



WALK to D-FEET MND 2021



This summer we aim to be back with our wonderful Walk to D'Feet along Southend Seafront. We need to make it Covid safe and follow regulations whilst having fun, raising awareness and getting lots of sponsorship. The route will be different to avoid the congested, narrow path by Chalkwell Station.

Plan A: Sunday, 4th July 10.30 a.m., starting from Southchurch Park East, Lifstan Way, SS1 2XE Walkers will be asked to wear their MND blue T-shirts and to have masks with them, which can be slipped on should there be congestion enroute. Please bring your own water bottles, which can be refilled at the water-stops: Adventure Island, Saltwater Cafe Chalkwell, Lifstan Car Park, Uncle Tom's Cabin and the car park.

- * There is a 6 mile walk to the west to the Saltwater Cafe by Chalkwell beach and back.
- * The more ambitious will do the above and then continue to Uncle Tom's Cabin, Shoebury, before returning, walking 10 miles.
- * Others may choose to go as far as Adventure Island, 2.5 miles, or Rossi's, 4 miles.

WALK to D-FEET MND 2021



Click on links below for a detailed Information Sheet and Registration Form.

<https://www.mndsouthessex.org/documents/Walk%20to%20D-Feet%202021/Registration%20Form%202021.pdf>

<https://www.mndsouthessex.org/documents/Walk%20to%20D-Feet%202021/W'dF%202021%20Info%20Sheet.pdf>

They will also be emailed to past walkers and available to download from the branch web-site

www.mndsouthessex.org

Those without the internet or printers should contact Sandy for hard copy:

01702 305759 or 07742 943472

The large car park at Southchurch Park East is now £1 an hour but we are hoping that the Council will once again waive the parking charge for our walkers as they have done in previous years. We will let you know whether we have this dispensation in the STOPPRESS on the web-site.

PLAN B: Should changes in the Covid situation make it unwise, or illegal, to have a mass Walk on the 4th July then we would ask our loyal walkers to have their own individual, or family walks throughout the summer, wearing their MND T-shirts and raising sponsorship money.

Whatever you do please wear your T-shirt and post on social media as recognition is key to help beat MND.



This will be the last walk that Sandy organises. We are looking for a volunteer to organise the Walk in future years. Please let us know if you are interested.



MORE TO COME

**Sunday 8th
August**



MND SUMMER PICNIC

We have missed seeing you all at our usual Indian, Chinese and Turkish fundraising meals.

It would be so good to see everyone on **Sunday 8th August, 12.30** onwards.

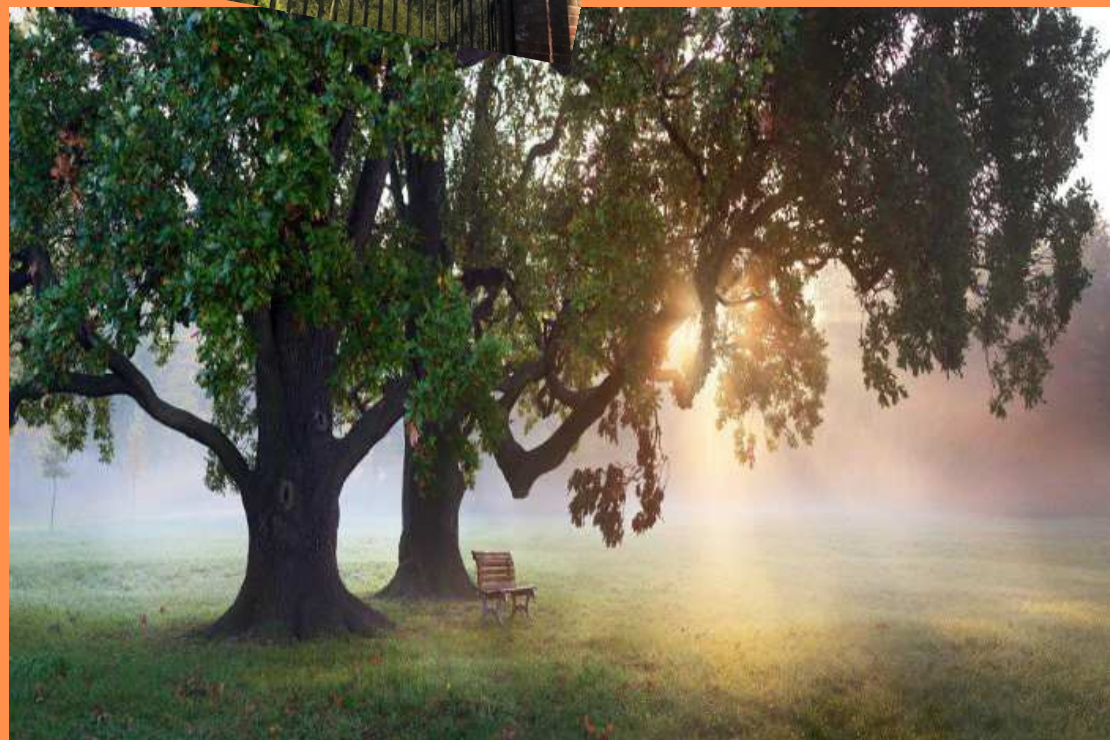
Do please come along to the Wat Tyler Country Park Centre in Pitsea and follow the balloons to our field. Bring your own food, drink, seating, sunhats and sunscreen. We will arrange the music and a raffle. The field is enormous so we hope hundreds of you will come and enjoy the afternoon and seeing everyone.

PLAN B (yes, we should have a contingency plan in case the forecast is for rain all day). The picnic will be on Sunday 15th August instead. If it is to be postponed until the 15th, a notice will be put in the STOPPRESS on the branch website on Friday 6th August.

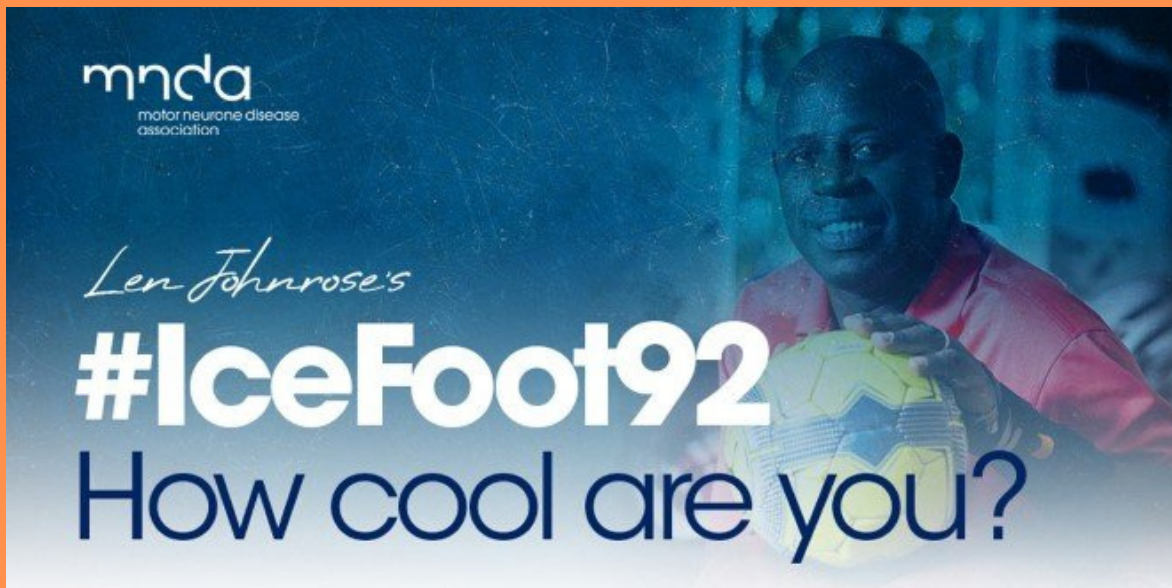
We are in negotiations with Basildon Council to have an area in the Wickford Memorial Park dedicated to those we have lost to Motor Neurone Disease. We envisage a dedicated park bench, facing a flowering cherry tree, underplanted with spring, summer and autumn bulbs and forget-me-nots. Families would be able to place small wooden name markers, or metal markers with names and photos. We hope to be able to give full details in the September Newsletter.



MEMORIAL to those we have lost to MND



FOLLOW IN THEIR FOOTSTEPS



Len Johnrose's Project 92, which includes the #IceFoot92 challenge, has now hit the halfway point to the £92,000 target - £1,000 for each of the 92 football clubs in the Football League. More than £46,000 has been raised so far and Len is urging people who haven't yet taken the plunge to take part. It's Len's take on the Ice Bucket Challenge, using the long-standing footballers' technique of dealing with feet injuries – icing them. Those who take on the #IceFoot92 challenge are asked to donate £10 to the MND Association by texting MNDLEN to 70085 and to nominate three friends, relatives or colleagues.

Find out more on MND Association website and follow the action on MND Association Twitter account or hashtag #IceFoot92.



Former Leeds Rhinos captain Kevin Sinfield will be running this October's Virgin Money London Marathon for the Association. He'll be doing it in honour of his friend and former team mate Rob Burrow and those living with MND.

Did you know you can run the London Marathon virtually at home on 3 October?

On the same day as the event, runners across the country will be completing the 26.2 miles around their local area. Find out more on MND Association website.

SPREAD THE WORD!



As the next step in the United To End MND campaign, MNDA has launched a petition calling for more government investment in targeted MND research. We've already had over 35,000 signatures in just one week. The petition, in the name of Scottish rugby legend Doddie Weir, is backed by a coalition of people with MND, researchers, clinicians and charities. Show your support by adding your name.

Conversations with ministers are going well – with Doddie Weir meeting Secretary of State for Health & Social Care Matt Hancock last year. Getting signatures on the petition helps make our case as strong as possible. For more information please see [MNDA campaign webpage](#).

Please also help us spread the word via social media and email by sharing a positive message.

Visit our website to find some images and suggested wording to help you do this.



Act 2 Adapt

Aim: To ensure that more people with MND can access suitable housing and home adaptations in a faster and fairer way.

Tactics developed with A2A Advisory Group:

- Phase 1: Launched to build awareness
- Phase 2: influence local authorities to improve local services in line with our report recommendations.

Latest update:

- Over 1,300 supporters have taken part in our e-actions
- 73 Councillors have expressed support
- 6 pilot campaigns are starting across all 3 nations
- Attended Home Improvement Agency Managers meeting
- Impact: Oxford and Northumberland
- We recently attended LGA Labour Conference and CCA Conference

ACT TO ADAPT
Access to home adaptations for people with motor neurone disease

A row of four small video thumbnails showing people in a meeting.

MNDA's Act to Adapt campaign, spearheaded by volunteers Debbie Williams and Lynda Roughley has led Wirral Council to launch a time-critical adaptation grant. This brand new grant means that for people living with MND and other terminal illnesses testing will be flexible, making the process to access much-needed home adaptations faster and easier. It is down to Debbie and Lynda's incredible tenacity and involvement that has pushed the council to improve the situation.

Read more about the success [here](#). Interested in Act To Adapt? Join the campaign.

RESEARCH UPDATE



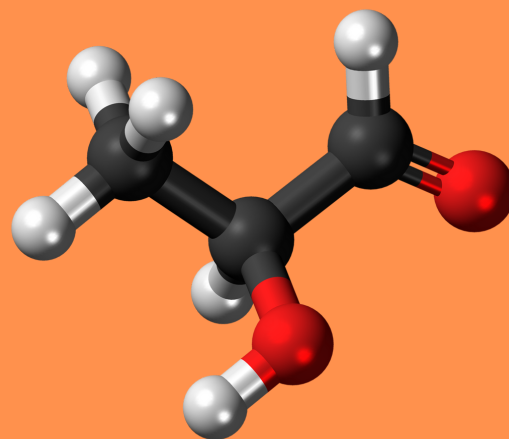
Researchers from the University of Bath are assessing the potential of a new communication device which uses a tiny ear muscle to control a keyboard.

Some existing switches to control electronic communication tools may be difficult for some people with MND to use. A company called Earswitch has demonstrated that a small muscle in the ear, called the tensor tympani muscle, can be voluntarily moved and effectively used to control a virtual on-screen keyboard to communicate.

It is not currently known what proportion of people can voluntarily move this ear muscle and therefore potentially benefit from this technology. This research project aims to establish what proportion of the general population as well as those with MND can move or control this muscle.

Take a look at the coverage on Sky News or read more on MNDA website including how to take part in the survey.

In a press release published today, biopharmaceutical company Orphazyme announced its phase three trial of **Arimoclomol (ORARIALS-01)** did not meet its primary and secondary endpoints to show benefit in people living with MND. Results from the study will be presented at the upcoming virtual European Network to Cure ALS (ENCALS) meeting in May and complete data will be published later this year.



VIRTUAL ANNUAL GENERAL MEETING

Report by Kevin Watts

On Saturday 20th March, the South Essex branch held their Annual General Meeting (AGM). This was an unique meeting as it was conducted virtually over zoom. Attendance was good with over 20 people either on their laptops, phone or tablets joining in.

Sue Nash, the branch Chair, led the proceedings with the formal matters of the meeting with a report to highlight what had happened during the most challenging of years with the outbreak of Covid-19. Sue then spoke about the roles that each committee member has responsibility for. Sue also warmly introduced our new president, Dr Stevan Wing and welcomed him to the branch.

Rowan Harvey, the branch treasurer, presented the accounts and was pleased to announce that all financial requests were met and that the branch's bank balance was looking good.

The meeting then voted that the whole committee should continue their posts for another year. Sue thanked them for all their work to help patients and carers with MND.

The highlight of the morning though was the presentation given by Dr Brian Dickie, the Director of Research Development from National Office. Dr Dickie, who has worked for the Association for 21 years, continued to give us hope with a presentation, which included information about research projects, and how the Association were working positively with other stakeholders. He stated that research was progressing well. Dr Dickie took questions from those at the meeting.

The meeting finished with everyone feeling positive about the future of the South Essex branch of the Motor Neurone Disease Association and looking forward to the next 12 months.



mnda
motor neurone disease
association

MND
Matters

The Association is launching a new podcast which will give people affected by MND access to information, informal advice and expertise.

MND Matters will explore a range of subjects alongside the experiences of people affected by MND, from communication to relationships, family to care. As well as being an extra information source for the MND community, MND Matters will also be a new tool for the Association to use to raise awareness more widely.

MEET UP?

Meeting Dates

Friday, 4th June, 2.30 to 4pm. Zoom

Tuesday, 6th July, 2.30 to 4pm. Zoom or Thurrock Garden Centre, RM15 6DU

Friday, 6th August, 2.30 to 4pm. Zoom or at Fairhavens, SS2 6PR

Tuesday, 7th September, 2.30 to 4pm. Zoom or Thurrock Garden Centre RM15 6DU

Please contact Sandy to take part
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>



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

Support after Loss Group

Share your experience with others in a similar position.

Every 6 weeks on a Thursday at 6 pm

Next dates are 27th May, 8th July, 19th August

Please contact Carmen for details
carmen.brown@mndassociation.org

Carers' Coffee and Chat

An Essex and East London Carers Group to get advice and gain peer support last wednesday of each month 6.30-7.30. Next one is 26th May.

We are looking for facilitators to lead this group.

Please contact Carmen for details
carmen.brown@mndassociation.org

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

FOR YOU?



Our South Essex Branch is currently trying to recruit the following

- **volunteer fundraisers**
- **Walk to D'Feet Volunteer**
- **Walk to D'Feet Coordinator**
- **Trusts and Grants Fundraising volunteer**
- **South Essex Association Visitor**

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 £4 each, including postage.

Quantity discounts available.



Equipment Available

Over the bed/chair table

Doorline Bridge 10cm high threshold ramp

Mattress Raiser

Customised stand to hold ipad or computer

Wheelchair

Please contact Sandy if interested.



WHO'S WHO in your BRANCH

NEW PRESIDENT

We are delighted to announce that

**Dr Stevan Wing, Consultant
Neurologist**

has accepted the invitation to be president of our South Essex branch. His experience with the patients and intricate knowledge of this disease will be a great asset .

Stevan Wing: President

Sue Nash : Chair

Sandy Lambert : Branch Contact &
Vice Chair

Rowan Harvey : Treasurer

Debbie Darke : Secretary

Kevin Watts

Lisa Gallagher : Digital Communication

Pat Ahlquist

Marianne Morgan

Philippe Udrzal : Newsletter

Association Visitors

Sandy Lambert

Pat Ahlquist

Liane Iles

Area Support Coordinator

Carmen Brown

Sandy Lambert

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Carmen Brown

Area Support coordinator

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