

New President

It is a great privilege for the Branch to welcome Dr Patricia Ahlquist who has agreed to be our President despite her busy work schedule. Dr Pat is the lead consultant at Fair Havens hospice, specialising in

palliative care.

Many of our people living with MND have experienced her care and sensitivity both at the hospice and in their own homes.

Running Mates

You may remember Sam Wall who ran the Barcelona Marathon.

Sam has not rested on his laurels but has continued organising events for the Branch. Since the marathon he has organised a meal for family and friends raising well over £1,000. He is currently planning his next marathon and is indefatigable in his fundraising efforts for us, ably supported by his girlfriend Jessie Calder.

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Another generous supporter is James Knight who, on Sunday October 20 ran a half marathon in Amsterdam having not run any long distances before. Before the event, James gave this account of the challenge ahead:

'Training for this run is the first time I have run on actual streets. Sure, I've kicked a football a few times. Sure, I've walked round a golf course. But I have never gone for a jog out of enjoyment. The thought perturbs me.

So training for (and hopefully completing) this run will be somewhat of a personal achievement. I imagine I will feel similar pride as the time I swam my first 10 metre length of the school swimming pool and got a badge sewn to my towel.'

Well as you can see from the photo James completed the race and the Branch would like to thank him for this terrific achievement. You can donate to James on his Justgiving page at www.justgiving.com/james-knight9



James at the finishing line in Amsterdam

Memorial Evening Cancellation

It is with regret that we have been forced to cancel this November's Memorial Evening due to issues with the venue. Sharon hopes to reintroduce the event next year, and if anyone has any suggestions about where it can be held please contact her on 01702-479219. We apologise for any disappointment this has caused.

Fundraising News

DONATIONS & FUNDRAISING

Donations

David Noble	£60.00
Hilary Barry	£40.00
Lucie Coath coffee Morning	£101.35
Gabriella Coath School Competition.....	£30.60
Grange Club.....	£47.13
Gift Aid	£510.73
Sainsbury collection (from NO)	£200.00
Foreign money sold (Grange tin).....	£14.27
Cyril Sadler.....	£84.51
Garden Fete	£140.00
Miss P Weaver	£50.00
In mem Andrew McAlister.....	£415.00
Christine Cannon.....	£50.00
Denise Calder	£9.48
ASDA Tilbury	£200.00
Thorpe Bay Methodist Church.....	£750.00

Tribute Funds

Terry McGregor	£250.00
Alex Moon	£1,001.93
Jean Lucas.....	£305.80
Lyn Patson	£650.00

Fundraising

Walk to d'Feet.....	£3,523.16
Leigh-on-Sea collection.....	£253.59
Open meeting raffle	£20.00

Bank Interest

Lloyds Bank	£46.73
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Miscellaneous

Unpaid cheque represented.....	£750.00
Refund from Beehive	£48.00

Grateful thanks to all donors and fundraisers

Summer party

On July 26 Sally, a friend of Sue Nash held a garden event at her house helped by Pat Mitchell, ladies from Garons Golf Club and other friends and colleagues, which generated not only support for the Branch but also more awareness as passers by also dropped in.

There were displays of jewellery, bags, scarves, knitwear and fancy goods at very competitive prices. There was also a deli table with homemade cakes, savouries and preserves.

It was a huge effort on the part of Sally and Pat and our thanks to all involved.

Since then these ladies have held a jewellery and handbag sale at the Lionesses Club in Chelmsford and the money raised will be topped by the Leigh Lions and then come to our Branch

Sue gives up many days from work to attend meetings and a variety of other events on behalf of the Branch and we owe her grateful appreciation.



Enjoying the summer delights

The proof of the pudding

Sandy has Christmas (and alternative) puddings still available for purchase. If you have already had samples of these you will know how delicious they are. The puddings are ordered from The Ultimate Plum Pudding Company who also supplies Fortnum & Mason.

Sandy would also love to hear from you if you can help on the walk to D'Feet day or volunteer for any other event. Please contact her on 01702-712032.



News from National Office

Research News

MND is thought to be caused by a combination of subtle genetics, lifestyle and environmental factors.. We know a number of genes that can cause MND, but there is less evidence for lifestyle and environmental factors.

Researchers in Australia have shown a toxin called B-N- methylanimo-l-alanine (BMAA), found in blue-green algae, causes proteins inside cells to clump and cause cell death.

When high concentrations of BMAA are presenting neurone-like cells, BMAA substituted itself with the amino acid l-serine during protein formation, creating a faulty protein within the cell. These changed shape, clumped together, and could no longer perform their role within the cell. The researchers also found once BMAA was substituted into the protein the cells died.

If motor neurones are susceptible to BMAA this could give rise to potential new treatments.

News on drug research

Another research project published by scientists in Leicester looked closely at nerve cells and their ability to make proteins.

It showed that in a mouse model of prion disease (variant CJD or 'mad cow disease'), chemically blocking a chemical known as eIF2 helped prevent disease development.

However, the chemical block, given to mice orally, had

serious side effects. While it's a possible turning point for drug treatment for neurodegenerative disease like Alzheimer's disease it's not the answer.

The processes involved in Alzheimer's disease, prion disease and MND are not identical, but there is evidence that arimoclomol, a drug under development for MND works in a similar way.

Improving MND care 2013 survey results

The results of the 2013 survey showed significant improvements since 2009, including:

- **People's ability to access and receive support with their breathing, in particular take up of non-invasive ventilation (NIV).** In 2013 28 per cent of respondents used NIV compared to 13 per cent in 2009.
- **The experience of getting a diagnosis.** For example, people having tests explained to them, the opportunity to ask questions and being given the news in a private place.
- **The number of people who have heard of MND by the time they receive their diagnosis.**
- **The number of people who have a named person co-ordinating their care**

Because of us, 80 per cent of people with MND now have greater awareness of the support available to them and 65 per cent say their quality of life is better than it would be without the Association.

Focussing our efforts from 2013

The Association has identified the following priorities:

- Working to further shorten the time to diagnosis, and influencing more neurologists, so people who have just been diagnosed, are referred to us.
- Seeking improvements to social care
- Providing more information and support for people about the later stages of MND including end of life decision-making
- Challenging NHS and social care providers to better co-ordinate all the different services that a person with MND needs.
- Improving the support available to family members and friends who care for people with MND.

While satisfaction with our services is high, we want to increase the proportion of people who give us a top rating.

For sale

Special build Handicare Beatle Powerchair. Sit-to-stand function, custom footplate system, electric seat height adjustment, pressure relief cushion and supportive back rest, front wheel drive, electric seat tilt, electric backrest adjustment/recline, swing away G90 control, multi adjustable head rest, puncture

proof tyres drive and castors, padded armrest and side cushions. Will be serviced before sale.

Price: purchased for £16,000; any reasonable offers considered. Area Leigh-on-Sea. Contact: Mrs Ingrid Moon 07967-636551.

Dates for your diary

2013 Meetings & Events

November 18..... St Luke's, 8pm
 November 26..... Thurrock Garden Centre
 November 29..... Stuart House

2014

January 20..... St Luke's, 8pm
 February 7 Stuart House, 2.30pm
 February 18 Thurrock Garden Centre, 2pm
 March 17 AGM
 April 4..... Stuart House, 2.30pm
 April 15 Thurrock Garden Centre, 2pm
 April 29 Chinese meal
 May 19 Walk to d'Feet
 May 20 St Luke's, 8pm
 June 6 Stuart House, 2.30pm
 June 17 Thurrock Garden Centre, 2pm
 July 21..... St Luke's, 8pm
 August 1..... Stuart House, 2.30pm
 September 2..... Thurrock Garden Centre, 2pm
 September 15 St Luke's, 8pm
 October 3 Stuart House, 2.30pm
 October 21..... Thurrock Garden Centre, 2pm
 November 17 St Luke's, 8pm
 November 28..... Stuart House, 2.30pm

Venues

Salvation Army Centre
 Hig 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

ACKNOWLEDGEMENTS

- The health and social care professionals who work with our people with MND
- The many donors and supporters of the Branch
- Pauline Godfrey, 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

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

Thank you

Thanks to our chairman, Sue for giving up most of Saturday September 7 to ensure that the collection on Leigh Broadway was manned throughout the day. Also thanks to the Homemade bakery for allowing volunteers to collect outside the shop and for their kindness throughout the day.

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

DENISE POPPLEWELL 01268-774213

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..... 08453-751840

MND CONNECT 08457-626262

MNDCONNECT@MNDASSOCIATION.ORG

MON – FRI. 9.00 AM – 5.00 PM AND

7.00 PM – 10.30 PM