



Walk to D'FEET 2025



This years walk to D'feet MND will be on Sunday 11th May, not only is it a day we raise much needed funds and awareness through sponsorship for people living with and affected by MND it's also a great day out. meeting up with friends and family at the seaside for a lovely walk along the sea front. We have lots of children join us and some even bring their dogs to make it even more of a special day. We always have a few pit stops along the way for a cheeky Ice cream or some donuts. Hopefully the weather will be kind to us as it has in the past and we can enjoy the sun at the same time.

Put your best foot forward 🦶



We've set up a JustGiving page for this walk.

If you wish you can use it to help your fund raising efforts.

Scan this QR code.

AGM

We had our AGM at St Luke's Hospice on Saturday 1st March. Richard Holden, local MP, expressed his commitment to support our All-Party Parliamentary group aiming to encourage investments in MND research. Matthew Cobble Head of Volunteering at the MNDA detailed all the help offered by the Association for people living with MND, their carers and families.



**JOIN
OUR
TEAM**

We would love to have more people volunteering as Association Visitors especially if they live in South West Essex. One needs good listening and communication skills to help support those living with MND and those closest to them, either by phone calls, emails or home visits. The Association provides really good training. If you need more information contact one of our existing AVs or look at [Association visitors | 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.

Friday 4th April - Fair Havens

Saturday 3rd May- St Luke's

Friday 6th June - Fair Havens

Saturday 5th July- St Luke's

Friday 1st August- Fair Havens

Saturday 6th September- St Luke's

Please contact Pat for more information

sessexmnd.pya@gmail.com



South East Region

Carers' Coffee and Chat

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

30th April / 28th May / 25th June

30th July/ 27th August/ 24th September

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

6th May / 3rd June / 1st July

5th August/ 2nd September/ 7th October

Please contact Pat or MND Connect

South East Region

Peer Support Group

3rd Tuesday of the month via Zoom 11am.

15th April/ 20th May/ 17th June

15th July/ 19th August/ 16th September

Please contact Pat or MND Connect

Veteran's Group

4th Wednesday of the month via Zoom 2.30pm.

23rd April / 28th May / 25th June

23rd July/ 20th August/ 17th September

Please contact Dawn Pond for details
dawn.pond@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 April/ 16th May / 20th June

18th July/ 15th August/ 19th September

Please contact Pat or MND Connect



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

Research Update

MND-SMART team releases update about trial drug amantadine

The MND Association welcomes today's announcement from the MND-SMART team confirming the drug amantadine will continue to be evaluated as part of the MND-SMART platform trial. Studies suggest amantadine could reduce abnormal clumping of proteins in cells, which is thought to play a role in the onset and progression of MND. Independent committees have looked at the latest data for amantadine at an interim analysis and said no safety concerns were identified. They also congratulated the trial sites on impressive recruitment and data integrity.



EXPERTS-ALS Drug Screening platform opens for recruitment

The experimental medicine Route To Success in ALS (EXPERTS-ALS) drug screening platform has begun recruiting participants. The platform, which aims to rapidly test promising treatments for MND, is now open at 6 sites across the UK and it is hoped that 5 more sites will open throughout the year.



The platform is designed to rapidly test promising treatments in people with MND to see if they show signs of benefit. It will initially test repurposed drugs (drugs that are already used for other conditions) to see if levels of a marker of neuron damage, called neurofilament light chain, decrease with treatment. EXPERTS-ALS will help to quickly prioritise which drugs are the most promising and should be tested in larger phase 3 clinical trials to test whether they are beneficial for people with MND. EXPERTS-ALS is funded by the MND Association, National Institute for Health & Care Research (NIHR), MND Scotland, My Name's Doddie Foundation and LifeArc.



InFlectis BioScience announce results of Phase 2 trial of IFB-088

Results have been announced for a Phase 2 trial testing IFB-088 in 51 people with bulbar-onset MND, where initial symptoms are changes in speech and difficulty swallowing. Participants were given either IFB-088 alongside riluzole or a placebo (dummy drug) alongside riluzole for six months. The trial found that IFB-088 was safe and well tolerated by people with MND and the company have suggested that the drug also shows signs of benefit for people with the disease. InFlectis BioScience said that trials showed signs of slowing functional decline, with a significant difference in ALSFRS-R scores between those on the drug and those on the placebo. Biomarkers measured in the trial also helped to confirm that the drug works as thought within the body. These results pave the way for a larger clinical trial to test IFB-088 in more people with MND.



IFB-088 is a new drug which is designed to boost the cells' integrated stress response that acts like a shield against things that cause the cell stress. It is also thought to reduce the production of toxic chemicals that cause damage to the cell, which may help to protect the neurons from damage and death.



Mate's Nutty Debates



Some folks in Southend have set up a new **WhatsApp group** just for those local people living with MND. They say "we're hoping for a nice intimate friendly group where we can have a giggle and be a bit more sociable and get to know each other better". They are also planning a get together on Friday 17th January, 12.30pm, at The Saxon King pub, next to Fair Havens Hospice. If you'd like to be part of this contact **Sean** on **07814 225155**. Just sending a text is fine.

Record Attendance

We had our largest turnout ever at our Fair Havens drop in on 7 February. 25 people turned up on a wet windy and cold February afternoon some who had not been before. We nearly ran out of cake but not the laughs provided particularly by Joyce. Several people said they had got a lot from meeting with others living with MND and their families. Shaun and Joyce told everyone about their WhatsApp group and their next lunch get together. If you haven't been to the drop in before, do come along. We can pay taxi fares if you get a receipt.



Pat Ahlquist

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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