

VIRTUAL ANNUAL GENERAL MEETING



Saturday, 20th March 11am

We hope you will attend our AGM on Zoom. Our guest speaker is

Dr Brian Dickie, Director of **MND Research**.

The agenda will include the Chair & Treasurer's reports
(available on the branch website after the AGM)

and to vote in new committee members.

Please contact Debbie to get log in details

rowananddebbie@btinternet.com

www.mndsouthessex.org

MANY THANKS to PETER JAMISON



South Essex Branch would like to thank him for his time as Chair of our branch. Since Peter has been the Chair of the South Essex Branch of the Motor Neurone Disease Association, he has continued to develop the branch and made it go from strength to strength. As a branch, we have always been looking for new committee members, new volunteers and continuing the fantastic fundraising for local people with MND and their carers and we have succeeded in all these areas under his leadership. Peter's warm, gentle and caring nature ensured that he listened to patients' needs and coordinated actions to make sure that all financial requests were met. The branch has continued to grow with Peter increasing the members of the committee and active volunteers. Peter will be a big loss to the local branch and we wish him the best for the future. Thank you Peter, on behalf of all of the people with MND and their carers in South Essex for making such a difference. The branch would like to welcome Sue Nash to the role of Chair who held this position prior to Peter.



MEETINGS IN TIMES OF COVID

Once we realised that we would not be able to meet for our usual drop-ins at Fairhavens and the Thurrock Garden Centre, Carmen set up virtual Zoom meetings for us. Free tea and cakes may have been lacking but at least those with the internet could chat to each other. Numbers attending have been variable but we have been very lucky to have some really dedicated Health Care Professionals join us for part of the session. Jan Clarke from the MND clinic at the National started the ball rolling. We then had the opportunity to meet Colette Bloomfield, the new MND Coordinator.



We were then delighted that Prof. Andrea Malaspina gave up his valuable time to join us in November. Jenna Venables a physiotherapist from Fairhavens and Danielle Foster a Speech Therapist from Basildon Hospital, both of whom treat many of those with MND, also joined us.

Those who were unfamiliar with Zoom were helped in the process by Carmen and Pat. If anyone else who is living with MND, their family and friends would like to join us each month please contact Sandy who will send you the link and direct you to Carmen or Pat if you need help. Dates and time of future meetings are on page 6.

31st International Symposium on ALS/MND

Report by Pat Ahlquist



Attending international palliative care research conferences every few years has been a highlight of my working life, but I could never justify taking time off to go to the Association's excellent Annual International Symposium on ALS/MND. They were due to meet in Montreal in December 2020 but early in the year decided to change to a virtual platform. Brian Dickie and his team then worked incredibly hard and created an extremely successful virtual symposium, and this time I could join in! They even allowed catch-up viewings online until the end of January.

Over 3 days, more than 1800 delegates from 48 countries took part. Lectures and presentations from leading world experts were followed by ample time for questions and over 400 e-posters could be looked at, with 'lightening explainer' videos to summarise the research with specific sessions when the presenters could present and discuss their work in real time. It was humbling and inspiring to see how much is being done to discover the causes of MND and thereby find targeted treatments. The international community is really working together and there was a lot of evidence of the benefits from this collaboration, and of co-operation with researchers in parallel fields.

One fascinating lecture was by Prof. Tanzi from Harvard, who was talking about neuroinflammation across neurodegenerative diseases. His work has been mainly on Alzheimer's and aging but provides valuable insights into how abnormal amyloid- β protein deposits in the cells cause inflammation and cell death. They have even developed 3-D neural cell cultures, growing in a dish, derived from human stem cells. This enables them to quickly test the effects of drugs on cell damage in Alzheimer's and MND, and make much more rapid progress.

The increased speed of research was also highlighted by Prof. Al-Chalabi from King's in London when he spoke at the preconference symposium hosted by Cytokinetics. Platform trial designs (a new concept) are enabling much more efficient evaluation of multiple interventions with the ability to keep trials running and adapt them for new discoveries from within and outside the trial. New diagnostic criteria, tools that measure the rate of progression and genetic profiling are also helping to stratify trials so that specific drugs can be targeted more accurately. The eventual future really does seem to be in Precision Medicine and a much more personalised approach to treatment.

One type of precision based medical therapy is anti sense oligonucleotides (ASOs), and I learnt a lot from a presentation by Prof. Chio of the University of Turin. ASOs are short, synthetic, single-stranded nucleic acids that attach to mRNA and modulate protein expression. He presented very encouraging data from exploratory clinical trials of an ASO drug called Tofersen. It reduces the production of the dangerous SOD-1 protein in people who have that genetic mutation and seems to significantly slow the rate of clinical decline. Results of the Phase 3 trial are expected later this year. Another ASO drug for the C9ORF72 mutation is now in phase 1 trials.

People having these drugs have to have lumbar punctures every month but one presentation even offered hope that targeted ultrasound may help drugs cross the blood brain barrier more effectively, though clinical trials with this for MND are only just starting.

The results of three large Phase 3 trials were presented at the meeting. These have been really well explained on the Research Blog of the MNDA website (<https://mndresearch.blog>). Unfortunately the trials of NurOwn (using stem cells) and levosimenden (repurposing a cardiac drug) did not meet their primary end points to show an impact of treatment. However the NurOwn study has a lot more work to do and their CSF biomarker data showed interesting results to work on. Also the levosimenden trial showed a trend towards slower progression in some people and they are hoping that the open label trial extension, reporting later this year, will throw more light on that. The trial results of an oral drug called AMX0035 were much more promising with at least a 6 month survival benefit. The extension trial data is still awaited and it is still an experimental compound without regulatory approval, but I'm sure we will be hearing more about it soon.

I must confess to not reading all 400 posters, but a few from the Sheffield research group caught my eye. They already support the useful website Home - myBreathing (mymnd.org.uk) which is targeted at people living with MND. They presented research on the best ways of providing NIV, inequities across the UK and the development of their new NIV toolkit website for health care professionals. Along with others they also presented information on the use of digital remote monitoring and telemedicine clinics. It was clear that one of the benefits of the pandemic is that it has accelerated development and assessment of the benefits of virtual clinics which could really reduce the future burden of clinic attendance, especially for those involved in clinical trials.

Sitting at my computer, attending the Symposium, I have watched how basic scientists, clinicians and drug companies are all working together, irrespective of international boundaries. It truly is an exciting era of MND research and my lasting impression was one of hope for the future. If you want to find out more do look at the MNDA website and their interactive Periodic Table of Research. (Periodic Table of MND Research | International Symposium on MND/ALS (mndassociation.org)).



MEET UP ?

WALK to D-FEET

We are hoping to hold this annual fundraising event on **Sunday, 4th July**, with a fallback plan of a Walk in the Autumn should Covid necessitate.

More details will be in our Spring Newsletter

Meeting Dates

Tuesday, 2nd March, 2.30 to 4pm. Zoom

Friday, 9th April, 2.30 to 4pm. Zoom

Tuesday, 4th May, 2.30 to 4pm. Zoom

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

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

Meeting for the Bereaved

Share your experience with others.

Next meeting on

Thursday 4th March at 6 pm

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>

Carers' Coffee and Chat

3rd Friday of each month 2-3pm via Zoom

Join our friendly group of carers, share tips, get advice and gain peer support. Please note this is a carers only group.

For more info or guidance in using Zoom contact Carmen

carmen.brown@mndassociation.org

NEW in our BRANCH

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

If you would find either of the items below of help please contact Sandy. Do ask your Occupational Therapist whether they are suitable for you. Only one of each so first come first served.



Rise Easy
Mattress Elevator

Walking Trolley



Donations

Donations Received Between 1st September and 31st December 2020

David Noble £60
Gillian Trevelyan £30
J C Boosey IMO Winnie Best
£40
Sheila Ball £75
St Aidan's Church £100
Golden Lion PH £68.90
Various IMO Val Shaw £75
Sandy Lambert £146
P Miller IMO Reg Griffiths £30
H Burrridge £30

Funds in 2020

This year has seen the income we receive greatly affected by the Covid 19 pandemic. Our income was £17.6k ie £29.2k less than 2018 (62% drop).

The majority of our income is raised through various fund raising events, some organised by Branch and others by third parties. Lockdown has decimated fund raising this year, with everything being cancelled. At the end of the year Branch normally sends 50% of any remaining funds to National Office who use this to fund research projects. This year they have changed the rules, which mean that we can keep our funds.

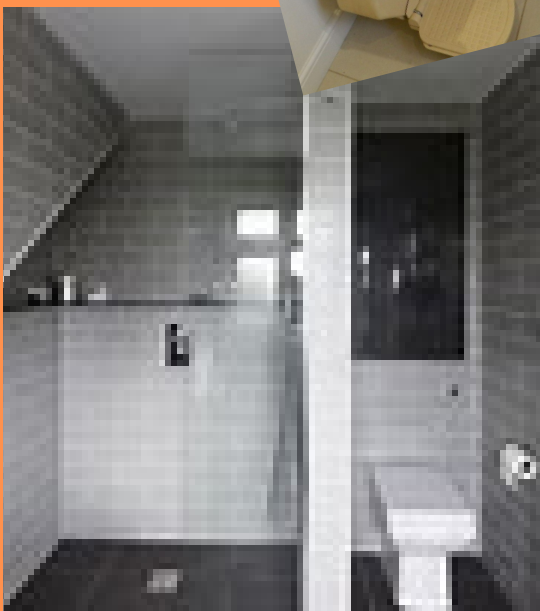
We are confident this concession will enable us to support the needs of patients and carers in our area, which is one of our key objectives .

With the rolling out of the various vaccines which have now been approved, we hopefully can start to return to normality in Spring.

How the Funds Raised are Spent

A primary reason why the branch exists is to support the needs of local patients and their carers in our local area. As mentioned earlier, this year it has been particularly hard for the Branch to reach all those who need our support. However we have been able to provide the following help in our area in 2020:

- Financial support for the creation of 3 wet rooms
- Reflexology to various patients (pre lockdown)
- £1,000 in Quality of Life Grants
- £ 500 in Covid Grants
- Stairlift installation
- A set of ramps to gain access into the home
- £250 Young Person's Carers Grant



CHRISTMAS CHEER



Money raised by Sandy's sponsored tricycling was spent on giving some Christmas cheer to those living with MND in our area. All those in touch with the Branch had a delivery of flowers, fruits, chocolates, or Christmas puddings in the weeks running up to Christmas.



THANK YOU

Michelle Bingham
for selling nearly £300
of Christmas Puddings.

WHO'S WHO in your **BRANCH**



Sue Nash : I have recently taken over as **chairman** of the local committee from Peter, I have very big shoes to fill! I became involved 10 years ago after working for a wonderful GP who had MND

Sandy Lambert : I started volunteering for MND 20 years ago, first as Branch Secretary, then as **Branch Vice Chair** and now as an **Association Visitor** and **Branch Contact** to better support those living with MND.
I organise the annual Walk to d'Feet MND.



Rowan Harvey : Branch's **Treasurer** for the last 5 years. My father in law got this disease and my wife and her sister volunteered me for the role. where I have found it hard to spend the funds, as in my previous life I had to reduce costs and save money.



Debbie Darke : Branch's **Secretary** for 4 years. I joined when my Dad fell ill with MND. With my family AKA 'Team Charlie' we have raised £23,400 in memory of Dad.

Kevin Watts : I have been involved since my dad died from MND. Headteacher of a large Primary School, I also manage a District football team and do amateur dramatics.



Lisa Gallagher : I joined our committee in April 2018. I look after our **Digital Communication**

WHO'S WHO in your BRANCH

Pat Ahlquist : The first person I knew with MND was a friend's Mum when we were teenagers. As a palliative care consultant I went on to support many people with MND and, now I am retired, I am volunteering as an Association Visitor.



Marianne Morgan : My husband suffers with MND and I want to do all I can to help fundraise to find a cure for this disease.

Philippe Udrzal : I recently lost my wife of 30 years to MND and now volunteer to edit our local branch's **Newsletter**.



Liane Iles : I have worked in Social Care for 10 years, supporting carers and their loved ones. I now have been an **Association Visitor** for two years .



Carmen Brown : As an **Area Support Coordinator for the MNDA** I work closely with our amazing volunteer led branches and groups in supporting people affected by MND locally.



NEWSLETTER

We would like to thank Lisa Gallagher for editing the Newsletter for the past two years. Philippe Udrzal has now taken on this task.

YOUR CONTACTS

Sandy Lambert

sessexmnd.sel@gmail.com
07742 943472 01702 305759

Carmen Brown

Area Support coordinator
carmen.brown@mndassociation.org
01604 800659



mndconnect
0808 802 6262
mndconnect@mndassociation.org



@mndasessex



MNDA South Essex Branch