

# South Essex Branch Newsletter February 2016

**President Dr Patricia Ahlquist MB ChB FRCP** 

**Registered Charity No.294354** 

www.mndsouthessex.org

# Oh yes we did!

Tollowing a donation from Grays Rotary specified to provide something special for people living with MND the committee decided to treat them to lunch at the Cliffs Pavilion in Westcliff with a matinee performance of their pantomime, Cinderella, on December 17.

The Cliffs did us proud on a fantastic meal, giving us the best seats in the restaurant, overlooking the estuary and plenty of room so wheelchairs were able to move easily. The panto itself was hilarious and

we all had a great time. Once again, many thanks to Grays Rotary who donated £1,000 to our group on the proviso we spent it on fun – it was certainly that.

It was wonderful to see this offer taken up by MND people from all parts of the Branch some of whom wouldn't have met before, as we have separate afternoon meetings in Westcliff and Thurrock and not everyone can attend the evening meeting in Basildon.

See selected photos from the great afternoon below











## **Chinese evening**

Join us on April 19 again at Zen City, Hamlet Court Rd, Westcliff for another evening where we are assured of excellent and bountiful food and most hospitable staff.



# **Fundraising news**

## **Christmas Fayre**

On 3 December Southend local businesses were also Council held a Christmas there. fayre in the Civic centre. A council choir sang carols for Sandy arranged for us to a lot of time and energy transporting books, bags, cards and puddings to it. Many other charities and

about an hour and although have a table there and spent sales for Sandy were slow it was an opportunity to create awareness of who we are and what we do.

# **Curry night**

On 20 October we had staff input were first another very enjoyable class. and profitable curry As usual the food meal at the Maharaja was excellent restaurant in Benfleet. As we have found before, the event was was very well attended and the service and

and we're already looking forward to this year's event! This will be on 18 October.

### **Craftable**

Craftable is a community group in Southend which meets every Wednesday from 1pm to 4pm and undertakes different craft works for people with long-term health conditions which make socialising difficult. Cost is £3.50 per week which includes refreshments and materials.

For more information contact visit their website at craftable@ outlook.com

#### **DONATIONS & FUNDRAISING**

	Donations
Southend BC	£10.89
Essex and Suffolk Water	£733.00
ZB News	£27.57
St Aidans Church	£100.00
Shoebury Model Railway	£275.70
Gill Gibson	
Rankin's Cricket Club	£120.00
Harrison's the Butcher	£23.45
G Trevelyan	£10.00
PA Stubbs	£10.00
	In Memoriam Donations
David Noble S/O	£60
	Tribute Funds
A Moon, J Scowen & B Storey	
A Moon, J Scowen & B Storey	
A Moon, J Scowen & B Storey	
A Moon, J Scowen & B Storey  Curry Evening	£2,540.00
Curry Evening Walk to D'Feet	£2,540.00  Fundraising £700.50 £1,761.70
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Curry Evening Walk to D'Feet	£2,540.00  Fundraising £700.50 £1,761.70
Curry Evening Walk to D'Feet Leigh Regatta Book sales	£2,540.00  Fundraising £700.50 £1,761.70 £170.00  Resale goods
Curry Evening Walk to D'Feet	£2,540.00  Fundraising £700.50 £1,761.70£170.00  Resale goods £1,115.40

Grateful thanks to all donors and fundraisers

## Hanningfield Sailability



If anyone is interested Hanningfield fisheries have a project called Sailability. It's run by disabled sailors who want to make it easier to sail the types of boats that have the stability and

ease of control for individuals to move in all conditions.

The reservoir at Hanningfield is ideal for this. Contact Chris Atkin at aceatkin@aol.com.

For anyone that hasn't visited the reservoir, it has a lovely café overlooking the waters and does one of the best breakfasts in the area. There always lots of hungry ducks waddling around and it's a peaceful beautiful place that's right on our doorstep. Visit their Facebook page at www.facebook.com/HanningfieldSailability.

#### 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

# Branch and BUncbU Office News

#### Formal Notification of South Essex AGM and call for nominations for the Committee

Our AGM this year will again be in the Salvation Army building in Hadleigh on March 16 at 8pm. You are all cordially invited to attend.

Members may put themselves forward for the committee which involves being nominated and seconded. If you feel you can help in this way then email Maura for a nomination form and further details maura@mndsouthessex.org

The AGM is usually on the third Monday in March but as the facilities were unavailable we have arranged to have it on Wednesday 16 March.

Our guest speaker will be Karen Pearce (pictured right) from National Office. Karen has kindly attended our AGM in the past and is always well received as a speaker. Hopefully the new NICE guidelines will have been published by the time of the AGM (just) and there should be some exciting news coming from that. As usual we will be providing light refreshments. Do come along and have a cake and chat and hear what the South Essex Branch is up to.

Karen qualified as a chartered Physiotherapist in 1978, and worked in the National Health Service in a variety of clinical and managerial roles for nearly 30 years. For five of these years she had the privilege of working solely with people with MND, whilst managing services across the community and acute hospital settings.

After gaining a MBA in 2008, Karen joined the MND Association in February 2010 as Director of Care (South) and feels very fortunate to be involved in an organisation with the ability to make such a difference for people with MND at local, regional and national

levels. She has responsibility for Regional Care Development Advisers, Association Visitors and the Care Centre programmes working closely with colleagues based at David Niven House to ensure consistent, quality care for all people affected by MND.



# **Our 2015 Symposium**

This was the 26th annual symposium – the largest scientific and medical conference specific to MND research. It attracted over 800 researchers and clinicians from 30 countries to Orlando Florida in December .Dr Gareth Miles from the University of St Andrews has a team working on growing motor neurones in a dish from stem cells to work out what goes wrong with them in MND.

Dr Rebecca Broad from the University of Sussex has been working on an imaging technique which looks at the density and organisation of parts of motor neurone cells, called neurites, within the brain tissue of people with MND. This could be a biomarker of the future. The Association is funding Rebecca's research and part of Gareth's.

The Symposium is the place for collaborations between laboratories across countries and even continents. It also pulls together the next generation of researchers and clinicians who are able to gain so much from their more experienced peers.

# Model talker

**Sue Nash** tells us a little about a new software package that might help people living with MND to communicate.

Model talker® is an American software package aimed at people with MND. It comprises software that records your voice and various phrases and sentences you would normally use (and I'm guessing a few swear words are included!)

One of our group is currently trialling it and has given really positive feedback. A headset needs to be purchased which is £35.00. The company do not however charge people with MND for the service they provide.

It can be time consuming – they recommend 1600 sentences be pre-recorded and the acoustics need to be correct for it to work. Our man in the know has suggested that a duvet over the head cuts out the background noise wonderfully. The downside is it can get a little warm!

I have asked for action photos and will keep you posted. He has recorded 550 sentences so far and it has taken him 3 hours. Our duvet man as I like to refer to him - has kindly offered to

help people in the locality to set this up which is fantastic. Details can be found on their website at www.modeltalker. org



# 2016 meetings and events

# **Dates for your diary**

March 1	2-3.30pm drop-in
Water I	Thurrock Garden Centre
March 16	7.45 for 8pm AGM
Water 10	Salvation Army Centre
Δnril 1	2.30–4pm drop-in
πριπ ±	Fair Havens
April 19	
	Zen City, Hamlet Court Road
	2-3.30pm drop-in
	Thurrock Garden Centre
May 15	WALK TO D'FEET
	8–10pm open meeting
, =-	St Luke's
June 3	2.30-4pm drop-in
	Fair Havens
July 5	2pm drop-in
	Thurrock Garden Centre
July 18	8pm open meeting
	St Luke's
August 5	2.20-4pm drop-in
	Fair Havens
September 6	2–3.30pm drop-in
	Thurrock Garden Centre
September 19	8–10pm open meeting,
	St Luke's
October 7	2.30-4pm drop-in
	Fair Havens
November 1	2-3.30pm drop-in
	Thurrock Garden Centre
November 21	8-10pm open
	meeting
	St Luke's
December 2	
	Fair Havens

#### Venues

**Salvation Army Centre** High Street, Hadleigh SS7 2PB

Fair Havens Day Room **Stuart House, Second Avenue** Westcliff-on-Sea SS0 8HZ

St Luke's Hospice Nethermayne, Basildon SS16 5NJ

**Thurrock Garden Centre** South Ockendon RM15 6DU

#### Walk to d'feet 2016

This year's walk will be on Sunday May 15 again along the seafront starting at the seawall behind Leigh Station 9 40 for 10.00am

It's a great day out with many stops for refreshments along the route. The total distance is 10 miles but any distance under that is acceptable. In the past we've had families, babies in pushchairs, dogs, anything goes!

For sponsor forms and further details email Sue.Nash@ pinneytalfourd.co.uk or sharon050680@gmail.com as Sandy (main organiser) will be away until 9 March although she hopes to attend the AGM.

#### 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

#### THE COMMITTEE

CHAIR
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VICE CHAIR
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TWITTER: @MNDASSOC

**REGIONAL CARE & DEVELOPMENT ADVISER** 

Liz Pybus...... 08453-751840