

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

Spring 2007

ISSUE No 6



Winning efforts!

Rise Park Junior School, Romford raised a huge **£242.10** through an 'England Football Kit/Supporter Day' dressing up as football supporters for the World Cup.

Carole Smith, volunteer with the east London group said: "Once again we say a big thank you to our friends at the Rise Park Junior School for their fundraising efforts. The entire donation came from the children themselves which makes their fundraising achievement even more significant. I wish England had done as well as the children!"

LOCAL GROUP CONTACTS:

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*Support Meetings
at YMCA, Romford*
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Maureen Agombar
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MND ASSOCIATION CONTACTS:

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Advisor*
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Volunteering
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Co-ordinator*
0845 375 1848

Association Visitor update

Since the 11th April 2006, we have had seven enquiries about the Association Visitor role. One person has sent her application form back and the MND Association National Office is awaiting references. Any one of these could be a potential visitor.

But we still need more people to apply! If you are interested and would like further information, please call Carole on 020 8502 2344.

Life Goes On

The MND Association launched a new national campaign last October called 'Life Goes On' to raise awareness of MND and the Association. The campaign has begun with a series of posters appearing on the London Underground each featuring a different person with MND.

The wording on the poster is meant to be hard hitting but the overall message is a positive one about the care and support the MND Association, its branches and groups provide and our desire to find a cure through research. For more information about the individuals featured and the campaign itself, log on to the website – www.lifegoeson.org.

The **Spring Conferences** are annual one day events presented by the MND Association. The content of the day focuses very much on current news in MND research and care. Everyone is welcome. For more information, telephone the MND Association on 08457 626262 or visit www.mndassociation.org.

Visit our local website – www.mnd-eastlondon.org.uk



FIGHTING MOTOR NEURONE DISEASE

FUTURE EVENTS



SUPPORT MEETINGS

We hold regular open meetings at the YMCA, Romford. These are social meetings as well as an opportunity for people affected by MND, their carers and families to meet others in a similar situation. Refreshments are provided and the group are happy to fund transport costs to help people to get to the meetings.

The YMCA, Rush Green Road, Romford RM7 0PH – Support Meetings take place from 2.00pm – 4.00pm on the following dates:

Wednesday, 21st February 2007
Wednesday, 21st March 2007
Wednesday, 25th April 2007
Wednesday, 23rd May 2007
Wednesday, 20th June 2007
Wednesday, 18th July 2007
No meeting in August
Wednesday, 19th September 2007
Wednesday, 17th October 2007
Wednesday, 21st November 2007
Wednesday, 5th December 2007

Call Lynn Sprague on 01708 551889 for further information.

YMCA Christmas 2006 support meeting

We held our Christmas celebration meeting on Wednesday, 6th December 2006. At this meeting, a group of therapists offered ‘taster’ sessions of reflexology and massage with a view to some of our group joining a pilot scheme to be run during this year.

Anne Earwaker said: “a wonderful selection of buffet food was temptingly displayed for our enjoyment. As always, there was lots of friendship and laughter. A group of therapists offered ‘taster’ sessions of reflexology and massage. Thank you so much to all who arrange and run our meetings and to Liz Edmonds who shares with us her knowledge and experience.”

Complementary therapies sessions

We plan to have a pilot scheme for eight people living with MND of six sessions each of complementary therapies. These will be run by the Complementary Health Trust. We will then get feedback from participants to see if this was of benefit to them. If all goes well, we will be extending it to other people in other areas of east London.

GROUP UPDATE

MND east London – future group meetings

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 from 7.30pm. The next meeting dates are as follows:

Monday, 19th March 2007
Monday, 21st May 2007
Monday, 23rd July 2007
Monday, 17th September 2007
Monday, 19th November 2007

Get in touch or just turn up to one of our meetings. The full address of the meeting venue is **Buckhurst Hill Information Centre, 62-64 Queens Road, Buckhurst Hill, IG9 5BY.**

Welcome

We wish **John Duffield** a warm welcome to the group. John will become our new treasurer.

Welcome also to **Lisa Taylor**, who is a trained Association Visitor working with Frances. She was previously with the Surrey branch.

USEFUL CONTACTS

Web-based support group

Have you been diagnosed with a slower progressing form of MND (progressive muscular atrophy, primary lateral sclerosis) and/or have you been living with MND for more than five years? If so, please read on...

We are looking at the need for a web-based support group for people who fall under this heading, who by the rarity of their disease are inevitably geographically dispersed and may want to be in contact with others.

There may also be additional opportunities in the future for this group to look at developing literature that is more geared to the needs of people with slower progressing forms.

Expressions of interest would be welcomed at this stage to care@mndassociation.org. We look forward to hearing from you...

This is a message from Jean Waters, who is living with slower progressing MND.

Message in a Bottle Scheme

The Lions 'Message in a Bottle' scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location – the fridge. Bottles are free of charge and can usually be found in your local chemist or doctors' surgeries.

You may also find you can obtain one through your nearest Neighbourhood Watch group, Age Concern, council offices, housing associations and other places including police stations.

If you have difficulty finding a bottle, please contact Lions International, telephone 0845 833 9502 or email: miab@lions.org.uk or website: www.lions.org.uk.

Alternatively contact the MND Association Helpline on 08457 626262 or email helpline@mndassociation.org.

Doctor Babel

This new website – www.doctorbabel.com enables individuals to create a simple medical record online that can be translated accurately into many languages. This is good news for people living with MND planning a trip overseas.

Individuals can record their condition along with their medication and other medical details. They can then translate this into any of a number of languages by simply selecting the relevant language and pressing 'translate'. They can then print the record and take it on their trip.

The usual cost for this service is £20 but if people living with MND follow the link from the MND Association website – www.mndassociation.org, they will get an automatic discount of £2.

Walking Aid

A West Midlands Branch Committee member living with MND recently trialled an innovative new product called MuSmate, which is a walking aid for people with drop-foot. It uses the action of elastic cord to support the lifting of the foot during the walking movement.

Product tests were carried out by people walking a 10 metre course without the product, then with the product and then again after one month. Users stated that they were walking faster and for longer.

A full set of MuSmate costs £378 to purchase, excluding VAT, which is zero-rated if purchased for people with MND. It would be advisable to seek advice from a health professional before purchasing any piece of equipment. For more information, contact MuSmate – telephone 07917 124910 or email sales@musmate.co.uk. Alternatively visit their website – www.musmate.co.uk.

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

Collection at Waitrose 8th and 9th September 2006:
£631.73

Rise Park Junior School, Romford **£242.10**

Woodcocks, Loughton – collection tin **£23.30**

We would like to extend a huge thank you to the family of the late Richard Henderson for their very generous donation of a lightwriter and carrying case, which will now and for the future be making life easier for those with limited or no speech through the effects of MND.

We wish to express our thanks to the RAF, who kindly purchased the lightwriter for Richard.

Donations in memory of Richard Henderson:

Mrs T V Ottey **£120.00**

S A Artell **£25**

F N Jarman **£25**

Miss L J Everett **£30**

Mrs C M Phillips **£25**

Mr F S Jarman **£25**

A H and I M Ottey **£25**

A H and I M Ottey **£55**

MONIES AWARDED

Our fundraiser recently submitted a small grant 2006/07 application through the Waltham Forest Voluntary Action Bureau. We are happy to report that our group have been successful in achieving an award of £1,000 from Waltham Forest Council.

These monies will be used to pay for costs of training an Association Visitor volunteer who will provide support to carers of people living with Motor Neurone Disease.



TRUST FUNDRAISING SUCCESSES

The following companies have kindly given us the following donations:

London Catalyst £2,000

Linklaters £250

Donations in memory of Mr Bill Earwaker:

A N Earwaker **£214.75**

D R Tansley and A L Earwaker **£30**

Mrs G Hoyte **£50**

Goodmayes Methodist Church **£50**

Mr and Mrs D A and J A Jones **£20**

K A Roland **£20**

Mr and Mrs Freeman **£45**

Mr and Mrs D P Manley **£10**

J M G Gosden **£20**

D H and Mrs L Colloff **£20**

Mr C B Wilson **£20**

Donations in memory of Christopher Hall:

Mr and Mrs Fitzgerald **£30**

R W Grey **£20**

D Castley **£10**

Plus **£40** cash.

S J Westbrook **£25** in memory of a friend.

Donations in memory of Mrs Harriet Golding:

£20 Lynn Sprague

£20 FW and Mrs D Clements

Christmas Cards **£188.50** (Carole and Maureen)
£130.00 (Lynn & Family)

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Loughton**

is pleased to support the MND East London Group by sponsoring the cost of printing this newsletter.