

## **South Essex Branch Newsletter May 2016**

**President Dr Patricia Ahlquist MB ChB FRCP** 

**Registered Charity No.294354** 

www.mndsouthessex.org

# **Honour for Sandy at AGM**

K Y held our AGM in The Salvation Army building, Hadleigh on March 16.

Our guest speaker, Karen Pearce from National Office certainly did not disappoint. She gave a very interesting presentation on the latest developments from the Association, the most topical being the guidelines from NICE. This is the National Institute for

Health and Care Excellence which provides advice on cost-effective healthcare to the NHS and those who use it.

The guideline sets out best practice of care for people with MND from referral and support at diagnosis through to the on-going management of symptoms. It uses a joined-up approach where different specialists work together to improve overall quality of life and awareness of the varying

This has come about after more than four years of campaigning by the association and will shape future care and influence the quality of life for people living with this disease.

Karen also spoke about the wheelchair service and how important it is to have the need for a wheelchair assessed by a health professional.

> She chatted to many of the attendees and answered questions about individual needs after the main talk over refreshments.

Sandy received a long service award and no one is more deserving, for her efficiency, time-giving and care for others is exemplary.

Sandy receiving her long service award from Karen Pearce



and changing needs of people living with MND.

### Walk to d'feet 2016

It is not too late to sign up for our sponsored walk and annual fun day out on Sunday May 15.

We would love this to be the biggest and best yet. If you fancy a nice leisurely stroll along the seafront, a mad full speed run or a waddle to the pub please come and join us.

We need you to sign up first and once you're registered, we can get sponsorship forms and T- shirts out to you. With a couple of weeks to go, numbers are looking good. Please help us to make it the biggest and best walk yet. Registration forms can be found on our website or ring Sandy on 01702-305759.

This is our main fundraising event and generates a lot of camaradie and enjoyment as people proceed along the seafront with its many attractions and activities.

## **Fundraising news**



Enjoying the band -Gill and Jerry Gibson and Sue



And enjoying the band!

# Trolley Boys sell out for MNDA

Saturday 16th April saw Sue and Sandy attend Sweyne School in Rayleigh for a charity concert. The Trolley Boys put on a sell-out gig with all proceeds going to MND.

Over 250 people were there and everyone had a great time dancing and singing to some real classic songs. The final amount hasn't been counted yet but it's going to be in excess of £2,500.00 - again massive thanks to everyone for organising it, playing it and dancing it!

### Thank you WI!

Sue attended the Westcliff Women's Institute and collected a cheque for a whopping £2,703.13. Absolutely fantastic so thank you ladies for your hard work in fundraising over the last 12 months!

#### **DONATIONS & FUNDRAISING**

	Donations
Essex and Suffolk water	£830.00
David Watts	£25.00
Cash found by Kevin at 2015 WTDF	£10.00
PA Stubbs	£20.00
G Trevelyan	£50.00
Angela Gambling	£50.00
Caroline Hendey	£40.00
	In memoriam
David Noble	£40.00
Hilary Barry	£40.00
Keith Prince (re Iris)	£150.00
	Fundraising
NO Credit for 2015 WTDF	£80.00
	Tribute Funds
Terry McGregor	915.00

Grateful thanks to all donors and fundraisers

### Water cycle triumph!

This is Lewis Banks (part of the Essex and Suffolk Water team) who completed a 30 mile cycle ride for the South Essex branch. Thanks to all the riders!



#### 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 news**

### And it's goodbye from him! (and hello to him!)

Ivor sums up his feelings as he takes his leave from the Branch:

'Finally I have retired as your Treasurer.

It has been a very rewarding time for me over the last 21 years. I have met some wonderful people and been involved in all sorts of activities that I never expected. I have enjoyed my time producing the accounts and being part of a committee who gave me great support and friendship.

Thanks must go to all those people who supported the branch and sent donations without which we could not exist. I am handing over the reins to Rowan Harvey who, I know, will enjoy the support I have had.

My good wishes to everyone, I shall miss you.'

As we say au revoir and many thanks to Ivor for his dedication and reliability, we extend a very warm welcome to Rowan who is already a great friend, along with his family, to the Branch.

#### Sue shares her thoughts with us:

We would like to welcome Rowan to our team as Treasurer. Ivor finally retired this year after trying to for over a year. In true Ivor the Trouper style, he wouldn't leave until we were in the safe hands of a new and able treasurer. Enter Rowan.

Rowan has been in post for just a few weeks but his cheerfulness and willing to roll up his sleeves and pitch in is fantastic. Even if he did nick all the chocolate biscuits at the last committee meeting. Welcome on board Rowan and here's to a healthy balance sheet!

### Fair Havens meeting

This was one of our drop-in meetings in Stuart House, Westcliff and we had a great response to the invitations to it. It was good to see so many sharing news and views.

Dr Pat Ahlquist looked in, despite her heavy workload and stayed to talk to all the MND people.

The next drop-in will be in the Garden Centre, Thurrock on May 2 and our next Branch open meeting will be on May 16 at St Luke's Basildon.

#### **MND** Awareness Month

June is MND awareness month and will see posters appearing at national railway stations and on the underground. Last year's poster girl (with the blue hair) was outstanding. Let's hope more awareness is raised nationally!

### How you can help - Email or snail mail

To all of you who now receive the newsletter by email – our greatest gratitude.

If anyone else would be willing to receive it by email it would help us greatly by reducing postage and stationery costs. It also means that it can be sent simultaneously as it goes to Grant for printing, about a week sooner than the posted ones.

Hard copies of the newsletter will always be available at our meetings and events. Just let Maura know on maura@mndsouthessex.org

### You couldn't make it up!

Hadleigh Castle Rotary club are hosting an evening of all new preposterous stories on the 21st May at 7.00pm. This is being held at St Peters Church hall Thundersley.

Tickets are only £8.00 and includes a fish chicken or pie dinner. How bad is that?

MND will be one of the three charities that benefit from this evening. For tickets please contact Mike Jones on mdjessex@btinternet.com

Rotary have been great supporters of us over the years so it would be nice to support them.

### **Charity of the Year**

Pinney Talfourd LLP Solicitors have adopted us as their charity of the Year (Sue the chairman is a lawyer there) They have a year of events planned included a sponsored 100 mile cycle ride, dress down days, cake days (always popular) balloon race, Christmas carol concerts and the like.

The partners will be donating £1 for every client satisfaction survey completed and returned. Follow the events and fund raising on www.pinneytalfourd.co.uk/ charityoftheyear

### 2016 meetings and events

### **Spring conference**

Some people from our Branch attended the MND spring conference at the Crowne Plaza Hotel, Gatwick. If you were unable to attend you can watch it live via our livestream service at:

www.livestream.com/eventstreamingcompany/mnda

Previous regional conferences can also be viewed here.

### **Dates for your diary**

May 15	WALK TO D'FEET
May 16	8–10pm open meeting
Speaker John Wilk	es, Regional Area Manager
	St Luke's
June 3	2.30-4pm drop-in
	Fair Havens
	2-4pm drop-in
	Thurrock Garden Centre
July 18	8–10pm open meeting
	St Luke's
August 5	2.30-4pm 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	2.30-4pm drop-in
	Fair Havens

#### **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

#### AGM and annual conference

The AGM and annual conference is taking place on the 10th September at the Radisson Blu hotel at East Midlands airport. We presume it will be live streamed again but watch this space for details.

### Keeping up to date

MND have published some new leaflets which you may find useful. They include the MND checklist, your rights to social care, support for you and understanding my needs. They can be downloaded at www.mndassociation.org/publications.

#### **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

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MON – FRI. 9.00 AM – 5.00 PM AND

7.00 PM – 10.30 PM

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