South Essex Branch
AUTUMN 26 NEWSLETTER

Registered Charity No. 294354

www.mndsouthessex.org

Branch President: Dr Stevan C. Wing Consultant Neurologist

Hot Summer of Fund Raising

Thanks very much for all your wonderful fund raising events, we can't list them all here but here are a few.

Essex County Bowling Club

Our very own committee member Marianne was invited to dinner at the **Essex County Bowling Club** to give a presentation of the work our MND branch carries out. After a raffle, a dinner with lovely food and the presentation, the club members carried out some very complicated games, which meant people had to put money on a tray and then bid for a bottle of port, a lot of money was raised.

The **Dennyside Bowling Association** was also present and after dinner the president gave out prizes to various club members.

At the conclusion the money had been counted and an amazing **£2400** had been raised and almost every member also completed a Gift Aid certificate, which will enhance the total.

Margaret Shillitto is this year's president and has chosen MND as the charity of this year. A heartfelt thank you to the very generous members of the bowling clubs, your contributions will go a long way to helping people living with MND in their time of need.

Fairwood Bowl's Club

Ian Charters, secretary of the club, informed us that **Fairwood Bowls Club** has chosen our branch as its club charity for the 2026 season, in memory of two of their retired members, **Margaret Desborough** and **Vivien Derbyshire**, who had MND.

Each year they have a fundraising day where the emphasis is on fun rather than bowls with several semi-serious competitions throughout the day, a raffle and a collection box passed around at the club's social events. This year the original date had to be postponed due to the heat but the then successive date of 27th August was a wash-out! Nonetheless, they still paid their entry fee and had a quiz and the raffle indoors, with plenty of cake and tea!

So far they've raised **£900** and hope to exceed £1000 soon.

Rankins Cricket Club

The charity cricket match hosted by **Rankins Cricket Club** was interrupted several times when rain stopped play - the first time rain has fallen on the match day since the event started some seven years ago. **£790** was raised on the day with donations made on line still to be added. The match was won by the Golden Lion.

Fund-Raising Climb

Mike Latham, whose father is living with MND, was joined by his young son **Harvey** and other family members to trek up Scafell Pike in July.

To date this has raised an amazing **£1,721**.

South Woodham Ferrers Rotary

We were invited by **Roger Gatford** in memory of his father who died of MND over 70yrs ago. He remembers how the only treatment for his breathing at the time was to be in an iron lung. There was very little understanding of MND and absolutely no support for the young family, who were not allowed to visit.

Gill & Pat gave a presentation about MND, explaining how things have changed, and the amazing work now done by the MND Association. The Vice-President, **David Shea** (pictured), then announced that they had kindly donated **£500** to help us continue all this work.

Have you thought of being a committee member?

I, **Rowan Harvey**, have been the Branch Treasurer for the last 12 years or so. I provide financial information for National Office and undertake the daily administration of our Branch Account.

It's so good to be able to provide financial grants to people living with MND, their carers and families, with the donations received from our local supporters. In many cases the NHS doesn't fund the support they need and it gives me great satisfaction that we can.

The committee would welcome new members to help fundraise, campaign, put on events and bring their own enthusiasm. Just get in touch with any of us

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 - Fair Havens 2nd October
Saturday St Luke's 7th November
Friday - Fair Havens 4th December
Please contact Pat for more information
patricia.ahlquist@mndassociation.org

South East Region Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.
28th October / 26th November / 30th December
27th January / 24th February / 24th March
Daytime: 1st Tuesday of the month via Zoom 11am
3rd November / 1st December / 5th January
2nd February / 2nd March / 6th April
Please contact Pat or MND Connect

South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.
20th October / 17th November / 15th December
19th January / 16th February / 16th March
Please contact Pat or MND Connect

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.
16th October / 20th November / 18th December
15th January / 19th February / 19th March
Please contact Pat or MND Connect

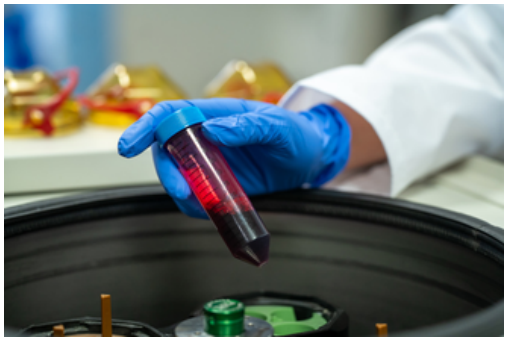
Veteran's Group

3rd Thursday of the month via Zoom 3 pm.
15th October/ 19th November / 17th December
21st January / 18th February / 18th March
Please contact Dawn Pond for details
dawn.pond@mndassociation.org

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

Research Update

Researchers find a new drug that could be a future treatment for MND



Researchers from the University of Arizona have discovered a drug that could be tested as a future treatment for MND. The drug, called XL20, has been tested in the laboratory and was found to protect motor neurones from damage in MND. XL20 is designed to reduce the activity of a protein that becomes faulty and toxic in MND, called TDP-43. This protein is found to be faulty in around 97% of people with MND.

The team identified a part of the TDP-43 protein they say is responsible for causing damage to motor neurones in MND. XL20 is thought to stick to this part of TDP-43 thereby blocking the harmful effects to reduce the damage that it causes, while still allowing the protein to carry out its usual job. Researchers tested the drug in mouse models of MND and found the drug reduced muscle weakness and extended survival of the mice by about one week. While these results are promising, the drug is still in very early stages of development and hasn't been tested in people yet. XL20 needs further testing in the laboratory to see if it should be taken forward for testing in clinical trials in the future.

New drug targeting UNC13A moves into clinical trials in the UK

Trace Neuroscience has announced its drug, TRCN-1023, has received approval to begin clinical testing in the UK and the Netherlands. The drug will be tested in a small Phase 1/2 clinical trial called FUNCTION ALS, which forms part of a wider global programme including the LAUNCH-ALS trial in China. TRCN-1023 targets the gene UNC13A that provides vital instructions for making a protein that allows motor neurones to communicate with other nerve cells and muscles.

This trial follows on from original research, carried out by a team at UCL led by Professor Fratta, funded by the MND Association and Medical Research Council through a Lady Edith Wolfson Fellowship. This work led to the discovery that UNC13A levels are associated with disease severity and TDP-43, a protein that doesn't work as expected in 97% of people with MND and can form harmful clumps inside nerve cells. When TDP-43 stops functioning normally, it can affect the UNC13A gene. This reduces the production of healthy proteins, which cells need to communicate effectively with other nerve cells and muscles. TRCN-1023 is designed to fix the UNC13A gene and help restore the production of functional proteins. TRCN-1023 is entering it's first stage of testing in humans and has not yet been shown to be safe or effective for people with MND.

Should the trial results be positive, we anticipate the company will announce plans for a larger trial, providing an opportunity for additional UK sites to participate.

Congrats!

Congratulations

to Karen and Sean who got married on 17th September!

New Events

Quiz night

Save the date for this fun evening organised by **Sheila Ball** in Canvey Island ,
Friday 13th November
Please contact Sheila for registration.

Fund-raising Dinner

Join us for a fund raising dinner at **Zen City** in Westcliff-on-sea on Thursday **28th January**.
£25 pp for a 3 course meal.
Please contact Debbie for tickets.
debbie.darke@mndassociation.org

NEWSLETTER

With the cost of postage these days and the time consuming effort of mailing the Newsletter we would like to move to sending it by email as much as we can.
However, we fully understand that some people might still prefer the printed version and we shall keep it going for them.
Please let us know by phone or email if you do want to receive a printed Newsletter.
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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
Gill Gibson : committee
Barry Mizen : web master/committee
Sophie Bell: Walk to D'feet

Association Visitors

Pat Ahlquist : branch contact
Gill Gibson
Barry Mizen

Community Support Coordinator

Chloe Rich