

## Walk to d'feet 2014

On May 18 in ideal weather our annual walk was started by Chris Walker, Mayor of Southend.

There was a great atmosphere of enthusiasm and energy from all the participants as they undertook the walk along the seafront from Leigh to the Halfway House. Many completed the whole 10 miles with others walking varying distances inbetween.

Those returning to Leigh had an excellent ploughman's lunch prepared by Sandy who has been the organiser of the walk for many years. She spares no effort in the work to make the day such a



Gill, Annie, Eleanor, Emily and Jenny

success. The time she spends before the event takes up many hours and days, not only with all the paper work, but in distributing forms and t-shirts, checking the route and contacting the council for a permit are only some of the tasks she has undertaken.

Our thanks to her and her husband Mike for his support and on the day those who helped especially Sharon's husband Ed who gave his time unstinting.

Pictured left are members of Jack Webster's family – daughter, daughter-in-law and granddaughters who did the walk in his memory.

## Ice bucket challenge



You may have heard about the ice bucket challenge due to the large amount of publicity that it has been getting in the media and the proliferation of people taking part in the challenge.

It involves participants being filmed having ice cold water thrown over themselves. Our very own chair Sue Nash gathered with a number of other members and volunteers in Bournes Green Park, Southend and a dramatic photo featured in the Evening Echo of her and the others (see left) being soaked in ice cold water along with some great publicity for the challenge.

Ice bucket challenge as featured in the Evening Echo

It has raised nearly \$80 million for the ALS (Amotrophic Lateral Sclerosis) charity in the US, where Motor Neurone Disease is usually known as ALS.

Our own MND Association has raised more than £3.5 million to date and although the challenge has also seen commentators question campaigns of this type particularly in relation to people taking part in the challenge and not donating, this amount as well as the awareness it has created are undoubtedly extremely valuable.

It is very easy to donate to through a simple text message of ICED55 to 70070 or visit [www.justgiving.com/icebucket4MND](http://www.justgiving.com/icebucket4MND) and if you're feeling really brave get that bucket of iced water!

## Race night

Hadleigh Castle Rotary Club held a Race Night for Motor Neurone Disease and raised £1,244. Huge thanks to them for this fabulous total. Picture below shows Sue collecting this wonderful donation.



## Leigh collection

Sue is applying for a street permit to collect in Leigh Broadway in September.

Anyone willing to join in the collection can contact Sue – the details are in the contacts section on page 4.

## Awareness month achievement

National Office wanted to get 200,000 charters signed by the end of June to celebrate awareness month – this was achieved thanks to all involved.

We had a huge effort in South Essex and several hundred were posted off to National Office.

## DONATIONS & FUNDRAISING

	Donations
David Noble .....	£80.00
Hilary Barry .....	40.00
Sale of crocheted hats .....	£70.00
Christine Dartnell .....	£49.10
Ann Broom – coffee morning .....	£225.00
Tony Delventhal .....	£300.00
Clarks Shoes Southend .....	£86.00
Christine Callis .....	£25.00
NHS Retirement Fellowship .....	£110.00
St Aidan's Church Fashion Show .....	£1004.80
Vision Pharmacy.....	£15.58
Westcliff Lawn Tennis Club.....	£162.50
Palace Theatre Collection.....	£149.44
ZB News.....	£57.87
Ruth Lattimore .....	£47.00
Thameside Theatre in mem J Scowen.....	£388.00
Leigh Constitutional Club.....	£35.19
John Scowen in mem.....	£2,377.77
Hadleigh Rotary Club .....	£1,244.00
Shabi in mem donation .....	£41.60
Southend Inner Wheel.....	£100.00
Grange Club.....	£89.82
R. Chell in mem .....	£40.00
Ros Pack in mem .....	£950.00
Various from N.O. ....	£110.00
<b>Tribute Funds</b>	
McGregor, Moon, Webster, Myers.....	£2,640.81
<b>Fundraising</b>	
Walk to D'feet.....	£10,018.80
Chinese Meal at Zen City.....	£823.00
<b>Bank Interest</b>	
Lloyds Bank Northampton.....	£34.33
<b>Gift Aid</b>	
National Office.....	£318.75

Grateful thanks to all donors and fundraisers

## Grange club

The club has been very generous to our Branch with regular collection boxes and events organised by its members . The next one for MND will be on October 4 and will include a live band, disco and supper for £5.00.

Unfortunately there is no disabled access to the function room but there is a bar area and toilets at ground level and a very welcoming staff. More details from Maura 01702-478661.

## Theatre collections

Recent collections at the Palace and Thameside theatres raised £149 and £388 respectively.

Many thanks to all involved.



## 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

## Research news

An important part of developing drugs to treat MND is understanding where exactly these drugs should be targeted – which protein and in which biochemical pathway – to put it in technical language.

Recently published research gives us new clues as to why one protein called TDP 43 may cause motor neurones to die.

MND Association grantee Prof Chris Miller, based at the institute of Psychiatry, King's College London, has

shown that TDP43 loosens the vital tether between two cellular compartments. The search is now on to restore the strength of this link.

Belinda Cupid, our Head of Research, said: 'These findings pull together several different areas of research that have been linked to causing MND and that's what makes it really exciting.'

It's a bit like finding a straight-sided jigsaw piece and really important for seeing the bigger picture.'

## Wheelchair service

National Office has now a wheelchair adviser who liaises with manufacturers to provide models of powered wheelchairs suitable for the long term needs of people with MND and which are adaptable to easily add or change controls, switches etc.

These are now available for wheelchair services to prescribe. National Office is continuing to promote the powered neuro wheelchair which is appropriate for the majority of people with MND.

### Late newsletter

This newsletter is late due to a computer malfunction. Apologies for this and the fact that former contacts' email addresses have been lost. Contact Maura on [maura@mndsouthessex.org](mailto:maura@mndsouthessex.org) if you would like to receive the newsletter by email.

## Requesting support from the Branch

The funds raised by the Branch are primarily used to provide practical help and support to people living with MND in our area. This support is provided in accordance with national guidelines set by the MND Association, which relate to the range of items and services we can help fund, the maximum contribution we can make per item, and the maximum per annum for an individual.

Within these guidelines, in many cases we are able to fund the entire cost of a piece of equipment or service that can make a real difference to people's lives.

The Association, and therefore the Branch, does not fund items where there is a statutory requirement for them to be supplied by health and social services, although we might step in if the delay in receiving this funding is unacceptable.

Please note that most items of equipment and adaptations require the recommendation of a health or social services professional. If you are hoping that the Branch will make a contribution, you are strongly advised against making any purchases or embarking on any adaptations without ensuring you have the necessary recommendation from a health or social services professional.

In any event, it is wise to obtain their input before incurring any expenditure, no matter who is to fund, to

ensure that it is appropriate to your ongoing need.

Please note that only in exceptional circumstances can we fund retrospectively and then only three months after the event, so do contact us before incurring any cost. Once requests have been received by the Branch committee or directly by the Association, they are dealt with as quickly as possible.

You may not be aware that we are only able to provide this support thanks to fundraising done by the Branch and others on our behalf. The Branch does not receive any funds from the MND Association or the state. If you, friends or family are thinking of raising funds for MND, please remember this and help us to help others living with MND in your local area, as we may have helped you.

We are always happy to discuss ways in which you might be able to raise funds and to offer support.

Finally, should any equipment no longer be required, please contact us to see if it could be used to help someone else.

We know how grateful many of our members have been for our support in the past. Why not help us to help the next family who has to cope with this devastating disease?

Branch Committee

## Dates for your diary Meetings

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

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

## Events

October 4 .....	Social evening Grange Club
October 28 .....	Curry night Maharaja, Benfleet

## AGM

The AGM is coming up on the 13th September at East Midlands Airport. We were thinking that it's quite a trek for some of our people so if there is enough interest we are going to hire a mini bus (and fund it) to take everyone there.

Can people let Sue know if they want a place.

They can do that either on the facebook page (see contacts) or by email [sue.nash@pinneytafourd.co.uk](mailto:sue.nash@pinneytafourd.co.uk) or home 01702-480806 or mobile 07500-043911.

## Early Christmas offer

If you have any Christmas cards or puddings orders ready for the September meeting you will not have to pay postage and they will be available in November.



## 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](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

## 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

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#### PUBLICITY

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#### ASSOCIATION VISITORS

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DENISE CALDER..... 01702-557859

MAURA IRWIN..... 01702-478661

SANDY LAMBERT..... 01702-712032

#### BRANCH CONTACT

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#### REGIONAL CARE & DEVELOPMENT ADVISER

LIZ PYBUS..... 08453-751840

MND CONNECT 08457-626262

[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: @MNDASSOC