

Raising Funds



Mission 5000

MNDA want us to cover 5,000 miles, that is a mile for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot.

www.mndassociation.org/mission5000

1. Sign up, pledge your miles receive a fundraising pack & a t-shirt.
2. Complete your miles.
3. Track your miles & submit your total.
4. Raise over £100 and receive a limited edition Mission 5000 medal



Christmas Cards For Sale To Raise Funds For MND South Essex Branch
 Order from Sandy Lambert to be delivered mid-Nov - £2 per Pack of 10 – more info on last page
sessexmnd.sel@gmail.com 07742 943472



Research Update – Dr Brian Dickie

Where are we now?

Clinical trials have been relentlessly testing drug targets ever since the first ever MND drug, **riluzole**, was licensed in the UK in 1996. However, although considered a standard treatment for anyone diagnosed with MND, riluzole only prolongs survival by around 3 months. Fast forward two decades when a second drug, **edaravone**, was licensed in Japan, South Korea, USA & Canada. Originally, edaravone was developed as an intravenous treatment for acute ischemic stroke. When it was later tested in rodent models & subsequently in people with MND, reduction of oxidative stress was observed. Follow-up trials were however only able to identify modest effect in small subgroup of patients whose symptom progression was moderately slow. To this date, data on survival are still sought.

Where do we go from here?

With only two drugs under our belt, and no effective treatment, the MND research community is far from losing hope and we are looking ahead of exciting times. There are many avenues researchers are exploring, each targeting a different mechanism by which the disease is suspected to develop and progress. Although the precise cause of why motor neurons die is not known, many pathogenic processes have been proposed. MND is a disease of a complex origin, and a combination of genetic, environmental and lifestyle factors is necessary for the disease to develop. And although some involvement of genes is suspected in the majority of MND cases, a subgroup of ~10% of patients have a specific proneness to the disease due to an inherited genetic variation. There have been many advances in identifying the genetic factors, though international gene-hunting initiatives such as **Project MinE**. This has led, to date, to the identification of the genes involved in almost 75% of the rarer inherited cases in the UK. It has also identified many of the more subtle genetic factors that predispose people to MND, but do not on their own cause the disease. Although a heterogenous disease, clinical manifestations of MND are similar across patients regardless of the cause. Therefore, having a number of genes identified to be associated with the disease provides the advantage of focusing treatment efforts into fixing these mistakes first.

The journey is long, but the target is getting closer

Researchers have made a great progress over the past few decades and with the recent boom of new technology, including whole genome sequencing, induced pluripotent stem cell modelling, and gene therapy, our community is hopeful and motivated than ever to tackle MND, by attacking it from every possible angle.

A number of treatments are now in Phase 3 clinical trials and interim results of these treatments appear very promising. Although some of these won't offer a cure, they may stop or slow progression in some people with MND. Genetic therapies are emerging that may be useful for subsets of patients with particular identified genetic forms of MND. There is a growing path from genetic discoveries to the development of gene focused therapies, so research is moving forward in this field.

There are also more new drugs to try than ever before (including repurposed drugs that have been shown safe and effective in other conditions). An innovative way to accelerate the process of drug development and the path for effective treatment in MND is through a **platform trial design** where multiple drugs are tested simultaneously and adaptively – as has been done in cancer trials and other diseases. This design allows fewer people to be on placebo (dummy drug) and has better ways to measure outcome. The MND Association are part of **TRICALS**, the world's largest network of trained specialised ALS (Amyotrophic Lateral Sclerosis) centres, which will be launching a platform trial to collect and combine patient data across the UK and Europe.

Role of the MND Association in MND Research

MND research is at the forefront of neurology research. As of 31 December 2019, the MND Association of England, Wales and Northern Ireland funds around £14m of research across 83 grants involving about 170 researchers. The MND Association is relentless in its fight against the disease and by funding research into the causes, treatments, symptom management and quality of life, while supporting the care needs of people living with MND and their carers, we hope for a world free of MND. To find out about the projects that the MND Association currently fund and how they decide which projects to fund, please visit: www.mndassociation.org/research.

We believe the key to defeating MND lies in fostering strong collaboration between leading researchers around the world and sharing new understanding of the disease as rapidly as possible. This was the MND Association's rationale behind creating the annual International Symposium on ALS/MND - the largest medical and scientific conference specific to ALS/MND. In response to the global pandemic, plans are well underway to unveil the first ever virtual version of the event in December 2020. Please visit the website for more information: <https://symposium.mndassociation.org>.

To read more about what's going on in the world of MND research, read the MND Association Research Blog: <https://mndresearch.blog>, which includes posts on important discoveries and developments, updates on clinical trials and research studies, the use of unapproved drugs, interviews with MND researchers, and reporting from events such as our International Symposium on ALS/MND.

**DONATIONS &
FUNDRAISING FOR JUNE &
JULY 2020**

Donations and Fund Raising	
Walk to D'Feet	£589.32
In Memory of PP	£1,249.00
Anna Colvill	£300.00
D E Noble	£20.00
Just Giving	£200.00
Gillian Trevelyan	£10.00

Grateful thanks to all donors and fundraisers



Buy Xmas Puddings to Help Raise Funds

Contact Sandy if you want to order Xmas puddings for delivery by mid-November.

£10 - 2lb Pudding

£5 - 1lb Pudding

£2 - Individual Pudding

Mission 5000



Our very own Sandy Lambert has pledged to cycle 73 miles – one mile for each person living with MND in South Essex – on her new tricycle. She is aiming to raise £730 to fund flowers/fruit at Xmas for each person. Please donate at:

[Justgiving.com/fundraising/LambertSandy](https://www.justgiving.com/fundraising/LambertSandy)

Individual Walk to D'Feet

The committee would like to ask supporters of our branch to consider organising their own sponsored walk. To date just under £1000 has been raised in 2020. Below are the amounts raised in previous years – it is normally South Essex Branch's biggest annual fundraiser.

2020 - £1,000

2019 - £16,524

2018 - £16,544

2017 - £18,174

2016 - £30,736

2015 - £15,688

Total from 2005 to 2019 = £217,000

South Essex Branch Virtual Drop-In

Virtual Get Togethers Via Zoom – connect with others and hear from a guest speaker, all from the comfort of your own home.

We were really pleased to have a few people join our virtual get together on 1st September, to share some tips, meet new people and connect with others. We also appreciated hearing from our **guest speaker, Jan Clarke, from Queens Square Centre for Neuromuscular Diseases** and would like to thank her for joining us.

Why not join us next time and give it a go! Drop into our next meeting and see if it is for you..... Don't have Zoom? Unsure how to use it? Have communication difficulties which you feel may get in the way? Then contact us either directly or through a loved one and we can assist with this.

Our next get together will be **Friday 2nd October, between 2:30-4pm** and our **guest speaker is Jenna Venables, Macmillan Community Physiotherapist who has a particular interest in MND.** She will attend for the first half hour for you to listen in to or ask some questions, followed by our social get together. Below are the next dates for this monthly virtual meeting.

For information on how to join, please contact your local branch or Area Support Coordinator:

South Essex Branch – Sandy Lambert 07742 943472

sessexmnd.sel@gmail.com

Area Support Coordinator – Carmen Brown 01604 800659

carmen.brown@mndassociation.org

Volunteer Required

We are looking for a volunteer to contact Trust Funds to determine if they have funds available to support those living with MND. If you are interest in this position contact:

Peter Jamison:

07580 404561

Peter.jamison@outlook.com

Donations

Due to Covid-19 South Essex Branch has not been able to organize events to raise funds for those living with MND in the local area Please donate if you are able:

**[justgiving.com/fundraising/
South-Essex-Branch](https://www.justgiving.com/fundraising/South-Essex-Branch)**

Ordering Info for Xmas Cards

1A – Newborn King/Bethlehem (Twin)
2B – Poinsettia/Holly Greetings (Twin)
3C – Highland Cattle/Robin Trio (Twin)
4D – Robin/Partridge Stamp (Twin)
5C – Xmas Wishes/Merry Xmas (Twin)
6A – Robin/Kingfisher (Twin)
7A – Frosted Snowdrops
8A – Midwinter Tree
9A – By the Lychgate
10C – Reindeer Choir
11E – 12 Days of Christmas
12A – Madonna & Child
13D – Horse Guards Parade
14A – Frosted Thistle

15A – Winter Walk
16A – Winter Town
17C – Christmas Cupcakes
18D – Sheep at Sunset
19A – Snowy Lane
20A – 12 Days of Xmas Tags
21A – Winter Feed
22A – Ice Skating
23F – Rudolf
24A – Snowy Horses & Building
25D – Christmas Tree
26C – Flying Santa
27A – Midnight Mass
28B – Tartan Stockings

Words in Xmas Cards

A – “Best Wishes for Christmas and the New Year”
B – Blank
C – “Merry Christmas”
D – “Season’s Greetings”
E – “Merry Christmas and a Happy New Year”
F – “Hope you have a Merry Christmas”

ACKNOWLEDGEMENTS

- The health and social care professionals who work with our people with MND
- The many donors and supporters of the Branch
- Mike Searle, for our website www.mndsouthessex.org
- Grant Flashman for printing and folding our newsletter

Peabody Trust

Peabody Trust provides care, support & advice to help access services & benefits

0800 28 888 83
peabody.org.uk/essex

Dates for your Diary

Oct 2..... 2:30-4pm Drop-In ZOOM Meeting
Guest Speaker – Jenna Venables

Nov 3..... 2:30-4pm Drop-In ZOOM Meeting
Guest Speaker - Prof. Andrea Malaspina

Dec 4..... 2:30-4pm Drop-In ZOOM Meeting

Jan 5..... 2:30-4pm Drop-In ZOOM Meeting

Feb 5..... 2:30-4pm Drop-In ZOOM Meeting

For details of the ZOOM Meetings contact Sandy Lambert
sessexmnd.sel@gmail.com

Useful MND Contacts

Benefits Advice.... mndassociation.org/benefits
0808 801 0620

Support..... mndassociation.org/mndconnect
0808 802 6262

Information.... mndassociation.org/information

Financial Grants ... mndassociation.org/grants

Local Support mndassociation.org/branches

Who's Who in the Branch

The Committee

Chair	Peter Jamison
Vice Chair	Sandy Lambert
Treasurer	Rowan Harvey
Secretary	Debbie Darke
Publicity	Kevin Watts
Communications	Lisa Gallagher
Committee Member	Liane Iles
Committee Member	Susan Nash
Association Visitor	Sandy Lambert Liane Iles Pat Ahlquist
Area Support Coordinator	Carmen Brown

Facebook: MND South Essex Branch
Twitter: @mndasessex
www.mndsouthessex.org

mndconnect
0808 8026262
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