

## Walk to d'Feet 2015

**M**any thanks to those who joined us on our annual Walk to D'feet. We had 153 walkers on the day and we were blessed that the sun shone throughout. A massive thank you to Stuart Bingham who agreed to lead off the walk with his world snooker trophy. As Stuart had only won this a few days before it was fresh in everyone's mind and he certainly attracted a lot of attention. He also generated a lot of contributions en route keeping in touch with his followers on social media.

It was great to see the healthcare professionals, including Dr Pat our President, field a team. The MND nurses are a lovely bunch and are always so supportive in everything we do.

Big thanks also to the Westcliff Women's Institute who took part and who have chosen us as their charity of the year as has Ella's form at King John School. Thanks also to the families who year after year support us and put out teams of friends, families, neighbours and the like. You are awesome!

The sponsorship money is trickling in. Don't forget we would like this by August 10 please. If you are able to gift aid, please do. For every pound you raise we can claim back another 25p from the government and who can object to that?

Thanks as ever to Adventure Island for sponsoring the water stop again; we certainly needed it this year. Our

gratitude also goes to Cheryl Hindle at Southend Council for suspending the parking charges and to Mike and his wife from Hadleigh rotary.

They did a wonderful job getting everyone parked neatly and taking donations from the boot sale bargain hunters who were using the car park.

This issue of the newsletter is dedicated to another

hugely successful walk – see the photos below and on page 3. There are more photos on our website and on our Facebook page.



# Fundraising news

## Generous Grays Rotary – oh yes they are!

We are delighted to announce that Grays rotary club have given us £1,000 with the condition that we spend it on something fun – what a fantastic condition! After much debate we have decided to combine our Christmas lunches into one venue and combine it with a panto!

Cliffs Pavillion in Southend is showing Cinderella and we will be using the money to pay for a two course Christmas lunch in the restaurant followed by panto tickets for a matinee show. Logistically this may be difficult so we do need your help. We will pay for a person with MND and their carer.

If you would like to bring along others please do so but you/they will be responsible for payment. If you need to have your carer with you the Cliffs has a disability access scheme that you need to register for and then

the carer gets a free ticket so if this includes you let us know and we will send you the forms to register.

We don't as yet have a date – it's likely to be a weekday and definitely a matinee. Once we have numbers we can book. We can have 11 wheelchair places so hopefully there will be room for all who want to attend. Please do come and join us for a lighthearted fun afternoon.

This does need to be booked asap so please let us know by August 30 so it can be booked on 1 September. If you have any dates you can't do please let us know and we will try to accommodate. We are going to be dependent on when the Cliffs Pavilion to fit us in and numbers so please please let us know asap.

**Contacts: Sue 01702-480806; Sandy 01702-712032; Maura 01702-478661.**

**mndconnect**  
03457 626262  
mndconnect@mndassociation.org

MND Connect has a new number – see left. Calls will cost less than the old number and the Association aims to lead on to a freephone number soon.

### Westcliff WI quiz night

Some of the committee and friends attended a quiz night organized by the Westcliff WI as part of their fundraising activities for our charity. This was held in the Windsor Suite, Westcliff Hotel – a great venue as it accommodated over 12 tables and has excellent facilities.

Thanks to all at the WI who made everyone welcome and created an atmosphere of fun and humour adding to the success of the evening.



### DONATIONS & FUNDRAISING

#### Donations

David Noble .....	£60.00
Cupids Country Club tin .....	£1.28
ZB News tin.....	£33.05
Church Rd Vange supermarket tin.....	£2.96
Derix Pharmacy tin.....	£47.92
Liverpool Victoria CAF voucher.....	£500.00
P A Stubbs .....	£30.00
Concord Ladies Club.....	£150.00
Lloyds Bank Southend tin.....	£1.81
Mary Fry .....	£20.00
Maura Irwin .....	£11.60
Miss Snelling .....	£20.00
Gillian Trevelyan .....	£10.00

#### Tribute Funds

Moon & Scowen .....	£1,453.86
Beverley Storey.....	£85.00

#### Fundraising

Chinese Meal Zen City .....	£844.20
Walk to d'Feet.....	£3,990.17

Grateful thanks to all donors and fundraisers

### 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

# 2015 Walk to d'Feet



## A walk for all

Congratulations to our fabulous walkers – young and old, tall and small, two-legged and four-legged!

Thank you for your amazing effort.



## Research Update

### Mirocals

We are backing a new clinical trial, known as MIROCALS which will aim to start recruiting 216 people living with MND in the UK and France in autumn 2016. The Modifying Immune Response and Outcomes in Amyotrophic Lateral Sclerosis (Mirocals) study will aim to investigate existing drug interleukin-2 as a potential new treatment for MND. It is a joint clinical trial between France and the UK, which consists of €1.5 million funding from the French government, €6 million funding and €0.5 million under consideration from the MND Association.

Interleukin-2 has been used for many years to treat cancer, however at low doses it is much safer but still effective against a number of immunological diseases. Because the immune system is involved in causing damage in MND, the researchers believe it could be beneficial in MND too.

The two scientists behind this project are renowned MND researchers Professor Nigel Leigh (Brighton and Sussex Medical School) and Dr Gilbert Bensimon (Hopital Pitie –Salpetriere, Paris).

Professor Leigh and Dr Bensimon will begin working on the essential groundwork from September 2015 before the trial can begin recruiting participants in autumn 2016.

More Information on our MND Research blog: [www.mndresearch.wordpress.com/tag/mirocals](http://www.mndresearch.wordpress.com/tag/mirocals)

### Oxidation resistance 1 - tackling oxidative stress

The Association-funded researchers Professor Dame Kay Davies and Dr Peter Oliver, both based at the University of Oxford, have identified the oxidation resistance 1 (OXR 1) gene as a neuroprotective factor in MND.

Published in the journal Brain on 9 March 2015, Prof Davies has shown through their recent research in mice that OXR1 may serve a new target for future drug development.

# Events, News and Contacts

## CAMRA

I am very happy to report that CAMRA – the campaign for real ale have also chosen us as their charity. They have a beer festival every year in November at the Freight House in Rochford.

Beer is bought by way of tokens and at the end of the evening there is a barrel for the spare tokens which go to charity. That's us this year!

CAMRA were very keen on the money going to local people so we will make sure it's spent where it is needed. Now if you ever needed an excuse to go out drinking for the evening you now have it!



## The MND Charter

On 16 June our Chief Executive Sally Light, patron and ITV presenter Charlotte Hawkins and a group of committed campaigners handed in to 10 Downing St., the Charter with 33630 signatures.

Thank you to everyone who signed the Charter which calls for the right care in the right place at the right time for all people with MND and their carers.

### 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](http://www.mndsouthessex.org)
- St Luke's and Fair Havens hospices for their continuing care and hospitality
- Grant Flashman for printing and folding our newsletter

## Storage space needed

If you have any space in a garage, shed etc, where some MND boxes and such could be stored and accessed when necessary, this would assist our Branch greatly.

Contact Sandy 01702-712032 if you can help.

## WHO'S WHO IN THE BRANCH

### THE COMMITTEE

#### CHAIR

SUE NASH..... 01702-480806

#### VICE CHAIR

SANDY LAMBERT..... 01702-712032

#### SECRETARY

SHARON CLARK .....01702 -479219

#### TREASURER

IVOR JENKINS..... 01702-547517

#### PUBLICITY

KEVIN WATTS..... 01268-572787

#### ASSOCIATION VISITORS

LERE AKINYEMI..... 01375-377729

DENISE CALDER..... 01702-557859

MAURA IRWIN..... 01702-478661

SANDY LAMBERT..... 01702-712032

#### BRANCH CONTACT

MAURA IRWIN..... 01702-478661

#### REGIONAL CARE & DEVELOPMENT ADVISER

LIZ PYBUS..... 0345-375 1840

MND CONNECT 03457-626262

[MNDCONNECT@MNDASSOCIATION.ORG](mailto:MNDCONNECT@MNDASSOCIATION.ORG)

MON – FRI. 9.00 AM – 5.00 PM AND

7.00 PM – 10.30 PM

[WWW.FACEBOOK.COM/MNDASOUTHESSEX](http://WWW.FACEBOOK.COM/MNDASOUTHESSEX)

TWITTER: @MNDAESSEX

## Dates for your diary

August 7.....2.30 drop-in meeting

Stuart House

September 1.....2pm drop-in

Thurrock Garden Centre

September 21 .....8-10pm open meeting, St Luke's

### Venues

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