

## Professor Shaw at the AGM

Our AGM on March 15 was an unqualified success, thanks to the committee and the guest speaker. Professor Chris Shaw, director of the Department for Clinical Neuroscience at Kings College Hospital, gave a superb presentation on his work in MND research and his hopes for the future.

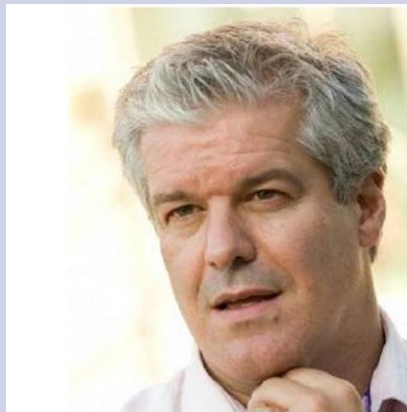
He spoke about two proteins TDP 43 and FUS which have mutations in people with MND, and there is worldwide research in analysing these.

There is now great interest in cell biology and at Kings they use Sanger Sequencing to read this data. In 2000 the first draft of the human genome was produced (one person's genome) taking 15 years and costing £200 million. Now, the same research can be done in less than a week and costs £2000.

Colleagues of Professor Shaw are modelling the disease in fruit flies and zebra fish and he is working with mice.

'We really want to discover drugs that are effective and having these cell lines helps us screen hundreds of thousands of compounds and take the very best of those to our fruit flies, zebra fish and mice to see whether we inhibit or reverse the disease process.

There is nothing about motor neurone disease that makes me think that it is going to be incurable. A lot of the clues will come from genetics, but we really need to work this into intercellular models and undertake complex drug screening before we can really make a difference.'



Professor Chris Shaw, King's College

After the talk we broke for excellent refreshments provided by Sharon and time to mingle.

Then we had the formal AGM chaired brilliantly by Sue who welcomed everyone with special appreciation for our President Dr Pat Ahlquist who gave us time in her very busy schedule to attend. We also had two of our health professionals who are very committed to the needs of our people with MND

Ivor gave his finance report tinged with sadness as this was his last AGM as treasurer. Kevin Watts paid tribute to Ivor, on behalf of the committee, sentiments echoed by all who have known him, and Sheila Ball spoke on behalf of the patients and carers.

Thanks to all who attended, especially our people living with MND and those who made long journeys or had to make special family arrangements.

## Walk to d'feet 2015



There is still time to register for our Walk to D'Feet on 17 May.

What could be better than a walk along the seafront with its many shops, cafes and attractions to make it more enjoyable.

Registration forms and information sheets are available from our website [www.mndsouthessex.org](http://www.mndsouthessex.org) or contact Sandy 01702712032 or email [sessexmnd.sel@gmail.com](mailto:sessexmnd.sel@gmail.com)

# Fundraising news

## Westcliff-on-Sea Women's Institute

Sally Ann Manthorp, the fundraiser on the committee of the Westcliff-on-Sea WI has put MND forward as one of the charities to choose from to support this year.

They had their AGM last week and Sally Ann commented:

'I am delighted to announce that MND won the majority vote. 50 per cent of all funds raised from now until this time next year will now donated to MND. I run a raffle

each month at our meetings and we have various fundraisers throughout the year.'

See page 4 for details of a WI event - a gala quiz night at the Westcliff hotel on Thursday 4 June.



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

### DONATIONS & FUNDRAISING

	Donations
Grange Club.....	£147.43
Ann Broom Coffee mornings .....	£700.00
Maura Irwin .....	£25.00
Vision Pharmacy.....	£44.15
Janet Tundervary.....	£136.31
Sale of diary.....	£5.00
Anne Watts .....	£19.13
DJ Watts .....	£25.00
ZB News.....	£41.50
Hilary Barry .....	£80.00
In mem R Griffiths .....	£450.00
David Noble .....	£60.00
In mem John Robertson .....	£436.00
In mem Emily Hornsby .....	£78.40
Angela Gambling Billericay Church Gp .....	£78.40
Harrisons Butchers .....	£34.65
James Cobbins .....	£50.00
Carol Cowling.....	£10.00

	Tribute Funds
Alex Moon .....	£20.00

	Misc donations
Gift Aid .....	£563.75
Bank interest.....	£58.89
Cancellation of duplication ac.....	£1,500.00

Grateful thanks to all donors and fundraisers

## Murder Mystery Evening

### Friday 15<sup>th</sup> May

@Gateway academy  
Marshfoot Road,  
Tilbury,  
Essex  
RM16 4LU

*An evening of murder mystery where you get to play detective, solve the crime and unmask the killer*

TICKETS £10 EACH BRING YOUR OWN FOOD AND DRINK

07479245053

WWW.GATEWAYMURDER.COM

GATEWAYMURDER@GMAIL.COM

8PM START

DOORS OPEN AT 7:30PM

### 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

# News from National Office

## Improving wheelchair services

Wheelchair provision is an ongoing process which is constantly reviewed and being improved.

The association has received funding from the Department of Health from a three year grant.

This also funds wheelchair therapist Jenny Rolfe at our MND Care and Research Centre in Oxford, and Christine Orr at Seacroft Hospital, Leeds.

The government grant has also funded work to develop four new powered wheelchairs designed to meet the changing needs of people with MND.

Karen Pearce, our Director of Care (South) said, 'Our prescription meets the needs of 80 per cent of people with MND who need a wheelchair. It is absolutely not our role to replace statutory provision, but we are working with the Department of Health and NHS England to make sure commissioners are aware of the needs of people with MND.'

Referrals to our wheelchair services are made by Association staff and volunteers, our MND care centres, NHS wheelchair services and individuals may self refer.

## Project MinE

Thanks to astonishing advances in genetic research, MND is running out of places to hide.

Recent discoveries mean that we now know about 60 per cent of the factors that cause the rare inherited form of the disease. But the majority of cases of MND, sometimes known as sporadic MND, still remain a mystery.

With your help, Project MinE could change all that.

This unique international collaboration aims to further identify more of the rarer predisposing genetic factors involved in the disease, develop effective treatments and to ultimately find a cure.

Project MinE will see research teams across 14 countries systematically analysing the genetic profiles of 22,500 people, 15,000 of whom have the sporadic form of MND and the remaining 7,500 are control samples from people without the disease. These researchers will be scrutinising the samples, looking for the genetic mutations – particular patterns of DNA code – that are shared by people with MND.

We need your support.

Thanks to the huge surge of support during last year's Ice Bucket Challenge we have been able to commit to sequence the total of 1,700 patient samples from our DNA Bank. But we urgently need your help to sequence a further 300 samples available from various other UK Banks at a cost of

£1,000 per sample.

.Each DNA sample contains 3 billion letters of genetic code arranged across 23 pairs of chromosomes. A gift from you will enable researchers to sequence a chromosome pair from a DNA sample and help develop effective treatments.

Please take this BIG opportunity – make a donation in support of a unique research study with MASSIVE potential. Every single penny you give in response to this appeal will go directly to fund Project MinE.

Be part of something big. Be part of Project MinE.

### Project MinE at a glance:



# Events and Contacts

## Race Night

Following the Walk to D'Feet our next main event is a Race Night in St Peter's Church Hall, Thundersley. We hope to see as many of you as possible there. This is thanks to Hadleigh Castle Rotary Club and dinner is included in the price.



## Gala Quiz Night

Come along to the Westcliff Hotel on Thursday 4 June to enjoy a great evening fundraising for MNDA and Westcliff-on-Sea Women's Institute.

The quiz starts at 7.30pm and will take place in the Windsor Suite.

Entry is £30 per table with up to eight people permissible on each team. There will be great prizes and a raffle and even a trophy for the winners.

### 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

## Dates for your diary

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 Speaker Ray Gardner, REMAP
May 30 .....	Race Night St Peter's Hall, Thundersley
June 4 .....	Quiz evening 7.30pm-10.30pm Westcliff Hotel
June 5 .....	2.30 drop-in meeting Stuart House
July 7 .....	2pm drop-in Thurrock Garden Centre
July 20.....	8-10pm open meeting, St Luke's Speaker Neil Penon, National Office

### Venues

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

Windsor Suite, Westcliff Hotel  
Westcliff Parade SS0 7QW

## WHO'S WHO IN THE BRANCH

### THE COMMITTEE

#### CHAIR

SUE NASH..... 01702-480806

#### VICE CHAIR

SANDY LAMBERT..... 01702-712032

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IVOR JENKINS..... 01702-547517

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MND CONNECT 08457-626262

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