

AGM 2014

We had our AGM on March 17 which was a huge success due to the preparation and organisation by the Committee – highlighted by their choice of the speaker, Karen Pearce, Director of Care (South), from National office.

The branch President Dr Pat Ahlquist was warmly welcomed by our chairman Sue, and, although attendance was up on last year, it was unfortunate that more people didn't hear Karen's excellent talk.

This included an overview of the different areas of expertise at National Office. The research advances were particularly interesting especially the update on stem cells. These can now be created from skin cells, avoiding ethical issues which formerly existed.



Karen Pearce, speaker at the AGM

Researchers can now re-programme skin cells from people with the inherited form of the disease and turn them into motor neurones and supporting cells. These will display characteristics of the disease and could be used to understand the underlying mechanisms of MND and as a screen for selection drugs that may be beneficial.

More information can be found in the stem cells and MND information sheet

Sharon provided a lovely buffet where everyone mingled and Karen stayed to talk informally with many of the attendees.

Other local meetings

In February and April we had our Westcliff and Thurrock drop-in meetings.

These are social occasions where like-minded people can meet and share ideas and experiences in a convivial atmosphere. We are delighted to have the use of the day room and facilities at Stuart House in Westcliff and the garden centre in Thurrock has most welcoming staff and a huge selection of cakes and lunches.

The centre is very interesting to look round and many of the items in the shopping area are too tempting to resist. These meetings are for people living with MND, their carers, friends and families.

Walk to d'feet



Sandy is still recruiting for our sponsored walk on May 18. This is a special occasion for our Branch, a day when families can have a fun time walking along the Southend seafront and in the past we have had a huge variety of people, buggies, dogs, young people on springs

(for want of the correct word). Sandy will provide a ploughman's lunch with fruit and extras but this must be ordered and paid for in advance. All details, registration forms etc. from her on 01702-712032.

Our young fundraisers

We are once again staggered by the enthusiasm, generosity and energy of so many young people who have shown their commitment to improving life for people with motor neurone disease by taking part in a wide range of fundraising events.

Our marathon man, Sam Wall ran the Paris Marathon on April 6 and has raised a total of over £1,000 which is halfway to his target. You can see his progress at www.justgiving.com/joggaz-in-paris

Sam has supported us by many runs and other fundraising events for our Branch.

Sarah Scowen has just completed the London Marathon in memory of her dad and hopes to raise £10,000. Her current total is now over £8,000 and her page can be found at www.virginmoneygiving.com/sarahscowen

Jane Bunting is planning to travel to Cambodia for the Jungle Trek Challenge later in the year. More details in next newsletter.

We are hoping for support from our local football teams and Sue has been busy recruiting support from them with varying levels of success. If you have any contacts with a football team perhaps you could check if they would give us a mention in their programme.

DONATIONS & FUNDRAISING

	Donations
Steve & Marie Bull	£85.00
Leigh Rotary Club	£200.00
Southend Mayor's Charity Fund	£4,500.00
Canvey Methodist Wives	£120.00
Anna Marie Colvill	£340.00
David Noble	£80.00
Sue Amos.....	£1,044.00
DJ Watts	£25.00
Mrs Marigold	£10.00
Grange Club.....	£54.25
Cupids Country Club	£33.84
Belfairs Pharmacy	£8.03
Lily Card Shop.....	£12.41
Woodland Wheelers.....	£50.00
Gokari Supermarket.....	£14.53
Benfleet Yacht Club.....	£41.16
Gillian Myers.....	£1,000.00
Vision Pharmacy.....	£35.73
Hilary Barry	£40.00
In mem Bupinder Singh	£759.50
Sam Wall.....	£225.00
	Tribute Funds
Charles & David Wells.....	£1,816.60
Alex Moon	£785.20
Terry McGregor	£10.00
	Legacies
Estate of late Fr Dorricott.....	£3,000.00
Grateful thanks to all donors and fundraisers	

Gift Aid

If you pay tax please add Gift Aid to your donations as this makes a huge addition to our funds.

We need full name house name or number and postcode. We cannot use work numbers and names. Thank you.

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Family spring fashion show

A fashion show for all the family will take place on May 10 at St Aidan's church, The Fairway Leigh-on-Sea at 3pm. Tickets are £3 from Margaret Brooks 01702 713506.

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

'Early access' drugs scheme launched

Severely ill patients and those with rare debilitating conditions could be given new medicines years before they are licensed, under new regulations.

The Early Access to Medicines scheme would enable a small number of promising medicines to be fast-tracked. The idea is to help patients in England with severe illnesses who have no other treatment options.

The Medicines and Healthcare Products Regulatory Agency (MHRA) will oversee the scheme, being launched in April. Health Secretary Jeremy Hunt said: "What patients want is sometimes to try medicines that may not be clinically proven to be effective but are clinically safe.

"We are streamlining the process so these medicines can be used much earlier - particularly if they have early promise - and that is something which will bring hope to a lot of patients."

The MHRA stressed that the early access scheme would in no way replace the system of bringing drugs to market via clinical trials, but that can typically take a decade of patient trials.

For unlicensed drugs to be used under the early access scheme, sufficient data from several years of clinical trials would be needed to show that it looks like a promising and innovative treatment.

The MHRA will also carry out an assessment of the benefits and risks, which will be available for doctors and patients.

The MHRA said seriously ill patients - with conditions like cancer or muscular dystrophy - might be allowed access to a drug before it is licensed, and outside a clinical trial, where it could be shown there were no other treatment options.

The MHRA has estimated that one or two medicines a year might qualify under the scheme, although some in the pharmaceutical industry think it could be higher.

Harpal Kumar, chief executive of Cancer Research UK, said: "Time is of the essence for many cancer patients, particularly those with more advanced disease. It can

mean the difference between life and death. Therefore this scheme, which has at its heart the potential to bring promising new medicines to patients faster, is to be warmly welcomed."

Department of Health officials said the scheme would benefit pharmaceutical companies by enabling them to gain experience of their medicines being used in the NHS. The Early Access to Medicines scheme will work alongside and not replace the current system of clinical trials.

When the MHRA has enough data to reach an opinion that a new drug works, and is sufficiently safe, it can issue a promising innovative medicines (PIM) designation. This could occur years before a medicine gets licensed while large scale Phase III clinical trials are still continuing or while drugs are waiting for authorisation.

Before it could be prescribed there would need to be a scientific opinion from the MHRA describing the risks and benefits of the medicine, which would enable doctors and patients to make an informed decision about whether to use the drug. This might enable companies to attract investment and help ensure new drugs are tested in the UK.

But there was concern from industry that the scheme is currently unfunded by government, so companies will not be reimbursed for the cost of unlicensed drugs.

Steve Bates, of the BioIndustry Association, said: "Without centrally funded reimbursement, the scheme runs the risk of being underutilised."

The plans have drawn criticism from the Faculty of Public Health (FPH) at the Royal College of Physicians.

In its response to a consultation it said the scheme would not be of overall value to patients. The FPH said the current licensing system had worked well, and patients with serious illnesses might be vulnerable to taking risks with medicines that had not been fully tested and which might shorten rather than prolong their lives.

Christmas lunch

Thinking of opportunities for future social events, we are already thinking about venues for our Christmas lunch.

We had hoped to have this at the Thurrock Garden Centre but the centre is not suitable for more than 10 people. We are currently looking for another venue

and hopefully will have a confirmed date and details in next newsletter.

Any suggestions will be welcomed and considered so if you have any ideas to put forward contact a member of the Branch Committee. Contacts are on the back page.

Dates for your diary 2014 Meetings

May 19	8-10pm Open Meeting	St Luke's,
June 6	2.30-4pm drop-in	Fair Havens
June 17	2-3.30pm drop-in	Thurrock Garden Centre
July 21.....	8pm Open Meeting	St Luke's
August 1.....	2.30-4pm drop-in	Fair Havens
September 2.....	2-3.30pm drop-in	Thurrock Garden Centre
September 15	8pm Open Meeting	St Luke's
October 3	2.30-4pm drop-in	Fair Havens
October 21.....	2-3.30pm drop-in	Thurrock Garden Centre
November 17	8pm Open Meeting	St Luke's
November 28.....	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

2014 Events

May 10	3pm Fashion Show	St Aidan's Hall, Leigh
May 18	10 am Walk to d'Feet	seawall behind Leigh Station
October 28.....	Curry night	Maharaja, Benfleet
December 7	Christmas lunch	venue to be confirmed

Race night

The Hadleigh Castle Rotary Club is having a Race Night on May 31 for our Branch. This will be held at the old fire station in Hadleigh. Further details not available at the moment but contact Sandy later in the month for more information. (Sandy 01702-712032)



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

WHO'S WHO IN THE BRANCH

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MON – FRI. 9.00 AM – 5.00 PM AND

7.00 PM – 10.30 PM