

# South Essex Branch

## SUMMER 22 NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist



[www.mndsouthessex.org](http://www.mndsouthessex.org)

### Mayor opened our Walk to d'Feet MND on Sunday 15th May



We had 107 registered walkers on the day.

The walk was started by Cllr Kevin Robinson, the new Mayor of Southend, the 100th Mayor and the first ever Mayor of the new City of Southend-on-Sea.

We were optimistic about this walk, as we were trialling a new start area and split route, both of which had mixed feed-back!

The sponsorship money is still coming in, to date we have raised **£6,464**. If you do still have sponsorship money outstanding, please try to get it donated and forward to Rowan, in order to get the total.

Well done to all walkers, supporters and donors and a special thanks to all the supporters who come back year after year.



# EVENTS

## Panto & Meal



Covid allowing, we shall resume our Christmas treat of a Christmas lunch followed by a matinee performance of the panto Snow White on **Friday 16th December** at the **Cliffs Pavillion**. There is no charge for anyone living with MND and one companion. We have reserved 40 places, including 8 wheelchair spaces, please reserve your place with Sandy 07742 943472 or [sessexmnd.sel@gmail.com](mailto:sessexmnd.sel@gmail.com).

## Turkish Night



Fund raising event at **Baboush**, on **Tuesday 13th September**, The Ridgeway, Westcliff-on-sea **SS08NU**. £25/pp paid on the night for food and 1 drink. We would recommend anyone attending to do a Covid lateral flow test on the day. Please contact Debbie if interested to join us [rowananddebbie@btinternet.com](mailto:rowananddebbie@btinternet.com)

## Concert



Summer Blues Evening featuring Bare Wire at **the Swan**, Horndon-on-the-Hill on **Saturday 3rd September**. Tickets are £20 including Hog Roast and profits are for MND South Essex. So book your tickets early if you would like to go. contact the Swan 01375 673707

## QUIZ Night

A MND quiz night is being held at The Memorial Hall, High Street Canvey Island **SS8 7AD** at 7:30 on **Friday 14th October** 2022. Entry fee is £5.00 per person and each team can comprise of up to 8 people. Please bring your own drinks and nibbles. All monies raised will go the MND South Essex Branch. There is free parking at the venue and you can also park in surrounding roads if the car park is full. To reserve your place, please contact Sheila Ball on 01268 692230

## Meeting Dates

Places need to be booked in advance with Sandy  
Fair Havens Hospice drop in meetings 2-4pm  
and **NEW! St Luke's Hospice meetings 2-4pm**

Friday 5th August- Fair Havens  
Saturday 3rd September - St Luke's  
Friday 7th October- Fair Havens  
Saturday 12th November - St Luke's  
Please contact Sandy for  
more information  
[sessexmnd.sel@gmail.com](mailto:sessexmnd.sel@gmail.com)

## 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.  
15th July/19th August/16th September  
Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

## MEET UP?

### South East Region

### Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.  
27th July/31st August/28th September  
Daytime: 1st Tuesday of the month via Zoom 11am  
2nd August/ 7th September/ 5th October  
Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)



### South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.  
19th July/16th August/20th September  
Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

## DONATIONS



### Club Kingswood Basildon Sahara Challenge

Heather Samson and her partner Darrell Jackson are taking part in a two-day marathon challenge in the Sahara Desert in October 2022 in memory of her father Jack Samson who passed away on the 8th July 2020 from MND.

He had been ill for about 18 months and lock-down just made things even more complicated but caring staff were fantastic.

Heather is a keen runner and her aim is to raise funds and awareness for MND.

This is the link to their youtube channel

<https://youtube.com/playlist?list=PLJkS0Ao5hCKCx75FVXUmjbJpjoIopuXOI>

Their just giving page is [www.justgiving.com/fundraising/heather-samsonmnd](http://www.justgiving.com/fundraising/heather-samsonmnd)



### Horndon-on-the-Hill Feast and Fayre

Horndon on the Hill Feast and Fayre Committee kindly decided to make the MNDA its chosen charity this year. Nicholas Tresidder, resident of the village for 35 years, married in the village church and ex-local GP, made an emotional opening speech explaining the issues with MND and support provided by the MNDA.

Bucket shaking on both days by family and friends collected just over **£1,020** and sponsored Horndon 10K run by Phil Schofield (coached by Fay Scott) raised nearly **£3,000**. Horndon's church congregation collection also added another £144.



### Essex Country Ball

This annual event raised in excess of **£1,000** for our branch!

### Waitrose

Jackie (Waitrose Community Matters Leigh-on-Sea) donated **£600** on behalf of their shoppers who nominated our charity!



### Tribute to Mark Wilson

The Essex County Bowling Club held a pairs competition over the Spring bank holiday weekend in memory of Mark Wilson. They raised **£1,000** for the branch, over £600 of which came from a raffle organised by his mother Kath. This event is to be held annually in Mark's memory.

### Fund Raising Concert

The Trolley Boys concert in April was a great night raising money for our branch. Dan Crysell from a company called FI911 based in Rayleigh and for which Steve, one of the band members, worked for 7 years also contributed £500 bringing the total donation to our branch to **£2000.65** !



# RESEARCH UPDATE

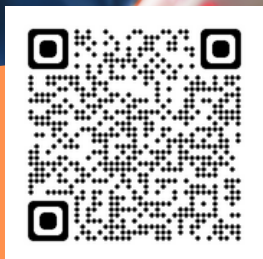
## Peer-to-peer Support Research trial

Researchers from King's College London are looking for participants to take part in a clinical trial which aims to test a new online peer-to-peer support programme for carers of MND. They are looking for current caregivers and peer supporters who have had experience caring for someone with MND. Peer supporters will receive training on how to provide one-on-one support, whilst current caregivers will either receive the virtual peer-to-peer support or be directed to educational resources.



## HIMALAYA trial opens recruitment

A Phase 2 clinical trial of investigational oral therapy SAR443820, called HIMALAYA, is recruiting about 260 adults at sites across the US and Europe, including Plymouth in the UK. The trial will test the safety and effectiveness of the drug in people who have been diagnosed with MND in the past two years. SAR443820 works by suppressing RIPK1, an enzyme whose over-activation is associated with abnormal microglia activity and nerve cell death. Microglia are the immune cells of the central nervous system, brain and spinal cord. RIPK1 levels and activity are significantly increased in people with MND. HIMALAYA's main goals are to assess changes in ALSFRS-R scores after 24 weeks of treatment. Top-line data may be available late next year



## The role of ALCAR in people with MND

Finding agents that can prevent the progression of symptoms by stopping the degeneration of motor neurons is fundamental for therapeutic development. Acetyl-L-carnitine (ALCAR) is a naturally occurring substance which, when given in super concentrated amounts, has been found to be neuroprotective. In a preliminary study, researchers in Italy investigated the effect of ALCAR on cell survival, oxidative stress and mitochondrial function and found marked alterations in the redox system. Fifty people with MND will now be enrolled in a study that will evaluate the effectiveness of ALCAR as a potential therapy for MND.





## MND Memorial Garden

We're still working on our reflection garden in Wickford Memorial Park and we know many of you have expressed an interest to remember a loved one this way.

However it would be much appreciated if you could formally send an email to Sandy highlighting your desire to take part.  
sessexmnd.sel@gmail.com

## Equipment Available

Rise Easy Mattress Elevator

1 folding aluminium ramp

1 basic wheelchair

Walker

Bed grab handle

Please contact Sandy or Pat if interested.

**Sandy Lambert**

sessexmnd.sel@gmail.com  
07742 943472 / 01702 305759

**Pat Ahlquist**

sessexmnd.py@gmail.com  
07383 568 585

**Carmen Brown**

Area Support coordinator  
carmen.brown@mndassociation.org  
01604 800 659

[www.mndsouthessex.org](http://www.mndsouthessex.org)

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



**@MNDsessex**



**@MNDsessex**

## Funding for the benches



Our heroic Sandy did actually follow suit with her tandem skydive on 27th May to finance the benches for our MND Memorial Garden.

She has raised **£1,121**, including gift aid, so far!

In her own words : " I'VE DONE IT!! Friday 27th was a beautiful day and we jumped out at 12,000ft. We fell for 6,000ft, (over a mile), before Steve pull the cord to open our parachute. It was a wonderful experience .....now what shall I do next?! ".



You can still support her on following link or QR code  
[www.justgiving.com/fundraising/sandyskydive](http://www.justgiving.com/fundraising/sandyskydive)

## 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

**Amy Coombes :** Insta ommittee

**Lisa Gallagher :** Fb/ committee

**Kevin Watts :** Twitter/committee

**Marianne Morgan:** committee

Association Visitors

**Sandy Lambert :** branch contact

**Pat Ahlquist**

**Gill Gibson**

Area Support Coordinator

**Carmen Brown**

