

**EAST LONDON
DEVELOPMENT
GROUP**
COVERING
EAST LONDON TO
SOUTH WEST ESSEX



**LOCAL GROUP
CONTACTS:**

Lynn Sprague
Support Meetings
at YMCA, Romford
01708 551889

Maureen Agombar
020 8504 1799

Carole Smith
020 8502 2344

**Gary and Sam
Sprague**
01708 524685

Geraldine Vallis
07946 410765

**MND
ASSOCIATION
CONTACT:**

Frances Carroll
MND Association
Regional Care
Development
Advisor
0845 375 1851



Family run for charity

Toni Ali and Tina Clancy, daughter and sister of Terry Wakefield completed a 13-mile run and raised a great **£565** for the East London Group. They wanted to thank all the people who sponsored them and look forward to their next charity run. *Pictured above are Toni and Tina.*

Fantastic donation

Ian Cook ran the British 10k in July this year on behalf of the Motor Neurone Disease Association. Ian from Upminster raised a fantastic sum of **£7,248** for the charity. His mother, Pam was living with motor neurone disease for 19 months and sadly passed away on the 30th September.

In a recent letter, Ian said: "I hope that this donation can help those now and in the future living with Motor Neurone Disease to maintain a quality of life that you and others associated with the East London Group were able to share with my mother."

Seasons Greetings

The Motor Neurone Disease East London Group wish you and your family a very Merry Christmas and all the best for 2009.



VOLUNTEER GROUP UPDATE

Coffee at the church



David Gray, one of our trustees with some friends had a coffee morning at a Romford's Church House on the 30th August and raised £314.27. **Team effort: pictured left to right - John, Karen and Victoria**

Here is David's report on the day:

On 30th August this year, a team of volunteers had a go at running a coffee shop for a day, to raise money and awareness for the Motor Neurone Disease Association. We arrived at Church House early in the morning and filled it with balloons and homemade cakes, donned our red MND T-shirts and got ready to welcome the hungry customers.

Church House, part of St Edward's Church in Romford, sits in the centre of town on the bustling Market Square and is a popular pit stop for weary shoppers to rest their feet and bags. It always does a roaring trade and our chosen day was no exception, being a sunny Saturday **and** the last weekend of the summer holidays. The customers came thick and fast and there was a good team of us on standby to serve them coffee, cakes and rolls. Myself and John managed the money-taking and made the drinks, Den and Victoria made the rolls. Karen cleared tables and did a bit of everything else! And oh Lucy popped in briefly too.

You'd think five adults running a coffee shop would be an easy task – well, so did we! We knew a little bit of what to expect, having raised funds for MND at Church House back in 2005. We knew we'd get orders for cheese and onion rolls at 9.30 in the morning (!) from market traders - so, in preparation, Den and Karen sliced tomatoes, boiled eggs and grated cheese for the sandwich fillings the night before. However, nothing prepared us for our "super-speedy and efficient" dishwasher breaking down at the start of the day! Disaster! Dirty plates and cups piled up at the sink in the tiny kitchen area, but luckily help was on hand in the shape of Karen's 85-year old mum, Eileen, who rolled up her sleeves and did our washing up! She was planning on popping in for cake and cuppa - little did she know she was going to donate a few hours of cleaning time too! Thanks Eileen!

Once the rolls and cakes were sold out and the lunch rush died down, it was time to shut up shop and count the money. We raised over £300, which made it all worth the effort! We hope to do another coffee morning again next year, so look out for the date in this newsletter nearer the time and pop in for a drink. Hopefully the dishwasher will be back up and running by then!

MND East London – meetings for 2009

If you are interested in becoming a volunteer member of our group, you are welcome to come along to any of our meetings.

We meet bi-monthly at the Information Centre in Buckhurst Hill.

Monday, 26th January

Monday, 30th March

Monday, 18th May

Monday, 27th July

Monday, 28th September

Monday, 30th November

(all from 11am until 1pm)

Get in touch with Carole on 020 8502 2344 to find out more.

New events organiser

Welcome to **Heather Kneale** who has recently joined us as the group's Events Organiser.

She is 25 years old and works at a London University. Heather lost her father, Eric to motor neurone disease about 14 years ago. She commented: "The East London Group in particular is very close to my heart as they were a key support for my family during his illness and for several years after."

She added: "I am really looking forward to helping raise both funds and awareness for the group. We have a few ideas that we hope to put into action over the coming months so watch this space!"

USEFUL CONTACTS

Coping with rising bills

Rising utility bills are of great concern to everyone, but this can be particularly so for people with motor neurone disease and their families. Here are a few hints and tips on what you can do to stay warm, while making those bills more manageable.

Be Energy Efficient. If you are receiving benefits such as DLA, Pension Credit or income based Job Seekers Allowance, you could be eligible for additional grants to insulate your home and improve energy efficiency. You may also be able to access special grants and services. Contact the **Home Heat Helpline free on 0800 33 66 99.**

Get on the Priority Services Register. If you are disabled you can request to be placed on your Suppliers' Priority Services Register, which among other things, entitles you to a free annual gas appliance safety check, as well as allowing you to nominate a relative, friend or carer to receive a copy of your bill. Contact the **Home Heat Helpline free on 0800 33 66 99.**

Deal with Debt immediately. If you experience difficulty in paying bills, don't ignore it. Contact your supplier immediately, explaining the situation. They should help you to find the best way forward, through manageable payment plans such as instalments, or the Fuel Direct Payment Scheme, which is available to people who receive Income Support. If the bill you received is an estimate, provide the company with the actual reading. Although utility companies are only obliged to carry out a proper meter reading every two years, they should read them for every bill if the customer and other members of the household, are unable to do this themselves.

Dial ICE for emergency

Many of us carry our mobile phones with names and numbers stored in the memory. But if we were to be involved in an accident or were taken ill it is likely the people attending us wouldn't know who to call in case of an emergency? Hence the 'ICE' (In Case of Emergency) campaign.

It is a method of contact during emergency situations. As mobile phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be called during emergency under the name 'ICE'. The idea was thought up by a paramedic, who found that when he went to the scenes of accidents, there were almost always mobile phones with patients, but emergency services didn't know which number to call. Emergency Service personnel and hospital staff would be able to quickly contact the right person by simply dialling the number you have stored as 'ICE'.

Please share this idea, it really could save a life, or put a loved one's mind at rest.

Information Online

The **Bereavement Register** is a service to reduce the amount of direct mail to those who have died, which can be distressing. To register a death, visit www.the-bereavement-register.org.uk and the name and address details will be removed from companies databases and mailing files.

Ceiling Hoist Users Club www.CHuC gives useful information about accommodation with ceiling hoists, including hotels, guesthouses, self-catering accommodation, motor homes and caravans.

www.yourlevelbest.com was created by a wheelchair user who recognised that although the law has changed, most pubs and restaurants are NOT disabled aware with wheelchair accessible toilets. Venues on this site claim to meet these criteria.

East London Support Group

St. Joseph's Hospice MND Support Group for people with MND and their carers meet once a month. Anyone interested, please contact Frances Carroll on 0845 3751851 for further details.

Just click for top tips

The website www.bluebadge.direct.gov.uk has a facility which allows people to find Blue Badge parking bays, Red Route parking bays, petrol stations and public toilets within many of the major towns and cities in the UK. Instructions on how to use the website are provided.

The parking bays etc are all identified by icons and if you click on the individual icon it will give you the street address, number of bays available and any restrictions. Listings for garages provide information on whether there is a cash machine and any disabled toilet facilities.

Information for Carers

Carers UK are urging carers to make sure they are paying the correct amount of council tax. It isn't widely publicised but some carers could qualify for up to 50% off their council tax bills. If you are a carer and want to find out if you should be getting a discount on council tax, contact Carers UK. Did you know there are pages on the Association's website specifically aimed at carers? Visit www.mndassociation.org/carers.

A BIG THANK YOU TO THE FOLLOWING FOR THEIR KIND SUPPORT IN RAISING AND DONATING MONIES TO MND EAST LONDON GROUP...



Collections update

Carole, Maureen and helpers came together again this year to take part in two collections:

Tesco on the 19th June. This was the first time we had a collect at Tesco, Barkingside and raised a great amount **£381.94**. Carole said 'I think we did very well for the first time!'

Liverpool Station on the 26th June and raised a fantastic **£752.60**. Carole commented: 'We wondered how it would go, people being short of money but as always they were very generous.'

Thanks you to all the shoppers and commuters for their donations and thanks to everyone who helped at the collections.

Many thanks to....

Ian Cook who ran the British 10k in July in aid of Motor Neurone Disease Association and the East London Group raising **£7,248**

Toni Ali and Tina Clancy **£565** – 13 mile run

Mr A C Sterry – ran the marathon in April raising **over £4,000** for the Motor Neurone Disease Association (nationally and **£175** to the East London Development Group

Money raised by Wendy Careford in memory of her brother, Leonard Benjamin Careford **£594.00**

Tony, husband of Alison Butcher ran the Paris Marathon and raised **£180**

Coffee morning, Romford's Church House David Gray & friends raised **£314.27**

Rotary Club of Loughton and Buckhurst Hill **£150**

Bus Stop Raffle – money raised so far **£126**

Collecting tin, Woodcock, Loughton **£28.03**

Fitness First **£18.85**

Donation from Sheila Stickland in memory of her mother, Irene Mott **£100**

Donation from Paul Reilly and Jill Wilkins in memory of mother, Rita Reilly **£60**

Funding secured

The East London Group has been successful in bids for three lots of monies.

Thank you to the three organisations. They are as follows:

London Catalyst **£2,000**
The City and Metropolitan Welfare Charity **£1,500**
Essex Fairway Charitable Trust **£1,000**

Meet Lou



Tony, husband of Alison Butcher ran the Paris Marathon on Sunday, 6th April and raised £180. Meet 'Lou' the dog who is pictured (and trained with Tony).



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