

Old Leigh Regatta

We had a very enjoyable day at the Old Leigh Regatta with full credit to Sandy who arranged a slot for the Branch at this family event.

Graham and Pat White and friends came to help and support in the morning. The star of the show was undoubtedly their granddaughter Ella who brought a selection of children's books. She was very persuasive in the most charming way in advising on suitability and persuading people to buy.

There was further support from Sharon and her family later in the day.

It was also an opportunity to create more awareness of MND and tell people about the Branch. Sandy summed up the event: 'Well folks, I think that was a long, but successful day.'

'It raised awareness very well - over 200 charter cards completed and some 270 balloons given out.

£45.80 of Christmas puddings were sold and £199.45 taken from the sale of books, DVDs, other sundry items and donations.

'Local MP David Amess spent quite a long time talking to us and was very interested in our work. He asked for more information on the problems we have getting the health service commissioners to fund the £50 to supply suction machines. We are hopeful



Pat and Graham White with friends including Ella and Sandy

that his influence might pay off!

'The weather was kind and Sharon and I were helped by a very good team of volunteers.'

Thanks go to everyone involved!



A colourful customer

Walk to d'feet 2015



Even though this year's event is fresh in the memory, we have a date for the 2015 Walk to d'feet. This will be held on Sunday 17th May.

Please put this date in your 2015 diary as soon as you get it. Information sheets and registration forms will be available to download by the end of January.

Festive greetings

We hope to see as many of you as possible at the Christmas lunches in Grays and Southend and hope to include some photos from these events in the first newsletter of the New Year.

We extend best wishes to all our Branch supporters over Christmas and for 2015.

Fundraising news

Curry Night

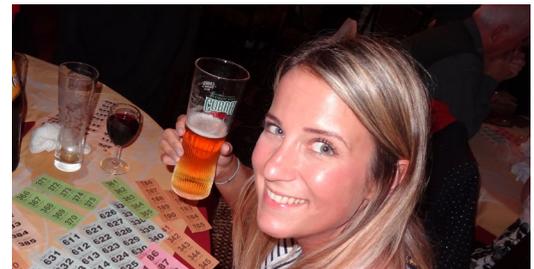
Our recent curry night at the Maharaja Restaurant in Benfleet was a huge success once again. In total 82 people (which included a number of children) generated a profit of well over £800.

The staff were, as ever, most helpful and provided excellent service. Thanks to all those who attended and those who helped on the night.

See right for a selection of photos from this thoroughly enjoyable evening!



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



DONATIONS & FUNDRAISING

| | Donations |
|-------------------------------------|----------------------|
| Jennifer Barry coffee mornings..... | £ 120.19 |
| Garden Party..... | £104.70 |
| In mem Amy Brabner | £21.77 |
| David Noble | £40.00 |
| Sheila Ball..... | £115.00 |
| Sir Francis Drake Lodge L4240 | £100.00 |
| Benfleet Motor Boat..... | £83.74 |
| MB Power..... | £241.84 |
| Sale of Foreign Money | £1.00 |
| Peter Pack friend's event..... | £20.00 |
| Belle Fabrics | £36.85 |
| 4 X in Memoriam..... | £100.00 |
| Iris Club | £500.00 |
| Spa Renaissance | £52.32 |
| Ice Bucket (Pateman) | £20.00 |
| Derix Pharmacy | £104.19 |
| | Tribute Funds |
| Terry McGregor..... | £50.00 |
| Bev Storey and Alex Moon | £748.15 |
| | Fundraising |
| Walk to D'Feet latest total | £14,391.75 |
| Ice Bucket Challenge | £226.31 |
| Curry Evening | £823.00 |
| Sale of cards and puddings..... | £500.00 |
| | Gift Aid |
| National Office..... | £330.25 |

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

News from National Office

Research news – developing existing drugs

One of our PhD students, Victoria Pugh (Universities of Bradford and Reading) is testing new versions of riluzole. Her research involves investigating a number of slightly modified versions of the drug (known as derivatives) testing them for their ability to protect motor neurones, and further modifying the most promising.

Miss Pugh said, 'Riluzole has many undesirable side

effects and we still do not fully understand exactly how the drug works. By only slightly modifying the original structure of riluzole the aim is to generate improved versions of the drug.

We hope the new versions of the drug will have a greater effect at halting the progression of MND, therefore being a better treatment against motor neurone loss.'

Don't let me die without a voice

Last month we launched our General Election campaign to ensure that people living with MND get the communication support they need.

Over 1,000 people have already taken action. This is fantastic! Thank you to everyone who has joined the campaign. But we still need your help

There's still time to submit evidence to the All-Party Parliamentary Group (APPG) on MND's inquiry into communication support for people with MND. The Group will publish a report from the inquiry in early 2015. This is a great opportunity for anyone who had experience of accessing communication support to share their story.

The APPG wants to hear from people with MND, carers, family members and professionals about their experiences of accessing communication support.

An online survey is open to help people share their experiences and takes 5–10 minutes to complete. Please help us promote this survey and encourage people to submit their stories

You can visit mndassociation.org/appginquiry to complete the survey online or download paper copies.

Contact the campaigns team by email at campaigns@mndassociation.org if you need support.

Please add your voice.

New film on Professor Hawking

You may have recently heard about a new film called 'The Theory of Everything', which is due out early next year.

The film is based on the diaries of Professor Stephen Hawking's first wife Jane, and covers their life from meeting at university until the break-up of their marriage. The couple are played by leading young British actors Eddie Redmayne and Felicity Jones. The film has already been touted as a possible contender for the 2015 Oscars.

As part of their research, Eddie and Felicity met people living with MND and their carers, supported by the North London and North West London Branches.

The film will raise awareness of MND, and our work. Since July 2013 we have been liaising with the film company, the Hawking family and, through the North London Branch, with Eddie and Felicity to see how MND can link in with the film.

The UK premiere is expected to take place in London on Tuesday 9 December and Britain's second biggest cinema chain, Cineworld, has given permission for Branches to hold bucket collections in any of their cinemas on Friday 2 January, the opening night of the film's general release.



Oscar contender? Eddie Redmayne as Prof Stephen Hawking

Treasurer Hunt

Ivor Jenkins, our much valued Treasurer and friend, will be standing down from the Committee at the next AGM (April 2015) after 20 years of service to the South Essex Branch. We are keen to find a new Treasurer as soon as possible so that they can benefit from a handover period with Ivor.

If you are computer literate with book-keeping skills, would be able to attend one Committee meeting a month, (usually on the second Wednesday), and would like to fill an essential role in enabling the

Branch to support those living with MND, we would be very pleased to hear from you.

Please contact Ivor for a 'no obligation' chat about what the role entails on 01702 547517. If you would like to come along to a Committee meeting to learn more please let him know.

For general information about how you can support the MND as a volunteer see their website at <http://www.mndassociation.org/get-involved>.

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

Late newsletter

Once again, sincere apologies for the lateness of this newsletter.

A local power surge caused the computer to malfunction and it took much longer than expected to locate the issue.

We hope to be much more on time with all newsletters next year!

Dates for your diary

Friday 12th December Christmas Lunch (12.30)
Waves
Thurrock Campus,
Woodview,
Grays RM16 2YR

Friday 19th December Christmas Lunch (12.30)
Waves,
Luker Road,
Southend SS1 1ND

Sunday 17th May 2015 Walk to D'Feet MND
Please put this date in your 2015 diary as soon as you get it. Information Sheets and Registration Forms will be available to download here by the end of January.

2015 meetings to be confirmed

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

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LERE AKINYEMI 01375-377729

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MAURA IRWIN 01702-478661

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REGIONAL CARE & DEVELOPMENT ADVISER

LIZ PYBUS 08453-751840

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

TWITTER: @MNDASSOC