
Michelle Bingham : Walk to D'feet/committee
Gill Gibson : committee
Barry Mizen : web master/committee

Association Visitors

Pat Ahlquist : branch contact
Gill Gibson
Barry Mizen

Community Support Coordinator

Chloe Rich