

# South Essex Branch WINTER 22 NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist

**mnda**  
motor neurone disease  
association



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

## IT WAS GREAT MEETING AGAIN!



We had our walk on 27th November around Memorial Park where tens of families enjoyed a glorious autumnal walk with the treat of hot jacket potato.

Our thanks to all those who took part; if you still have sponsorship money to come in please try to get it donated and then let Rowan know how much you have raised.

[rowananddebbie@btinternet.com](mailto:rowananddebbie@btinternet.com)



## MND restaurant night out



On behalf of our branch Debbie and Rowan (Team Charlie) hosted this bi-annual event in an Indian Restaurant in Benfleet on 18th November. The food was delicious and raffle prizes were appreciated too. The event raised £988 for our branch.



## DONATIONS

Thorndon Park Golf club have nominated our branch their Charity of the Year, they already generously donated £700 to us in September and now they have raised another £1,375 for our branch. What an achievement!

Billericay & Wickford Trefoil Guild have been incredibly generous in raising and donating £700 to our branch.



## Pennies from Heaven



Ruchi Nanda sadly lost her battle with MND on New Year's Eve 2020, she worked as Account Manager for the Department for International Trade and in November 2020, she received the prestigious MBE award for service to Trade, Investment and to Business Support.

Ruchi was a great supporter of the branch and where she could, attended many of the events we held. A lovely lady with a great sense of humour who carried on working until the very end.

The branch received £9,218 from family and friends in memory of Ruchi, which was mind blowing. Ruchi has a cousin, Vishwal who lives in USA and is a member of the Karuna Charitable Trust Foundation. He wanted to support the branch in recognition for the help we gave Ruchi. The Trust sanctioned a \$25,000 Grant which converts to £17,805 to support people living with MND in our area. We have 20 months to use the grant, which we are sure we will do.

The Branch would like to thank Ruchi's family, friends and the Karuna Trust for their overwhelming generosity. These donations will be used to support those living with MND, their carers and families.

## Christmas Cheer

One again baskets of fruits, bouquets of flowers, boxes of chocolates or Christmas puddings were delivered to those living with MND.



Sandy manned the Christmas sale at St Aidans church and raised £180 bringing the total raised with Christmas cards and puddings to a fantastic £1,237.

*Thank you!*

And a special mention to Michelle Bingham who managed to sell an additional £475 worth of cards and puddings on her own!

## MEETINGS

Unfortunately due to the current increase in Covid cases and the new variant, National Office has informed us that face to face meetings must not take place for the time being. We are hoping that as things improve we might be able to go ahead in the Spring. The latest position will be in the STOP PRESS on the branch website :

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

Your safety is our top priority

### Meeting Dates

...if they're allowed to proceed

Saturday 12th March 11 am-1pm **AGM on Zoom**

**Please contact Debbie to get the link**  
**[rowananddebbie@btinternet.com](mailto:rowananddebbie@btinternet.com)**

Friday 1st April 2-4pm drop in Fair Havens

Sunday 15th May 10 am Walk to D-Feet Southend sea front

Friday 3rd June 2-4pm drop in Fair Havens

Please contact Sandy for more information  
[sessexmnd.sel@gmail.com](mailto:sessexmnd.sel@gmail.com)

### 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>

### South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.

18th January/15th February/15th March

Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

### South East Region

### Carers' Coffee and Chat

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

26th January/23rd February/30th March

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

1st February/ 1st March/5th April

Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@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.

21st January/18th February/18th March

Please contact Carmen for details  
[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

# VCR Project

Providing amazing virtual reality experiences could help improve the quality of life and mental wellbeing of individuals living with MND by creating lasting memories for them and their families.

The Hadleigh Castle Rotary Club have teamed up with partners at Challenging MND to provide virtual reality equipment and develop a number of new high quality virtual experiences to be used by those living with MND including those in the advanced stages of the disease when their ability to participate in a physical experience may be very limited or have gone.



A crowd funding site for the project on the Global Giving platform has been created. And there is also a bonus available in the form of a share of a \$1 million additional funding. Visit [www.globalgiving.org/projects/mnd/](http://www.globalgiving.org/projects/mnd/) or scan QR code



More information to come on our Facebook page and in next Newsletter when headsets are to be made available.



## GRANTS

Did you know, we have a number of grants for people living with MND? Whether you need some equipment that isn't available from statutory services or there's something to just put a smile on your face, there's a grant for you.

We also have a Carer grants for loved ones that may help with your care and grants for children and young people that may live with you too. Want to know more? Go to our website for more info or email [carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

## Raffle Prize Appeal

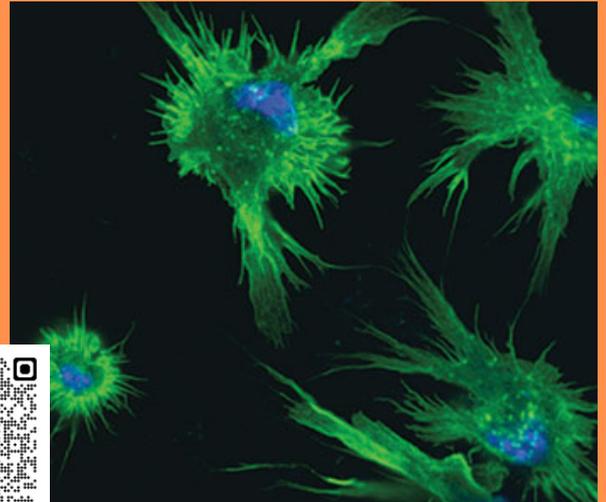
When we do events, raffles are a great way to raise money for our association in order to help as many MND patients as we can. So if you have unwanted gifts, left over hampers, spare toiletries or new items to donate please think of us.

Please contact Debbie  
[rowananddebbie@btinternet.com](mailto:rowananddebbie@btinternet.com).



## The retina a new MND biomarker?

New research suggests that degeneration of motor neurons in the brain takes place independently of the death of motor neurons in the spinal cord and may also contribute to the onset of MND. The study also indicated that, in a mouse model of the disease, a gene therapy given to increase the activity of a protein called UCHL1 could improve the health of these brain motor neurons.

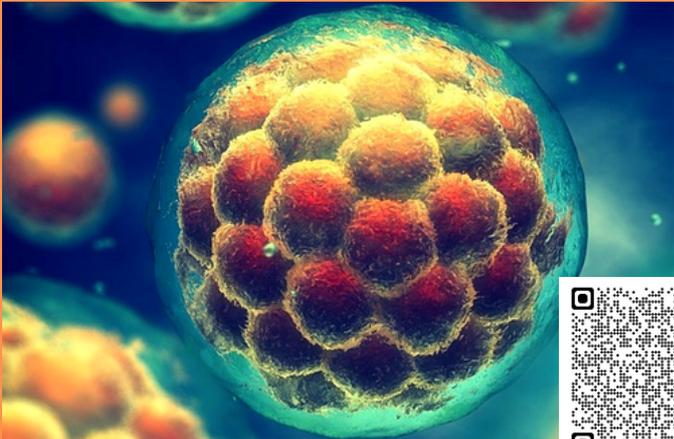


Scan the QR code for more info



## Stem Cell Therapy has Potential

A small Phase 2 clinical trial, that involved 20 people with MND (disease duration of less than two years) showed that repeat injections of mesenchymal stem cells (MSCs) into the spinal canal were safe and well tolerated and showed potential to significantly slow the rate of disease progression. A significant reduction in the slope of progression (measured by ALSFRS-R scores) was seen after each treatment cycle, providing indications of clinically meaningful benefits. These results will need to be confirmed in a larger, randomised, placebo-controlled trial.



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## Investigational Therapy to target MND inflammation

TQS-168, an investigational therapy being developed by Tranquis Therapeutics, reduced inflammation in mouse and human models of MND, and prolonged survival in the mice according to a preclinical study. Based on these findings, Tranquis is moving the therapy into Phase 1 clinical studies to assess the safety of the drug and how it moves through the body and the effects of the drug on the body. Inflammation is believed to play a key role in the development of MND. Myeloid cells, which normally provide a first line of defence against harmful molecules, can become overly active in MND which damages nerve cells. In models of MND, TQS-168 reduced the percentage of inflammatory cells compared to controls.



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The Phase 3 ADORE trial of an oral formulation of edaravone (FNP122), has enrolled it's first participant in Europe. FNP122 is being developed by Ferrer, and the trial is being conducted in collaboration with the Treatment Research Initiative to Cure ALS (TRICALS) consortium – the largest European initiative working towards better treatments and a potential cure for MND. Edaravone is a free-radical scavenger that helps eliminate potentially harmful molecules that can cause oxidative stress. It is already licensed as a treatment for MND, administered intravenously, in several countries (although not the UK). A full list of participating centres is not yet available

## New Drug in Phase 3 trial in Europe



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## Goal Achieved!

After 2 years, the United To End MND campaign has successfully secured a Government investment of £50 million, over 5 years, into targeted MND research which is exactly what we had been asking for.



## New President for our Branch

We are deeply honoured that Dr Stevan Wing, Consultant Neurologist at Mid and South Essex NHS Foundation Trust has accepted being the President of our MND South Essex branch where his knowledge and experience of the disease will be extremely useful. Dr Wing has also worked as Clinical Research Associate at the University of Cambridge and is familiar with all aspects of Motor Neurone Disease.

No doubt his in depth knowledge of MND will help us serve better the community of patients we aim to help and support.



## Stay mobile

Anyone living with MND who has mobility issues should be provided with a suitable wheelchair by the Wheelchair Services. Should there be a delay we have several basic wheelchairs and one electric one in store. (You might also like an additional basic wheelchair to keep in the boot of your car.) Just let Pat or Sandy know and it will be delivered.

## Equipment Available



Rise Easy  
Mattress Elevator

1 folding aluminium  
ramp



1 electric Wheelchair  
+ several basic wheelchairs

Please contact Sandy or Pat  
if interested.



### Sandy Lambert

sessexmnd.sel@gmail.com  
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### Pat Ahlquist

sessexmnd.pya@gmail.com  
07383 568 585

### Carmen Brown

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



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mndconnect@mndassociation.org



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## Changes in the Committee

As said before Sandy Lambert has decided to slowly wind down her involvement with our association to enjoy a well deserved retirement.

Unfortunately we also had to wave good-bye to Sue Nash who has re-located to Norfolk to be closer to family members and enjoy a less hectic way of life. Big thank you for everything Sue did for the association in the last 10 years.

We now have a new Chair Philippe Udrzal and a new Vice Chair Pat Ahlquist.



## Association Visitor Wanted!

Do you have experience of MND? Maybe you worked as a Health or Social Care professional and have recently retired? Do you have some time to spare and want to make a difference to people with MND? Then why not consider applying to be an Association Visitor Volunteer. Contact Carmen Brown, Area Support Coordinator on [carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org) for more info.

## 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

**Lisa Gallagher :** Digital /committee

**Kevin Watts :** committee

**Marianne Morgan:** committee

Association Visitors

**Sandy Lambert :** branch contact

**Pat Ahlquist**

Area Support Coordinator

**Carmen Brown**