



NEW EVENTS FOR 2025



OH YES IT IS!

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



The Thames Walk

Barry and his friends from
Runwell Bowls club will walk
London's 15 bridges on
13th September to raise money
for our branch.

Link to their JustGiving page
through QR code.



Bar Sports Marathon

Led by **Stuart Bingham** a
24hr snooker/pool/darts marathon will take place on
21st and 22nd November
 at Q Ball sports bar in Basildon to raise money for 3
 charities of which we are one.



Liverpool Fan

Phil Butt from **Thorpe Bay Tennis Club** is
 organising a 282 miles charity cycle ride starting in
 Anfield Liverpool and finishing at the tennis club on
 24th August in honour of their die hard Liverpool
 FC supporter tennis club member **Paul** who is
 living with MND. All donations are going to our
 South Essex Branch of the MND Association.



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.

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.

19th September / 17th October / 21st November /

19th December / 16th January / 20th February

Please contact Pat or MND Connect



South East Region

Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.

24th September / 29th October / 26th November /

31st December / 28th January / 25th February

Daytime: 1st Tuesday of the month via Zoom 11am

7th October / 4th November / 2nd December

6th January / 3rd February / 3rd March

Please contact Pat or MND Connect

South East Region

Peer Support Group

3rd Tuesday of the month via Zoom 11am.

16th September / 21st October / 18th November

16th December / 20th January / 17th February

Please contact Pat or MND Connect

Veteran's Group

4th Wednesday of the month via Zoom 2.30pm.

24th September / 22nd October / 26th November /

24th December / 28th January / 25th February

Please contact Dawn Pond for details
 dawn.pond@mndassociation.org

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

Research Update

Ice sculpture marks Prescribe Life petition hand-in



Earlier this year, our Prescribe Life campaign called on supporters to join us in calling for the drug tofersen to be made accessible for people living with SOD1 MND.

This month, we handed in our petition with 21,000+ signatures to the Department of Health and Social Care.

Each one calls for urgent action so people with SOD1 #MND can access Tofersen, a treatment that could slow progression but is out of reach for too many.

To illustrate the urgency of this issue, we unveiled a life-sized ice sculpture, modelled on Seckin McGuirk in Parliament Square, Westminster.

Seckin is one of around 20 people denied access to tofersen because of NHS constraints – even though round 30 other

people are already benefiting from the drug. As the sculpture melts, it symbolises the devastating impact of MND. People with SOD1 MND don't have time to wait #PrescribeLife.

Thank you to everyone who has promoted and supported this campaign. Please continue to further amplify our socials content and any media coverage you might see.

AB Science receives the 'go ahead' from several European countries for a new confirmatory Phase 3 trial of masitinib

AB Science have announced that they have received approval from the first set of European countries (Spain, Greece, Slovenia) to begin a new Phase 3 study testing the therapeutic potential of masitinib as a treatment for amyotrophic lateral sclerosis (ALS), the most common form of MND. This announcement comes after the European Medicines Agency and the FDA validated the trial protocol. The trial, called AB23005, replaces the previously planned Phase 3 confirmatory trial of masitinib, which faced challenges with study recruitment. Following recommendations from the US and European regulatory authorities, this new study addresses some of the limitations that contributed to enrolment issues for the previously planned trial.

Masitinib is designed to block the action of a protein which is involved in inflammation in the body. Inflammation in the brain and spinal cord is thought to play a role in the progression of MND. It has been suggested that reducing inflammation in the brain may help to reduce the damage to motor neurons and slow the progression of the disease. The previous phase 2/3 trial suggested that masitinib might be beneficial for a subgroup of people with MND.

This new trial plans to enrol 408 people with ALS across the US and Europe. At the time of recruitment, participants must have a change of less than 1.1 points per month on the ALSFRS-R scale and have scores of at least 1 on all 12 items of the ALSFRS-R scale. Those on the trial will be randomly selected to receive either masitinib or a placebo, alongside riluzole, for 48 weeks. US patients receiving edaravone will also be eligible to participate in the study.





Joyce Afternoon Disco

On Saturday 9th August 70 people attended an afternoon disco at The Moonraker Club in Westcliff, which gave the venue for free. This event was organised by **Joyce Esser** and her friend Edwina. This was a great success dancing to the music of the 80's and raising a fantastic amount of **£2,190** for our branch.

Donation

Many thanks to **Russ Andrews** who donated **£1,480** to our branch for the 24 hour swim in memory of **John Cobbold**.

Dog Show

The Branch had an awareness raising stall at the **K9 World Dog Show** in Chalkwell Park on 13 July. The event is in memory of the organiser's mother who had MND. Gill paraded her cocker spaniel Tiro round the show ring in his MND T shirt and he won a trophy for the fastest recall too. The event raised **£40-60** for our branch.



Scooter Needs a New Home

One of our branch members no longer needs this Mobility Scooter and wants to pass it on, so it can still be used. It is a Boston S120 and swivels 90 degrees for ease of access. There would be no cost involved. Please contact Pat if you are interested and she can put you in touch with the owner.

Pat Ahlquist

Branch Contact

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Chloe Rich

Community Support Coordinator

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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