

South Essex Branch

SPRING 22

NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist



www.mndsouthessex.org

Have YOU registered yet to join our Walk to d'Feet MND on Sunday, 15th May?



We are hoping that you will join us for this fun walk along Southend seafront to raise funds and awareness of MND.

This year we are starting and finishing in the car park of Southchurch Park East, SS1 2XE, and the newly elected mayor of Southend will be there to start everyone off at 10.30 am. The route is suitable for wheelchairs and pushchairs.

Scan QR code for full details or find Information Sheet on our website www.mndsouthessex.org.



Pre-registration is much appreciated and avoids congestion on the day. It also ensures we have a t-shirt for you.



If you do not have internet access or a printer for the **Registration Form please contact Sandy: 07742 943472** and she will send you hard copy. You need to do this soon as she will be in Corfu from May 4th - 11th.

So please talk to your family, friends and work colleagues and encourage them to join you for this special walk which is our major fundraising event of the year.





Memorial Park

Our much anticipated memorial garden in Wickford Memorial Park has finally been given the green light by council and will be a lovely way to remember those we have lost to MND.

There will be handsome teak benches with plaques bearing the names and dates of our loved ones. We will be able to plant bulbs in the flower beds which will thrive and increase over the years. Please let Philippe know if you would like to participate.
philippe.udrzal@live.co.uk



Funding for the Memorial Garden

Sandy is planning to do a tandem skydive from 15,000ft on 20th May to finance the benches for our MND Memorial Garden.



Please support her:

www.justgiving.com/fundraising/sandysskydive



MEETINGS

Meeting Dates

Places need to be booked in advance with Sandy

Fair Havens drop in meetings 2-4pm

Friday 29th April

Friday 10th June

Friday 5th August

Friday 7th October

Please contact Sandy for more information

sessexmnd.sel@gmail.com



South East Region Carers' Coffee and Chat

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

27th April /25th May/29th June

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

3rd May/ 7th June/ 5th July

Please contact Carmen for details

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>

South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.

17th May /21st June/19th July

Please contact Carmen for details

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.

20th May /17th June/15th July

Please contact Carmen for details

carmen.brown@mndassociation.org

DONATIONS

Team Charlie

Final tally for the London Marathon ran by Alex and Dan for a whopping **£7,163!**



Clacton Gold Club

Members of the Clacton-on-Sea Golf Club Seniors Committee presenting a cheque for **£2,250** to Lisa and John Gallagher, representatives of MND. Members of the committee are (LtoR) David Needham, Conor Kinnerk, John Kemp, Geoff Haslam, David Reid and Jim Wiggam, in whose year of Captaincy the money was raised through competitions and other events.



Leigh-on Sea Constitutional Club

We are very grateful for the Constitutional Club's generous donation of **£543.07** to our branch.

FUND RAISING EVENT



Dance all evening with **The Trolley Boys** who will perform in aid of MND at Sweyne Park School, Rayleigh SS6 9BZ on **Saturday 23rd April 7.30pm.** Bring your own Food & Drink.
Adult £10 Child £6

For tickets contact Barry Chasmer
07764 561 466

Working Together



Challenging MND was founded by Alex Gibson, an ex GB decathlete who was diagnosed 3 years ago. His vision was creating lifelong memories for individuals living with MND and their family, through provision of a challenge or activity of their choice.

Originally the activity was through physical participation, but they have now developed a Virtual Reality option for those whose illness has limited their mobility. Experiences can be delivered at the individuals home through Virtual Reality goggles, via partnership with our **MNDA** branch and funded by the wonderful work of the **Hadleigh Castle Rotary Club**.



Please see the short videoclip at their website showcasing the experience www.challengingmnd.org.

In addition their newly launched offer involves holistic, bespoke support including respite for family carers, who over the course of their loved ones illness will have some really tough times and are often forgotten.

Challenging MND fund respite, allowing carers to recharge their batteries, to continue supporting their loved one. This should help them get time out to meet friends or to benefit from some relaxing therapy such as massage or reflexology.

The **MND Association** also have a variety of grants, such as Quality of Life Grants, Carers Grants, Children, Emergency Grants and the Young People Grants. These are crucial in offering support to people living with and affected by MND.

Your AV will be able to tell you more and help you apply for these. However, where the request is higher than what is on offer or can't be funded through the **MNDA**, with consent, your MND Association Visitor can contact **Challenging MND** directly to apply for a top up grant or a separate grant where appropriate. If this is of interest to you please contact your **MND Association** Visitor or contact **Challenging MND** direct.

liane.iles@challengingmnd.org

Challenging MND

Join them on **28th April** at 10am via
Zoom to find out more. For joining
details email
carmen.brown@mndassociation.org

Rotary
Hadleigh Castle



RESEARCH UPDATE

Want to take part in MND research?

Find a list of current opportunities to take part in studies and subscribe to receive updates. Scan QR code.

www.mndassociation.org/takepartinresearch



New data from RESCUE-ALS

Additional results from the RESCUE-ALS trial, which investigated CNM-Au8 as a potential treatment for MND, were announced at the Muscular Dystrophy Annual Meeting. These results included evidence of significant survival benefit when compared to the validated ENCALIS survival prediction model. Additional analysis of the MUNIX scores found that the score decreased less in those with limb-onset MND when taking CNM-Au8 compared to placebo.

CNM-Au8 is an oral suspension of gold nanocrystals developed to restore neuronal health and function by increasing energy production and utilisation.



Latest news on AMX0035

Amylyx have announced that the Market Authorisation Application (MAA) for AMX0035 has been validated by the EMA and is now under CHMP review. The MAA submission is based on data from the Phase 2 CENTAUR trial which demonstrated a 6.5-month difference in survival between people who took AMX0035 and people who took a placebo. AMX0035's benefits are now being confirmed in a larger Phase 3 trial – PHOENIX. This trial is open to people with MND who are less than 24 months from symptom onset. Sites are set to open in Dublin, Liverpool, London, Plymouth and Sheffield in the coming months.





Remap

REMAP is a charity which designs and makes, or adapts, equipment for people with disabilities if it is not commercially available.

For more info, email
carmen.brown@mndassociation.org

Join them on **3rd May** at 11am or
4th May at 6pm via Zoom to
find out more.
Joining details
carmen.brown@mndassociation.org



Sandy, our Hidden Hero

Many of you will know first hand the marvellous work Sandy has done and still does for people affected by MND locally. She has now been recognised as a Hidden Hero in the first ever nomination that the MNDA National Office has made to **Room to Reward**. This is in recognition of Sandy's selfless contribution and commitment to volunteering and gives her a free 2 night stay for her and a friend in a hotel of their choice. Many of us wrote in support of her nomination and Room to Reward said that her nomination was quite exceptional and blew them away. We all know that she is a superhero! She was presented with her certificate by Carmen Brown, our MND area support coordinator.



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



Walker



Bed grab handle

Please contact Sandy or Pat
if interested.

Sandy Lambert

sessexmnd.sel@gmail.com

07742 943472 / 01702 305759

Pat Ahlquist

sessexmnd.pya@gmail.com

07383 568 585

Carmen Brown

Area Support coordinator

carmen.brown@mndassociation.org

01604 800 659

www.mndsouthessex.org

mndconnect
0808 802 6262
mndconnect@mndassociation.org



@MNDsessex



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Volunteers Wanted!

Do you have experience of MND? 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

or our new

Walk to d'feet Coordinator.

Contact Carmen

carmen.brown@mndassociation.org

Newsletter

Get our longer digital version sent by email.
rowananddebbie@btinternet.com

Both newsletters are available to view on our website: www.mndsouthessex.org

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 : Digital /committee

Lisa Gallagher : Digital /committee

Kevin Watts : committee

Marianne Morgan: committee

Association Visitors

Sandy Lambert : branch contact

Pat Ahlquist

Area Support Coordinator

Carmen Brown