



South Essex Branch

SUMMER 21 NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist

A SUMMER OF FUND RAISING EFFORTS



WALK
to d'FEET MND
PLAN B



We were very disappointed when Southend Council told us we could not hold our organised Walk on July 4th. We are delighted that several groups switched to Plan B and did their individual walks raising many thousands of pounds between them.

Are you ready to do a Walk with your family, friends or colleagues? We can supply the T-shirts, you can set up a Motor Neurone Disease Just Giving page naming the South Essex Branch, or we can give you Sponsorship Forms.

You can do it any time, anywhere.

We really do need your help!





Due to the great British weather, we had to revert to Plan B for our Summer Picnic. We met at Wat Tyler Country Park on Sunday 15th August. Unfortunately, we didn't get to meet as many family groups as we had hoped, but the select few that attended had a lovely afternoon in the sunshine. It was especially nice to meet up face to face with our MND friends and families – we have missed socialising with you all over the last 18 months. Everyone enjoyed their picnics and ice-creams! We held a raffle where Rowan was looking forward to using his new toy, a card machine, but he forgot to turn it off so the battery was flat! Luckily everyone had good old cash and we raised £150 for our Branch. Thank you to everyone who attended and to Sandy for all her hard work organising the day.

MND SUMMER PICNIC





CHARITY HOCKEY TOURNAMENT

Team Charlie had a fun filled weekend with Hattie Marden taking part in a Charity Hockey Tournament on Saturday August 21st where teams competed for the Gibbo Hockey Trophy.

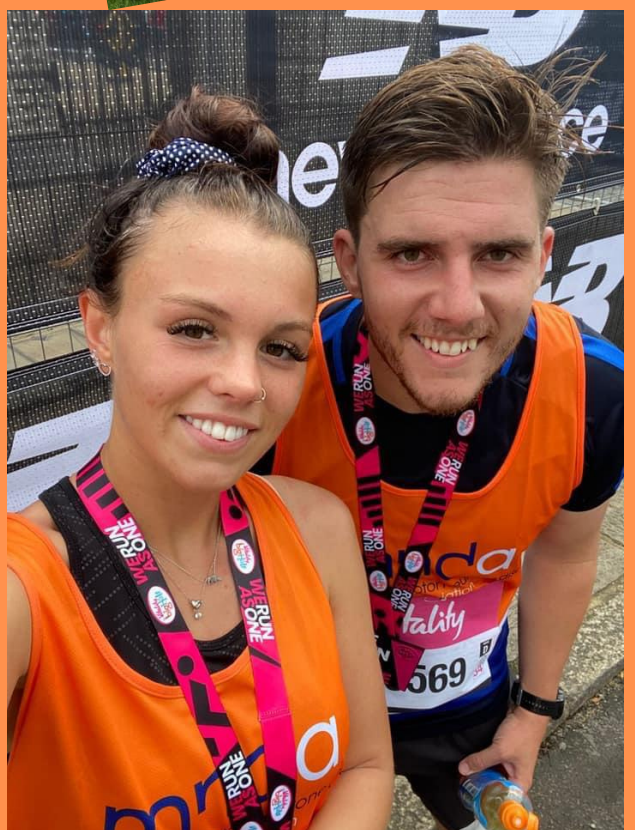
The tournament was played between Southend HC, Brentwood HC, and Old Southendians HC. All money raised through registrations will go towards Challenging MND, a local charity founded by Alex Gibson, which helps people living with motor neurone disease complete memorable challenges or experiences with their friends and family.



VITALITY BIG HALF

On Sunday 22nd, Team Charlie's Dan & Beth took part in The Vitality Big Half; they completed their first half marathon in 1:56 hour. They ran together raising more than £600 to be split between two charities close to their hearts - MNDA and Cancer Research UK.

Dan will also be running the London Marathon in October with his cousin Alex. They are running for the MNDA in memory of their Grandad Charlie Marden



AWESOME TEENS!

Fantastic achievement for Flora Farrant (age 11) and her cousin Kitty Gundry (age 10) who have just completed a fundraiser of nearly £3,565 by swimming 5km, inspired by their grandmother who has MND.



GARDEN PARTY FUND RAISER

Held in memory of Marie-Louise Udrzal, it raised £426 thanks to the glorious sunshine and Ikea ex-co workers



BOWLING CLUB CHARITY EVENT

It was organised in memory of Mark Wilson who was an active member of Essex bowls club. His mum Cath, who had collected some fabulous raffle prizes, raised £685 for our branch. After the 2 days event the club was able to give another £1,000 to our association too. And they have also decided to make the Mark Wilson memorial cup an annual event. Trophy is presented here by Mark's Mum and daughter.



LET'S KEEP IT UP!



Walk in the Park

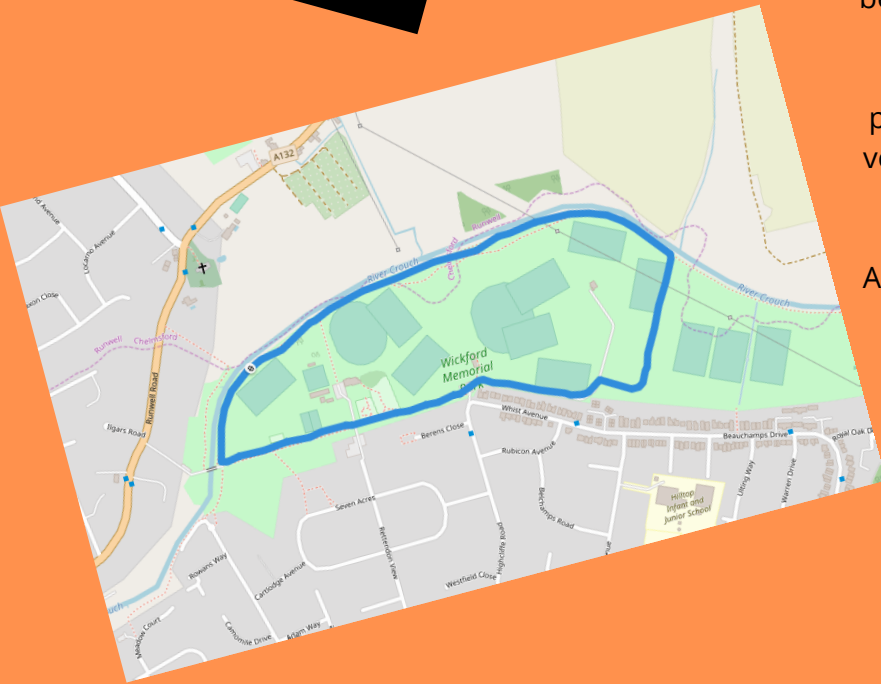
Now that our idea to remember our beloved ones at Wickford Memorial Park has been given the go ahead (see below), why not join us for a **Walk to d'feet** there on **Sunday 28th November**.

The weather will be an unknown factor, but there is a beautifully smooth circuit pathway and 5 circuits is 10k. There is a cafe, for hot drinks and all the facilities. Our supporters will be able to see the proposed site of the memorial area and will get a voucher for a hot jacket potato upon registration.

Get your T-shirts, Just Giving page and sponsor forms ready.

All details will be published on our facebook page. If interested please contact Clair to take part

foxshullbridge@hotmail.com
07818 436 058



Restaurant MEET UP

It's been too long since we've been able to meet up for a fund raiser dinner!

It would be fantastic meeting as many of you as possible with carers, supporters and families at the

Tandoori Parlour Benfleet on

Thursday 18th November

from 7.15pm for 7.30 start.

This is a very large room with enough space to social distance all the tables.

Book early!

Please contact Debbie to take part
rowananddebbie@btinternet.com



MND CHRISTMAS SUPPORT

£2 for a pack of 10 cards

Inside the cards reads: **A** Best wishes for Christmas and the New Year / **B** Blank for your own message / **C** Merry Christmas / **D** Season's Greetings / **E** Merry Christmas and a Happy New Year

Christmas Puddings: 2lb Pudding £10 / 1lb Pudding £ 5 / Individual Pud. £2 (6 for £10)

Please place your order with Sandy.
sessexmnd.sel@gmail.com



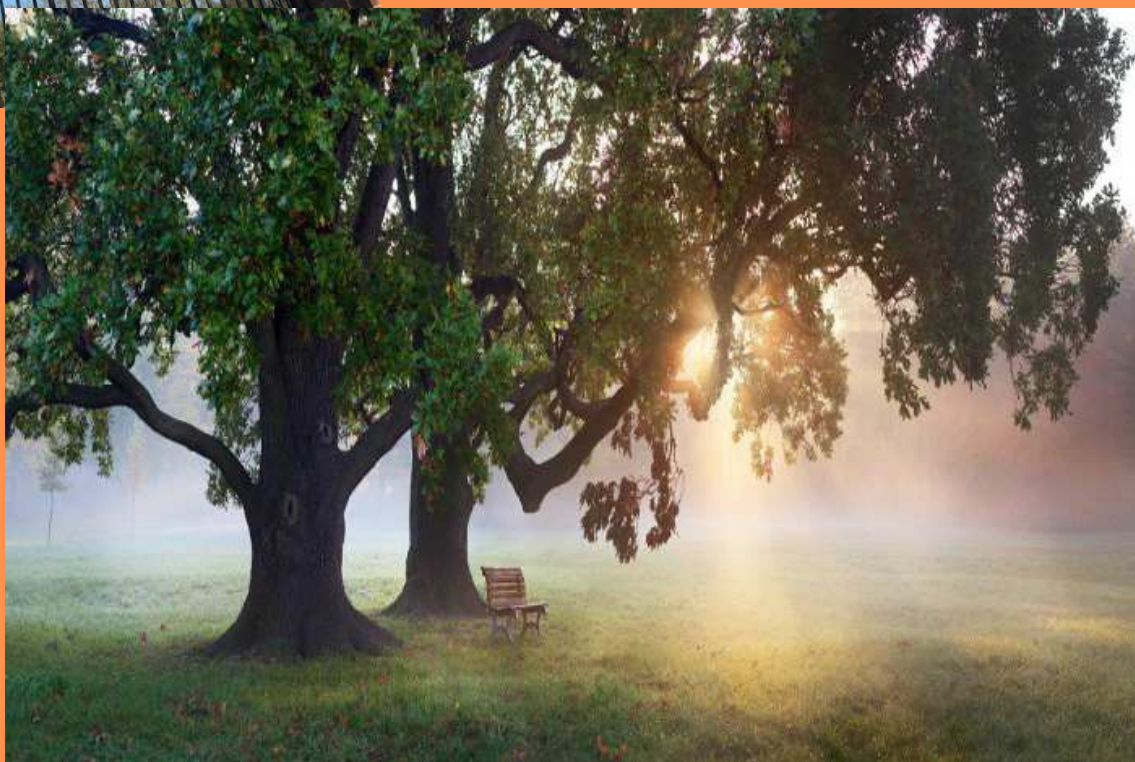
MND CHRISTMAS SUPPORT





Memorial to those we have lost to MND

Good news is that Basildon Council has agreed to let us have an area in the Wickford Memorial Park dedicated to those we have lost to MND.



Families will be able to place a marker with a photo, name and dates.
If you would like to commemorate your loved one please contact Sandy:

sessexmnd.sel@gmail.com or 07742 943472

Planting should take place this winter.

Final details will be in the next Newsletter and on the website.

Meeting Dates

Friday, 1st October 2 to 4pm Physical meeting at Fairhavens

Tuesday, 2nd November 2.30 to 4pm Zoom

Friday, 3rd December 2 to 4pm Physical meeting at Fairhavens

Please contact Sandy to take part.

sessexmnd.sel@gmail.com

Carers' Coffee and Chat

Join us for a friendly, supportive chat with other families of people living with MND in London and Essex.

This is for carers only (loved ones who look after someone with MND).

6.30-7.30pm and next dates are :

Wednesday 29th September

Wednesday 27th October

Wednesday 24th November

Please contact Carmen for the joining link.

carmen.brown@mndassociation.org



Forum update

This is an online community for people affected by MND. We currently have over 1000 members who use the forum to share experiences and support one another through their journey with MND.

<https://forum.mndassociation.org>

Recently Diagnosed Group

Once a month via Zoom.

Allows all affected people to ask any question and find out about available support.

Please contact Carmen for details

carmen.brown@mndassociation.org

RESEARCH UPDATE

New Genetic risk for Sporadic MND



Rare mutations in the TP73 gene, which is involved in the regulation of a cell's life cycle, may put a person at greater risk of MND, according to a genetic analysis of nearly 2,900 people living with sporadic MND. Using a technique that examines all of a person's protein-coding genes, researchers found that some people with sporadic MND had rare mutations in the TP73 gene which were absent in people without MND. TP73 provides the instructions to produce p57, a protein which regulates cell death. Researchers assessed the effects of the identified TP73 mutations in lab-grown muscle cells and found these mutations affected the cells' maturation and increased their rate of death. Deleting the TP73 gene in zebrafish impaired motor neuron development and increased motor neuron death, similar to that seen in people with MND. These findings highlight that TP73 mutations have a damaging effect on protein function and that the protein created by this gene is necessary for nerve cell health.

Cholesterol and MND?

Defects in cholesterol metabolism may account for some of the neurological damage that occurs in MND, a recent study reports. As cholesterol is crucial to nerve cells, restoring its metabolism may be a useful treatment approach. Cholesterol is used to make the myelin sheath, a coating that wraps around neurons and helps them to send electrical signals more effectively. A team led by researchers in Singapore conducted cell and mouse experiments to explore how TDP-43 protein abnormalities, which are a major feature of MND, affect oligodendrocytes, which are the cells in the nervous system that make myelin. Oligodendrocytes either make the cholesterol that they use to produce myelin, or they import it from outside. The researchers demonstrated that oligodendrocytes lacking TDP-43 experienced impairments in both processes. This suggests that defects in cholesterol metabolism may contribute to MND and other neurodegenerative diseases characterised by TDP-43 aggregates.



New Clinical Trial

Dosing will begin in a Phase 2b/3 clinical trial of SLS-005 (trelahose), designed to prevent protein clumping in cells, in people with MND by the end of September, and is the fifth drug to be added to the HEALEY ALS

Platform Trial. SLS-005 consists of a natural autophagy-promoting (the process by which cells breakdown and recycle old or damaged proteins and components they no longer need, preventing potentially toxic accumulation) sugar molecule found in plants, fungi and bacteria called trelahose. The toxic build-up of proteins such as TDP-43 and SOD1 in nerve cells is seen in MND. Preclinical studies showed that SLS-005 promotes the clearance of these proteins, delaying disease progression.



Badges Available

The Branch had iron-on embroidered badges made and these have been seen on the televised snooker matches worn by Stuart Bingham and his professional snooker playing friends to raise awareness of MND. If you would like one to go on your fleece or jacket contact Sandy.

They are £3 each, incl. postage.

Quantity discounts available.



New Text to Donate

Easier to collect funds with our NEW text service Text.

MND4SESSEX to **70085** to donate £5 directly to the South Essex Branch.

To donate more, add the amount at end of text
£20=MND4SESSEX20

Equipment Available



Mattress Raiser



Customised stand to hold
ipad or computer

2 basic Wheelchairs

Please contact Sandy if interested.
sessexmnd.sel@gmail.com

Sandy Lambert

Branch contact

sessexmnd.sel@gmail.com

07742 943 472

Carmen Brown

Area Support coordinator

carmen.brown@mndassociation.org

01604 800659

mndconnect
0808 802 6262
mndconnect@mndassociation.org



@MNDsessex



@MNDsessex

Changes in the Committee

After 20 years as a formidable powerhouse in our Association Committee, Sandy has decided to rescind her committee's responsibilities.

Her enthusiasm and contagious energy will be gravely missed but Sandy will continue working as an Association Visitor bringing comfort and support to our MND patients in South Essex.

We are delighted to welcome a new member to the committee Clair Fox who will bring her expertise to help us raise awareness and fight the disease.



Radar Key

RADAR keys are for people who have a disability to gain access to locked public toilets found in shopping centres, restaurants, stations ..etc around the country. If you would like one please contact Rowan, Pat or Sandy and we shall give you one free of charge.

<https://www.toiletmap.org.uk/>



WHO'S WHO in your BRANCH

Stevan Wing: President

Sue Nash : Chair

Sandy Lambert : Branch Contact

Rowan Harvey : Treasurer

Debbie Darke : Secretary

Kevin Watts

Lisa Gallagher : Digital Communication

Pat Ahlquist

Marianne Morgan

Clair Fox

Philippe Udrzal : Newsletter

Association Visitors

Sandy Lambert

Pat Ahlquist

Area Support Coordinator

Carmen Brown