

Football Fever

Sue collected £1,194 from Thurrock Football Club as a result of a match played in memory of Sue Amos's husband.

Subsequently she has contacted a number of football clubs and has lined up visits to some of them to create awareness and encourage them to support our Branch. This follows a feature in



Sue collecting the cheque from Thurrock FC

the Autumn Thumbprint on 'awareness through football'.

Hopefully they will donate space in their match programmes and allow us to collect at some of their matches.

Fundraising round-up

Sam Wall featured in the last two newsletters is continuing to raise funds and raise awareness for MND. Mark Merry is planning to do a 100 mile bike ride for the Branch and a friend of Sue is also planning a sponsored bike ride.

It is thanks to the commitment and inspiration of supporters like this that the Association is able to carry out its many activities for people living with MND. Our thanks go to them all.

Walk to d'feet

We need more people to take part in our annual walk on May 18 as we hope to keep this event our biggest fundraiser. Thanks to all the time and hard work that Sandy puts into it before, during and after the day. More details and registration form from Sandy or from our website www.mndsouthessex.org.

MND Charter and about the Association

You can help influence the standards of care for people affected by MND by signing our MND Charter. It is possible to sign online at www.mndassociation.org/mndcharter.

The MND Association funds and promotes research to bring about an end to MND. Until then, we will strive to enable everyone with MND to receive the highest quality of life possible and die with dignity. We will also

do all that we can to support the families and carers of people with MND.

As a charity we rely on voluntary donations. Our vision is a world free of MND. Find out more on our website www.mndassociation.org or through our social media channels such as our online forum – a safe place for people with MND to share experiences at <http://forum.mndassociation.org> or on Facebook www.facebook.com/mndassociation

DONATIONS & FUNDRAISING

Donations

Hilary Barry	£40.00
David Noble	£60.00
Chalkwell Methodist Ladies' Club	£50.00
Sam Wall.....	£1,029.30
Christ Church Billericay.....	£50.00
Derix Pharmacy	£28.74
Ruth Hawley.....	£100.00
Rayleigh Parish Cameo Group.....	£700.00
Ivor Jenkins.....	£30.00
Anne Watts	£12.69
Sheila Ball.....	£50.00
Leigh Motor Boat Club	£52.16
John Law	£500.00
Thurrock Youth Football Club	£150.00
Gift Aid	£293.00

Tribute Funds

Beverley Storey/Alex Moon.....	£703.00
Lyn Patson	£20.00

Fundraising

Walk to d'Feet.....	£30.00
Curry Evening	£451.00
R.Chell extra to curry evening.....	£48.00
Curry Evening Donation	£20.00
Open Meeting Raffle	£17.00

Resale Goods

Christmas Cards and Puds	£683.75
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Grateful thanks to all donors and fundraisers

Keeping secure

Below, Emma Clark, Essex Police Crime Prevention Officer for Rochford and Castle Point gives some useful guidance on keeping safe in your own home.

Cold callers, rogue traders and bogus callers are always looking for ways to make money from residents. They operate in many ways using door knocking or leafleting to generate business. They will offer work at a 'bargain' price which will then escalate.

The traders may try to frighten you into having work carried out, for example, your chimney is dangerous, your roof tiles are loose or that tree needs cutting back.

Within the Rochford district, police are receiving a number of reports of cold callers offering paving and driveway improvements.

Most people who call at your home will have a genuine reason for doing so, but by taking a few simple precautions you can protect yourself and your home.

1. Don't sign on the spot – don't feel pressured to commit to anything before having the chance to carry out further checks.
2. Check the trader's identity – ALWAYS ask for an identity card and look up the organisation if you are unsure. Don't be frightened to ask for identification and always check it carefully. If you're not sure, do not let them in. Most utility companies offer a 'password' scheme that can be set up free of charge and if they do not know your password you can happily refuse them entry.
3. Be wary of special offers or warnings about your home – some cold callers claim that your home is at risk and use scaremongering tactics to sell you alarms or home security products. The caller may use high pressure sale techniques, such as suggesting that your home is at serious risk without an alarm, but trading standards advise you not to be pushed into signing up for anything on the spot. If you require an alarm it is advised that people deal with companies that come under the NACOSS or SSAIB umbrella which are industry approved.

Goodbye Denise

We are sorry to lose Denise Popplewell from the committee but we know she and her family will continue to support the Branch in many other ways at events and various fundraising activities. We thank Denise and will keep in touch with her.

Saving postage

If you have an email address, we can send the newsletter to you without the expense of posting. This would mean that you receive it more promptly and save the Branch the cost of stationery and postage.

Please email Maura at maura@mndsouthessex.org if you would like an ecopy. Hard copies will be available at our meetings.

Red Flags to alert GPs to MND

The MND Association has been working with the Royal College of General Practitioners on an early diagnosis Red Flags system for MND.

The purpose of the Red Flag is to raise awareness of MND with GPs and help them to make an accurate and speedy referral to a neurologist, rather than to another professional.

It is also, of course, of use to other healthcare professionals who may be the first to notice the signs of MND in a patient.

The tool, which explores the symptoms of MND under the four headings limbs, bulbar, respiratory and cognitive, has been launched and is ready to be used as widely as possible to raise awareness.

The Association recognises that its members feel that a prompt empathically given diagnosis is vital. The value lies in both removing uncertainty for the person experiencing symptoms, allowing for care and support to start as early as possible.

It also helps by enabling the person with MND and their carer to plan for the future – increasing the window of opportunity to research into and better understand, the condition.

Many professionals have stated the importance they place on timely diagnosis too, and for that reason have expressed their interest and support for the tool.

Articles will be appearing in professional journals over the coming months with the aim to keep the profile of Red Flags high.

The more people that are aware of MND the better chance we have to help those living with this condition and their carers.

For more information on the Red Flags tool you can contact Jennifer Bedford at email address jennifer.bedford@mndassociation.org

A copy of the Red Flags tool can be downloaded at www.mndassociation.org/redflag

Have your say on research

A new survey enabling people to have their say in setting future research priorities for palliative and end-of-life care welcomes feedback from those living with MND, current or bereaved carers, their families and frontline social and healthcare professionals.

You can complete the simple survey online, over the phone or by asking for a paper version (with freepost return envelope) to be sent to you. The deadline is 30 April 2014.

To take part and to find out more visit the Palliative and end-of-life care Priority Setting Partnership website at www.palliativecarepsp.org.uk or telephone them on 020-7091 4153.

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

International Symposium

The 24th International Symposium on ALS/MND took place in Milan 6-8 December. Over 950 clinicians, scientists and Health Care professionals attended. The hope and passion to find a cure for MND is shared by all of them.

A full report on the symposium can be found at www.mndresearch.wordpress.com

It is too long and too complex to summarise for this newsletter but is a most interesting read.

Our association currently funds over 40 research project

Dates for your diary 2014 Meetings

February 7	2.30–4pm drop-in Fair Havens
February 18	2–3.30pm drop-in Thurrock Garden Centre
March 17	7.45 for 8pm AGM Salvation Army Centre
April 4	2.30–4pm drop-in Fair Havens
April 15	2–3.30pm drop-in Thurrock Garden Centre
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

April 29	Chinese evening Zen City, Westcliff
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 Thurrock Garden Centre

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**