

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

2009 marks
the 30th
year since
the
Association
began.



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

**LOCAL GROUP
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at YMCA &
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Royal opening of Care Centre

The 17th MND Care Centre was officially opened by HRH The Princess Royal at St Bartholomew's Hospital in West Smithfield recently on 15th May.

It was The Princess Royal's first official engagement as Royal Patron of our association. During the day The Princess Royal was able to see first hand how the partnership between the MND Association and Barts and The London NHS Trust directly benefits people living with MND and their families.



The Princess Royal with Frances Carroll

The Princess spoke to many people with MND, their families and healthcare professionals and took a tour of the clinic, including the treatment rooms. Just before unveiling the new plaque The Princess remarked on the growth of the association and the importance of care centres like this for people affected by the disease. The new centre will provide people with MND in Essex and east London a multi-disciplinary approach to patient care and access to all health professionals under one roof. Lynn and Carole from the East London Development Group also attended the opening and met the Princess.

Charity with top number of discs

Instead of collecting at stores, Waitrose now give shoppers a disc and asked to choose one of three charities to dispense the disc in a big clear perspex box. The charities with the most discs get the lion's share of £1,000 each month. Shoppers at **Waitrose Buckhurst Hill** chose the MND Association charity as their chosen charity recently. Carole commented: "It was very exciting watching the discs mount up. We would like to say thank you to the staff and shoppers at Waitrose for their support and helping us to raise **£600**, the largest amount given, I was told."

VOLUNTEER GROUP UPDATE



Friends of the East London Development Group

Thank you to the people who have volunteered to be "Friends of the East London Development Group." Our development group are few in number. Friends would be people we could call on to hold a collection tin at a supermarket or help with an event. If you are interested and can help, please ring **Carole on 020 8502 2344**.

Next collection

Our next Liverpool Street collection is on **Thursday, 25th June**. If you can help, please let Carole know on 020 8502 2344.

Dunk-it

A dunk-it event is planned to be held at the next support meeting at the YMCA, Romford on **Wednesday, 17th June**. A range of dunkable food, sweet and savoury, will be available for a donation to the group. All patients, families and friends were invited to attend to make the afternoon as successful as possible.

Southend walk

Well done to **Heather Kneale**, our new events organiser took part in a 10-mile sponsored walk, organised by the South Essex MND Association group on Sunday, 17th May.

Heather commented: "I did the full 10 miles in the wind and rain! It was hard work but worth every step and I managed to raise **£250** for the group. Sandy Lambert, who organises the walk for the South Essex Group, kindly agreed that any funds raised by members of the group could stay with us. There were over 300 hundred walkers registered and I dare say at least 250 were there on the day.

She added: "It was a huge success and a great example to follow for the walk we hope will take place in October. **Anne Earwaker** and **Carole Smith** also came along to lend a hand on the day and they made a good effort holding on the gazebo that was threatening to take off!"

Many thanks

Andrew Smith has been fundraising for our group for the last few years and has decided to now step down. Many thanks for your support and fundraising efforts from the group.

From us all - a very big thank you to **Geraldine Vallis** for our newsletter. "A great job well done."

Get well soon

We would like to wish **Pat McHenry** a speedy recovery. All the best from her friends at the open meeting.

Welcome to...

New volunteer - welcome to **Stacy Brown** who have recently joined our group. Stacy will help with people living with MND in the London area.

New local contact - **Annabel Lotsu** is the new Volunteer Development Coordinator for London. Welcome Annabel and the group look forward to working with you.

Change of web master - We have now got a new web site master. Welcome to **Mwirikia Mjongo** who has taken on the role of looking after our local web site. Many thanks to **Kevin Joyce** who has helped develop our MND East London Development Group web site. Kevin has decided to step down as web master.

USEFUL CONTACTS AND INFORMATION

Know your rights and entitlements

The **Disability Alliance** is a national registered charity striving to relieve poverty and improve living standards of disabled people. It provides information on benefits to disabled people, their families, carers and professionals. They also campaign and undertake research into the needs of disabled people. Contact the Disability Alliance on **phone 020 7247 8776** or visit www.disabilityalliance.org

MND Connect offers support, information and advice to: people living with MND, health and social care professionals, staff and volunteers. Contact MND Connect on **phone 08457 626262** or email mndconnect@mndassociation.org

Restructure of area – update from Frances Carroll

We have recently had a restructuring of areas in last few months at the Motor Neurone Disease Association. The main difference in our area is that in London we now have a new Team of 3 Regional Care Development Advisers (RCDA), Senior Team Leader and Volunteer Development Coordinator.

Previously an RCDA was responsible for a part of London plus a county. They will now be working only in London which will give more time for influencing and developing services for people with MND in London to ensure that people with MND will be receiving the appropriate support and services.

In the North East London area, I will be working across nine London boroughs including Haringay, Hackney, Tower Hamlets, Newham, Waltham Forest, Redbridge, Havering, City of London and Barking and Dagenham. This comes at a time when the MND Association have in partnership with Barts and London NHS Hospital Trust just opened the MND Care Centre at Barts. There will also be MND Clinics now running at Queens, Romford and Basildon Hospital.

The aim of this MND Care Centre is to ensure that all people with MND living in the area have access to Specialist Neurologists in MND (Dr. Malaspina and Dr. Radunovic) and ensure that they receive continual assessment and support at these centres by therapy teams including respiratory support, physiotherapy, speech and language therapy and dietetics. Also, that they are linked into community services in the areas in which they live. So a lot is happening in the area at present, which will improve support and services for people with MND and their families and carers.

Local MND Support Groups

We have two MND Support Groups for people with MND and their carers and families. The first is at the YMCA in Romford, which has been running successfully for some time now by **Lynn Sprague** and her Team. If people wish to attend this meeting, Lynn will be happy to give details and she can be contacted on **01708 551889**. Meetings are held on the **third Wednesday of the month (2 – 4pm)**. The remainder of the 2009 meeting dates are **July 15th, no August meeting, September 23rd, October 14th, November 18th and December 2nd**.

The second MND Association Support Group is held at **St. Joseph's Hospice in Hackney**. Here meetings are held on the **second Monday of each month (1.30-3.30pm)**. These meetings are organised by the MND Association and the Hospice jointly and if people would like to attend if they ring the **Hospice on 020 8525 6030 or Frances Carroll from the MND Association on 0845 3751851** for further information. If people live within the Boroughs of Hackney, Tower Hamlets and Newham, Hospice transport can be arranged.

The MND Association can provide some financial help with transport from other boroughs within the North East London area. There is usually staff at this Support Group from the Hospice and the MND Association along with therapist including physiotherapist and dietician who can give advice as well as complimentary therapists. Complimentary therapy is available to people living with MND and their carers at this meeting.

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

Many thanks to....

In memory of Pam Cook **£2,020**
In memory of Pam Cook **£500**
Patrick O'Regan donation **£50**
R. Lee **£50**
Pocket money of Daniel, Michael and Alex Warman **£10**
Christmas card money **£368.40**
In memory of Terry Wakefield **£415.00**
In memory of Pam Cook **£800.00**
Waitrose Buckhurst Hill collection **£600.00**
Janet Bedford **£502.20**
Bus stop raffle **£41.00**
JF and MJ Shirley **£50**
Heather Kneale **£250**
Liz Edmonds **£70**

Thanks for the presents

The organisations who contributed were Waitrose, Buckhurst Hill; W.H.Smith, Ilford; Fairheads, Ilford; Boots, Ilford; and Morrisons, Loughton.

Anne and Carole gave a talk to the Loughton and Buckhurst Hill Rotary Club recently. Many thanks to the Rotary Club who supported the group by donating **£150**, which helped to pay for, Christmas presents.



Quiz fundraising - well done to Janet Bedford who held a quiz on Saturday, 9th May in aid of MND and raised a fantastic **£502.20p**. Pictured Janet and Sophie Bedford (and not of course forgetting Sophie the dog), Rosina Lee, Shirley and Sylvia (Rosina's sisters), Alan Cook, Linda Rumsey and Lynn Sprague. Who also supported the wonderful quiz evening. Also thanks to many of Rosina's lovely family who were in attendance and Sam and Jacqui, and also many thanks to Janet, Sophie and Brian Bedford and Derek (the Quizmaster) for their hard work in putting together the evening and for supporting MND for the chosen charity.

Great party All at the YMCA Christmas party had a great time last December. Carole added: "A big thanks to all the staff who helped make it such a success and supplying good food. We raised **£368.40** through selling Christmas cards with commission on this of **£65.53**."



Sponsored walk – well done to Liz Edmonds who raised **£70** after taking part in a three-mile run.

Pictured is Liz Edmonds (MND Specialist Nurse for Havering PCT) presenting a cheque to Pam Manning (one of the original founders of the Romford Support Group).



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