

Date: Summer 2012

**Registered Charity
no. 294354**

In this issue

June is MND Awareness Month.

Open Garden and Teas
Sunday June 10th do **come**.

Local people fundraise for
EKMND Group.

Jim retires from his role as
Chairman for our group
and Brian steps up to the
hot seat!

Could you become a
volunteer visitor?

Diary dates

Support meetings:

- Saturday 23rd
June. 11am to 1pm.
Ramsgate Garden
Centre. CT11 7ET
- Saturday 8th
September. 11am to
1pm. Guide and
Scouts H.Q, Sturry.
Canterbury
CT2 ONR
- Saturday 24th
November. 11am to
1 pm. The Red
Cross Centre,
Folkestone.
CT19 4AY

East Kent Motor Neurone Disease Development Group



Boxing Day Dip in aid of East Kent MND (See article inside.) It looks cold!!!

Thank You Jim

Jim West hands on the title of chairman for our group after over a decade in this role. Jim (on the left) receives a certificate from head office from Brian who is the new chairman. We are delighted that Jim and his wife Astra will continue on the EKMND Group committee.



Useful Contacts

Branch Contacts:

Chairman	Brian Sackett 7 Ashdene Grove Sturry Canterbury Kent CT2 0NA Tel 01227 710769
Secretary	Astra West
Minutes Secretary and Newsletter Editor	Wendy Sansom
Treasurer	John Hamer
Committee Members	Hazel Watts Jim West Joan Whitehead Chrissie Batts Beryl Gisby Judy Keay Sheila Ramdular
Regional Care Advisor (Kent and East Sussex)	Sara Murray Suite 34 30 Churchill Square Kings Hill Kent ME19 4YU Email: sara.murray@mndassociation.org Tel: 0845 375 1849
Volunteer Development Co-ordinator	Vacancy
Thumbprint available on line	www.mndassociation.org/membership
Online Forum	http://forum.mndassociation.org
National Helpline Mon – Fri 9.00am – 5.00pm and 7.00pm – 10.30pm (a local charge call)	Tel: 08457 626262 Email: mndconnect@mndassociation.org

MND Association Contacts

Regional Care Development Advisor – Sara Jane Murray, c/o MND Association, Suite 34, 30 Churchill Square, Kings Hill, Kent, ME19 4YU

Email: sara.murray@mndassociation.org

Tel: 0845 375 1849

National Office: 01604 250250, enquiries@mndassociation.org

MND Connect: 08457 626262, mndconnect@mndassociation.org

MND Association website: www.mndassociation.org

Offers support, information and advice to people living with MND and to health and social care professionals and volunteers.

Ben Terry Boxing Day 'Dip' 26.12.12

On the 26/12/11 I attended a boxing day swim in aid of Motor Neuron Disease.

I would normally do the swim each year, but usually donate the sponsored money to the RSPCA. Unfortunately my father was diagnosed with MND a few months before Christmas, so I decided I'd now do charity events in aid of MND, after seeing how it affects lives. It's changed my life a lot since he was diagnosed, and things have been quite tough, but knowing I'm doing something useful definitely helps me, and the people the money is going towards. I wanted the money to go to a smaller, local charity, so the money could go towards equipment, such as stair lifts, oxygen tanks etc.

Before my dad had the disease, I knew very little of it at all. It's not a very common disease, so I never really heard of it until quite recently. It's been tough for everyone seeing the rate at which his strength is declining, but fortunately I have a very strong bonded family, and we're all working together to make the best of a bad situation. We recently went to New York, and are doing all we can to enjoy life as much as possible, despite my dad's condition.

On the day, I decided to dress up as a super hero - Banana Man. I wanted to stand out from the other swimmers and make the swim as fun and comical as possible, despite the extremely cold temperatures! I stayed in the sea for 3 painful minutes, then got dried off as quick as possible.

We had sent sponsor forms round to family, friends, work colleges etc, and everyone was extremely generous with their donations. So generous that we raised an amazing £1,317.00!

I hope to do more events in the future, and raise more awareness of the disease.



Alistair's Album

Alistair Banks has recorded an album, the CD is priced at £7 plus £3.95 p.p. Available from www.mndassociation.org/shop or by phone 0845 375 1857

The album is also available to download and there are links to the download sites on www.alistairtheoptimist.org

The national MND Association receives all of the profits from the CD and 22% of the profits from the download.

Katy Baxter and the Great South Run!

Katy recounts her experience following her stepmothers death from MND.

My beloved step mum Josette Baxter was diagnosed with Motor Neurone Disease in December 2010, although I had heard of this illness I had been fortunate never to have witnessed someone suffer from it.

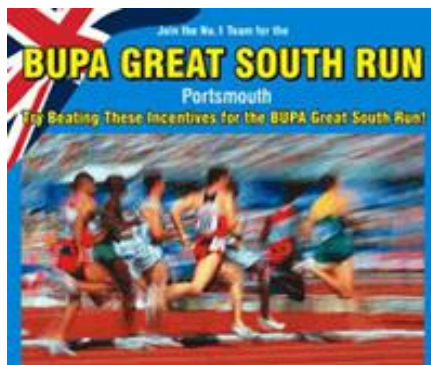
Over the following eleven months our family watched the most full of life person we had known deteriorate in front of our eyes. Although she was unable to communicate we still saw glimpses of the old Jo when she would manage a smile and her eyes would shine to let us know she was still there.

My father was incredible and cared for her with love and determination until she passed away at home on 7th November 2011. Although much of this was due to him being a stubborn so and so he would not have been able to do this without the care and support of the daily carers that attended and knowing if he had any concerns or questions he could contact the local MND Group for answers and reassurance.

Me and my partner were already registered to do the Great North Run in September 2011 and had committed ourselves to raising £600 for a children's hospice.

Following Jo's diagnosis we felt we would like to do something to help others going through the same thing so we decided we would also do the Great South Run and any extra money we raised would go towards MNDA.

After hours of agony, sore feet and falling down a hole in the road we completed our task and managed to raise a total of £1000, a cheque for £400 going to the East Kent MND Group.



The Saltwood Boxing Day Run

This marvellous annual event raised £1,750 for the EKMND Group and a cheque was presented to Jim West in January 2012. Jim said "We are all very grateful to everyone who organised, marshalled and took part in the event".



Thank You to All Fundraisers

The money you raise is used to help local people living with mnd and their families ,one of the most popular items requested is the Closomat ,a toilet which also washes and dries ! these are not provided by statutory agencies and are not cheap to hire and install but are an invaluable help to maintaining independence and dignity.

Other items the group has funded include alternative therapies such as reflexology , very individual help such as help for travel costs ,help for special seating , purchase of specialized clothing, family outings , or any request which will help improve the quality of life for a person living with mnd or their carer.

So please let us know if you need something, usually requests come to us via Hazel Watts (Care Manager) or Chrissie Batts (Specialist Nurse) We also produce this local newsletter twice a year to keep you in touch with what is going on locally.

The local committee members also fundraise and in the last few months these have included.....

Producing and selling a booklet on household cleaning tips!
Tabletop sales , bootfairs and coffee mornings. Making a donation instead of sending Xmas cards. Being Father Christmas! Applying to local charitable trusts.

Well done to Betty Spicer for her coffee morning and to her granddaughter Nina Spicer for completing the London Marathon in approximately four and a half hours.....raising money for the national MNDA.

Here's an idea..... a charity head shave!



Joan (committee member) is opening her country garden on Sunday June 10th 2-5pm Ivy House ,The Street ,Stourmouth . Nr Sandwich Kent CT3 1HY.

Park at the pub about 50 yards away .

Teas and cakes will be served. Do come and meet us .



Motor Neurone Disease Awareness Week

This covers the whole of June 2012 so get baking , hold a coffee morning, have a sponsored walk or run or something more adventurous!

Pub quizzes , dinner parties , talent shows , dance competitions or sponsored head shaves , are all fun ways of raising money .

MNDA have free fundraising materials, posters ,balloons etc contact them on 01604 611860 or email fundraising@mndassociation.org.

Could you become a Volunteer Visitor?

The support from an association visitor can make all the difference to someone living with mnd and their families. The MND Association offers training and support for this role ,at its core it means befriending and supporting someone at a very difficult time in their lives.

Training Dates Sunday 24th June, Tuesday 21st August, Friday 5th October, Saturday 6th October, Sunday 7th October and Wednesday 21st November . All in London.

Contact volunteering@mndassociation.org

Calling For A National Strategy for People With Neurological Conditions.

The MND Association is calling on the Government to produce a national outcome strategy for neurology ,develop a neurological network and appoint a national clinical director for neurology (a “Tsar”) to champion improvements that we urgently need.

On the 1st of May an event will be held in Parliament hosted by the Neurological Alliance bringing together charities parliamentarians,and clinicians to recommend urgent government action.

What You Can Do

Email your MP-visit www.mndcampaigns.org/naoreport to send a prewritten message to your MP.

Send a letter to your MP-Call Raj Johal MNDA on 020 8551 2152 for a template letter.

Informative Bits

The New Carers Pack Caring and MND : Support for You is available from MND Connect 08457 626262 (free of charge)

Changes to Blue Badge Scheme These are to be introduced soon with the funding for the scheme shifting from the NHS to local authorities.

From April next year eligibility will have to be confirmed by an independent assessor, unless it is “self evident”.

Badges will have a new design to help prevent counterfeiting and the maximum fee will be £10 from Jan 2012.

Holiday in Norfolk (Recommendation from a reader of Thumbprint)

In 2011 we had the good fortune to find an ideal holiday location, we stayed in Horning on the Norfolk Broads.

It was a luxury cottage complex set up at a converted farm. My wife has MND and is unable to walk and I am her carer. We also had my son , wife and two grandchildren with us.

The place is Hall Farm Cottages and is in a quiet location , the complex has six cottages that sleep six self catering. One room is a double downstairs with an en suite wet room. Upstairs are two more bedrooms and a bathroom.

Hannah and the staff are ever so helpful and can provide many different aids. We had a riser recliner chair and a power scooter all at no extra cost (donation for more support items is voluntary) . Also they provide a list of providers of specialist equipment hire companies.

We really enjoyed the experience and would go back if we can.

Support Meetings

See dates for these meetings on the front cover and all members will be sent an invite each time , membership of MNDa is free and means you will also receive this local newsletter.

Its an opportunity to see Chrissie and Hazel and chat to others in the same situation in an informal setting.

Brian has worked hard to raise awareness and you may find an MP or local mayor attending support meetings to find out more about the challenges of living with mnd.

The East Kent MND Group Committee

We are a small group meeting every six weeks at the Old Gate Inn Canterbury ,some members have specific roles such as chairman and treasurer ,others support the fundraising activities and the running of support meetings.

If you would like to join the group please phone Brian for a chat , we welcome new ideas and skills...perhaps you would like to produce the newsletter , take the minutes at meetings , hold a fundraising event or become an association visitor.

The members are a great inspiration and Its very satisfying and can be great fun so don't be shy !

See inside front cover of this newsletter to find out who is on your local MND Group Committee.

A note for fundraisers

If you would like the funds raised to go to local people living with mnd please send your cheques directly to Brian or if you send the cheque to MNDA Head Office please send a covering note to say you wish the money to go to East Kent MND Development Group,
Many Thanks.

Finally we wish you all an enjoyable and sunny few months ahead!