

Future of the Branch – new treasurer needed

In the last newsletter we appealed for a treasurer to follow Ivor who is standing down at our AGM in March. So far no one has come forward but it is not too late although time is of the essence.

If we have no treasurer we shall no longer be able to operate as a Branch.

This would mean becoming a Group with no control over how we spend our funds as all will be managed by National Office. At the moment we can provide a

wide range of equipment and financial support locally when it is needed but as a Group this would take much longer and be much more regulated.

We feel there must be someone among the friends and acquaintances of our newsletter recipients who could fulfil this role. Ivor would hand over most meticulous accounts and be ready with advice and support.

Please contact the Branch if you feel that this is something that you could help out with.

The life of the South Essex Branch

Fun evenings

We have a Chinese evening coming up at Zen City in Hamlet Court Road on 21 April. These are always occasions with very scrummy food and great raffle prizes so do come along, eat too much and enjoy an evening raising funds for us.

We hope to announce a Race Night soon organised by Hadleigh Castle Rotary Club. These are very enjoyable evenings and dinner is included in the price. More details will be forthcoming when a date has been fixed.

A proud tradition



fundraisers.

Year after year we have seen so many of you walk along the seafront and not only raise funds but also awareness. This two objectives are at the heart of the Association's activities.

Registration forms and information sheets are available from our website or contact Sandy 01702-712032 or email sessexmnd.sel@gmail.com

Walk to d'Feet is the jewel in our crown for fundraising and Sandy is the Queen of

Wonderful support

We are very grateful to The Grange Club and especially to Tony McAndrew who keeps MND to the forefront in their fundraising events.

We've had a huge donation from a social evening in October and we receive regular funds from their MND collection boxes.

Thanks go to everyone connected with the Club who have shown us some much generosity and support.

Fundraising news

Christmas lunches

For the first time we decided to arrange Christmas lunch for our people with MND, friends and Health and Social Care Professionals. Because of the geography of the Branch area no one venue seemed suitable or accessible for everyone.

After due consideration we found that the higher education colleges could accommodate us. This meant we had two venues, one in Thurrock and one in Southend. Each restaurant is called the Waves and all food and service is done by the students. Judging from the quality of the food, there are definitely some

budding Jamie Oliver's in the making there.

The food was delicious with choices to suit everyone and it was great to spend time with everyone at such a sociable and festive event.

We loved Jean's earrings and Ivor's jumper - see below along with a selection of other happy diners.

Ideally it would be our wish to host Christmas lunch at one central venue as it seems a pity that people in the extreme west of our area don't meet those in the east. We would welcome any suggestions.



For information, advice and support
MND Connect 08457-626262
Monday - Friday 9am - 5pm and 7pm - 10.30pm

DONATIONS & FUNDRAISING

	Donations
Mr & Mrs Seely.....	£30.00
Canvey Methodist Wives Club	£100.00
ZB News	£48.22
Joseph Genovesa	£120.00
Sheila Ball.....	£70.00
Charities Trust RBS matching.....	£250.00
David Noble (in mem)	£40.00
Hilary Barry (in mem).....	£40.00
JA Law	£500.00
Belfairs Pharmacy.....	£4.14
J & R Higginson	£25.00
Maureen Livings.....	£10.00
Southend Council re card sales	£96.00
Grange Club.....	£1,056.00
	Tribute Funds
J Webster and J Scowen	£749.34
	Fundraising
Walk to D'Feet latest total	£150.00
Sale of cards and puddings.....	£478.00
	Misc donations
Contributions to Thurrock lunch.....	£60.00
Contributions to Southend lunch	£176.00
Bank interest.....	£330.25

Grateful thanks to all donors and fundraisers



News from National Office

New report brings response from PM

The All-Party Parliamentary Group (APPG) on motor neurone disease (MND) has launched a new report, *Condemned to Silence*, showing the shocking truth about access to communication equipment for people living with MND. The NHS is failing people living with MND. This is totally unacceptable, and urgent action is needed.

Around 50 MPs were represented at the report launch

in Parliament, which is a fantastic result as it will help us to continue to raise the profile of our campaign 'Don't let me die without a voice'. Yesterday, we even had David Cameron MP respond to the report during Prime Minister's Questions. He said: 'I will certainly look at the report, and make sure that the proper meetings are held with the Department of Health so that everything we can do to support these people can be done.'

The 25th Symposium

Researchers chose our International Symposium to reveal the work done to create a diagnostic test for MND. They have found a potential trait for MND that can be detected in a blood sample. Importantly, the researchers have found that this biomarker increases with disease progression, making it an ideal marker for monitoring future clinical trials.

Researchers in this field are Dr Martin Turner, University of Oxford and Dr Andrea Malaspina whom many

of you will know from his clinic at Basildon Hospital. Dr Malaspina said that without the participation of people living with MND this research would not have been possible.

A full account of the symposium and updates on research and services are in the latest Thumbprint. This is free to members. People with MND can become members at no cost. For others, membership at £12 per year is excellent value.

Aims of the Association

- To provide care and support for people living with MND
- To promote scientific research and provide funding to specialists seeking to find treatments and ultimately a cure for this disease
- To speak on behalf of people with MND, demanding the best possible standards of care and campaigning locally and nationally
- To increase awareness of this disease

The Theory of Everything

This film has certainly put the spotlight on MND especially with Oscar and Bafta nominations for both the main stars Eddie Redmayne and Felicity Jones.

We are grateful to the Manager at the Odeon Southend for giving permission to collect after its showing there. The King John School motivated by the White family (particularly granddaughter Ella) covered the opening night and, as we are their charity of the year, this was part of their fundraising.

Interestingly, Benedict Cumberbatch, Association Ambassador, is also Oscar and Bafta nominated and we await with interest to see if his remarkable performance is recognised with these awards.

Keep up with the Association's latest celebrity news on Twitter @mndvipteam



Oscar contender? Eddie Redmayne as Professor Stephen Hawking

2015 meetings and speakers

Our next meeting is the AGM on March 16 and we are delighted that our guest speaker will be Chris Shaw, Professor of Neurology and Neurogenetics at Kings College Hospital – where some of you will have met him already. He is incredibly busy and lives on the other side of London so we hope we will have a good response to our invitations to the AGM. He is a charismatic and well-informed speaker and very interested in MND.

On May 18 Ray Gardner from REMAP will be our speaker. REMAP is a wonderful group who invent and adapt pieces of equipment suited to individual needs. They have made various gadgets and bits and pieces and this will be a fascinating talk.

On July 20 we will have Neil Penson from National Office coming to talk about the latest updated

news on care, research fundraising and the charity generally. Some of you may remember him from a previous visit and know that he is always interesting. Our numbers at St Luke's have been declining recently and while it can be difficult to come out in the evening especially when it is dark and cold hopefully numbers will increase in the brighter days ahead. Perhaps the renovations at St Luke's, when parking was difficult, put people off, but this has all been completed and parking is available as before. Us sae.

Dates for your diary

March 16	7.45 for 8pm AGM
	Salvation Army Centre
April 4.....	2.30–4pm drop-in
	Fair Havens
April 15	2–3.30pm drop-in
	Thurrock Garden Centre
May 5	2pm drop-in meeting
	Thurrock Garden Centre
May 17	Walk to d'Feet 10am
	behind Leigh station,
May 18.....	8–10pm open meeting
	St Luke's
June 5	2.30 drop-in meeting
	Stuart House
July 7	2pm drop-in
	Thurrock Garden Centre
July 20.....	8pm open meeting
	St Luke's

Venues

Salvation Army Centre
High Street, Hadleigh SS7 2PB

Fair Havens Day Room
Stuart House, Second Avenue
Westcliff-on-Sea SS9 8HZ

St Luke's Hospice
Nethermayne, Basildon SS16 5NJ

Thurrock Garden Centre
South Ockendon RM15 6DU

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
- St Luke's and Fair Havens hospices for their continuing care and hospitality
- Grant Flashman for printing and folding our newsletter

WHO'S WHO IN THE BRANCH

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MNDCONNECT@MNDASSOCIATION.ORG

MON – FRI. 9.00 AM – 5.00 PM AND
7.00 PM – 10.30 PM

WWW.FACEBOOK.COM/MNDASOUTHESSEX

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