

# West Sussex North Branch May 2011

[www.mnd-westsussexnorth.com](http://www.mnd-westsussexnorth.com)

## Diary of Events

**Meetings at the ARK, Turners Hill** - 26th June, 25th September, 4th December  
**Please** bring a few flowers to the one on 26th June so that we can make a floral heart similar to the one we made previously.

**MND Association's Annual Conference and AGM** - 10th September at the Radisson Blu, Stansted

### AGM was a Huge Success

This year's AGM was held at the Age Concern centre in Haywards Heath and was attended by forty-three people.

It was a wonderful evening, where we were given two fantastic presentations by Dr. Kirstine Knox Chief Executive of the MND Association and Dr. Steve Dyer our branch President.

Kirstine spoke about the history, work, achievements and aspirations of the MND Association. She highlighted that it has some 3,500 volunteers and 155 staff all working together to promote research around the world and to provide care, support and information for people living with MND and their families. Also that all the hard work and commitment of local branches has raised an amazing £2 million over the last year!

She discussed last years fantastic achievements in research including Martin Turner's work in developing a diagnostic test for MND and the finding of international stem cell research at Edinburgh University, to name but a few.

Dr. Steve Dyer gave a wonderful talk on his work and the patients he sees, and focused on the importance of communication and how listening can transform lives and help people to overcome fear through translating medical knowledge into

### Emma Stolton Receives Extra Mile Award

Emma Stolton from Bluebird Care was presented with an Extra Mile Award by Dr. Kirstine Knox, at this year's AGM.

**Congratulations Emma and thank you for all the wonderful work you do.**



Steve Dyer, Emma , Kirstine Knox & Carol Rieley



## Fundraising

### Jo Stone's Marathon run

Congratulations to Jo Stone, who completed her run in the London Marathon in 5 hours, exhausted but triumphant. This is her description of the event

*'I decided last year when I watched the marathon that I was going to run it in 2011 for MNDA. I knew that Darran would want to be there to support me and I wanted him to have an "aim" as well as me. I started my serious training in December once I had been given my golden bond place. Sometimes it was hard making myself go out of the house at weekends – 4 hours running is a long time to be out when you have so many other things to do. I have had so much support from my family and friends who came and looked after Georgia and Darran while I was training and they continued that support on the day.*

*The day itself was one of the most amazing experiences. I felt scared being on my own – but I met two people, Dave and Kylie, at the start who were also running for MNDA and we swapped stories. From then on it was like running with friends on a Sunday morning. I absolutely loved it – it was hard at points but I was lucky enough to see my family and friends at four different places along the route. This gives you such a boost, and when you run the last bit down Birdcage Walk and can see the finish I cannot describe the elation that you feel.*

*Having said before I ran the London Marathon that this was a one time experience – I have changed my mind and will run it again.*

*I have raised approximately £2,600 – but I think the final total will be higher as a couple of sponsor forms have still to be collected and I have no idea how much is on them.'*

### MND Art Exhibition

**In March, an Art Exhibition, organised by Rachel Cowell (on the right, in picture) of the Ginger Moo Gallery at County Mall in Crawley, was held at Staplefield Village Hall. As well as featuring work by local people affected by MND a number of portraits by Patrick, 'the incurable optimist,' were on display.**



**It was an excellent event which raised £850 for our branch.**

### City Quiz

Alf Bodimeade, the organiser, reported that the total, when all has been received, should be £6,760. He was very pleased, as this year it was held at a new and completely untried venue without any fancy technology and which could accommodate 42 teams, as opposed to 52, last year.

Everybody seemed to prefer the new venue, which was more personal and friendly and certainly less chaotic.

## A Royal Run



Royal Parks Foundation  
Half Marathon

Fancy taking part in a fantastic opportunity to raise money and challenge yourself this year?

The Royal Parks Half Marathon is set to take place on the 9th of October, the route is set to take in some of the beautiful sites London has to offer and will be a fantastic day for everyone involved.

The MND Association have 60 golden bond places up for grabs, on a first come first served basis, and places are sure to get taken fast so don't delay!!

For more information, please contact Anita Frith, event manager, on **01504 611867** or email [anita.frith@mndassociation.org](mailto:anita.frith@mndassociation.org), or alternatively contact Anita Solan, event administrator, on **01604 611832** or email at [anita.solan@mndassociation.org](mailto:anita.solan@mndassociation.org).

## Dexpramipexole Trial Begins Worldwide Recruitment

In March of this year, Biogen Idec and Knopp Biosciences announced that a worldwide clinical trial for the drug Dexpramipexole recruited its first participants. The UK part of the trial is however, not yet recruiting.

The trial is a phase 3 study that will be testing the safety and effectiveness of Dexipramipexole in over 800 people living with the most common form of MND called ALS or amyotrophic lateral sclerosis. The trial will last for at least twelve months and cover eleven countries.

The UK trial is set to open for recruitment in the coming months and will involve approximately sixty people across six MND Association care centres in England.

Criteria for participants are that they must:

- Be diagnosed with ALS
- Aged between 18-80
- Have had symptom onset within twenty-four months of day one of the study

Other criteria are outlined on the webpage: [clinicaltrials.gov](http://clinicaltrials.gov). You will also be able to find information for it on the MND Association's website, which will be updated as soon as UK trials begin.

If you find that you are unable to participate in the drug trial and would like support, the MND Connect team can provide emotional support and be contacted on: **08457 626262**, or visit [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

### Join Forces to Challenge Benefit

The MND Association has joined with disability charities across the UK to challenge the Government's welfare reform agenda and cuts to disability benefit support.

The MND Association believe that the proposed changes will disadvantage many people with MND and their carers, so they are asking for everyone's support to make the Government listen.

To give your support, please write to David Cameron, join the online protest or contact Raj Johal on **020 8551 2152**.

For more information, please visit: [www.mndcampaigns.org/take\\_action](http://www.mndcampaigns.org/take_action) or [www.hardestdit.org.uk](http://www.hardestdit.org.uk)

### HRH Princess Royal Visits Lab in Forefront of MND Research

On the 20th April 2011, Her Royal Highness, The Princess Royal, visited the Euan MacDonald Centre for MND Research based at Edinburgh University, in her role as the MND Associations Royal Patron.

This centre has been working in collaboration with London and New York, in its research to manipulate stem cells so that they may provide a unique tool for studying MND.

HRH The Princess Royal said: "My perspective is long-term but there are such signs of hope"

Dr. Kirstine Knox, Chief Executive of the MND Association, said "We are thrilled that HRH The Princess Royal was able to see first hand an example of the cutting edge research the MND Association is finding."



**Chairman**

Carol Rieley  
01444 482387

**Vice Chairman**

Chris Sheridan  
01444 245486

**Secretary**

Liz Carter  
01444 232099

**Treasurer**

Alf Bodimeade  
01444 482260

**Newsletter Editor**

Natasha Newton  
07812122932

**Association Visitors**

Chris Sheridan  
Linda Smilie  
Robert Mynors



**Helpline:** 08457 626262

**Email:**

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

**Website:**

[www.mndassociation.org](http://www.mndassociation.org)

**Address:**

PO BOX 246, Nothampton, NN1 2PR

**National Office:**

David Niven House, 10-15 Notre Dame Mews, Northampton, NN1 2BG

**Telephone:** 01604 250505

**Branch Email:**

[westsussexnorth@mndassociation.org](mailto:westsussexnorth@mndassociation.org)

**Branch Website:**

<http://mnd-westsussexnorth.com>



**1st Orient Express**  
or  
**£3000 cash**



**2nd Digital Camera**  
or  
**£500 cash**



**3rd Spring Weekend Break**  
in Snowdonia

**The MND Association  
National Raffle is upon us again!**

All tickets, posters and payment slips will shortly be sent to our branch and will be made available to all who would like them.

**As ever, there will be some amazing prizes to be won, so don't wait to take part, and good luck to everyone!**



**4th Garden Furniture**  
or  
**£150 cash**



**5th Luxury Hamper**  
or  
**£100 cash**



**20 Runners up**  
Cupcake vouchers

### Treasurers List of Monies Received

Mrs Stone	73	J Rieley - Sale of Sweet Peas	168
Linda Smillie	100	N Hodson - Sale of Cameras	230
Alison Buckley	18	J Rieley - Sale of Calendars	125
Carman Eyre	20	Sue Charman Tribute Fund	46
Christmas Sales	217	Jenny Rimmer Hat Hire	520
In memoriam MR	1,143	Brighton Road Baptist Church	81
J Rieley - Birthday	140	Staplefield Art Exhibition	827
Eve's Tea Rooms	44	Sam Hopkins Half-Marathon	1,407
Fireman Calendars	5,487	Tim and Stevie Roberts	870
In Memoriam RH	330	Burgess Hill Fabric Shop	49
David Adley	20	Mr. and Mrs. Drake	20
Stephen Edwards	30	E. Hill and W. Gillies	100
Pam Setford & Dolphin Medical Practice			65