

**MOTOR NEURONE
DISEASE
ASSOCIATION**

**WEST SUSSEX - NORTH BRANCH
NEWSLETTER**

JANUARY 2009

HAPPY NEW YEAR

Diary Dates



Please note:

If you need help with transport to a meeting, we can help.
Contact Carol Rieley on 01444 482387.

Social Get Togethers

Sunday 15th March

*The Ark, Turners Hill
3 pm to 5 pm*

Sunday 28th June

*The Ark, Turners Hill
3 pm to 5 pm*

Sunday 27th September

*The Ark, Turners Hill
3 pm to 5 pm*

Sunday 6th December

*The Ark, Turners Hill
3 pm to 5 pm*

AGM

Tuesday 21st April

The speaker is to be announced. All are welcome.
Please bring family and friends. The formalities will
be short and there will be wine and cheese.

The Age Concern Hall, Haywards Heath



Fundraising

Monday 20th April
Quiz in the City

For details contact Alf Bodimeade

Saturday 28th February
'Letz Zep' (Led Zeppelin tribute band)
plus three supporting groups.
Doors open 5.30 pm
First band 6.00 pm
All profits to the MND Association

*Worthing Assembly Hall
£15.00*

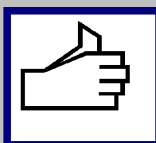
*For tickets, ring box office
01903 206206*

Street Collection

Saturday 6th June
Saturday 4th July

*Horsham
Haywards Heath*

Fighting
Motor Neurone Disease



*Our Thumbs Up symbol represents David
Niven's last defiant gesture. It remains
our symbol of hope.*

West Sussex North Branch Quiz

Following the enjoyable and successful quiz in 2007, another one was held at the social club at the Princess Royal Hospital, Haywards Heath last October. 96 people attended and Alf Bodimeade again ably took the part of question master. There was a tie for first place but this was sorted out by way of a tie-breaker question (to the dismay of your editor's team who did not know how many rivets are in the Forth Bridge!!) and each member of the winning team won a bottle of wine. There was a wooden spoon for members of the team which came last. A fish and chips supper was enjoyed, there was a superb raffle and a marvellous £867 profit was raised.

My Great North Run by Adrian Carter



The day has arrived. Instead of feeling fit and able to take on the World, I'm standing in shorts, T-shirt and bin liner shivering like a whippet along with 51,999 other runners. The clock seems to take an eternity counting down to the start time and finally BANG the gun goes off and..... I don't move for another 25 minutes as the thousands before me slowly move forwards to cross the start line. With a beaming smile from Tony Blair, my race begins.

The noise and support from the crowd is fantastic. The "Oggy, oggy, oggy - oi, oi, oi's" echoing through the tunnels and people shouting encouragement from every pavement and bridge. You can't help but read the shirts of other runners, some running for lost and loved ones and others running for so many good causes. I pass a couple of other MNDA runners and breathlessly give my support.

A slow climb to mile 6 where we were greeted with a sign that stated this was the highest point in the race and that the next three miles were all down hill. I plod on happily. Legs feel good. Note to self – look up the Northern definition of 'down hill' as I seem to have missed those three miles.

The road is a sea of runners before me all pushing on and up. From mile 10 to 12, it feels like I'm running through treacle. A slight gradient and the road seems to pull my legs backwards. Spurred on by the supporters and the steel band, I reach the top of the hill and look down the steep hill to the sea. The blast of fresh sea air and the big 'You're nearly there' sign refocus the mind.

As I turn the last corner and make my way along the seafront to the finish, the noise from the pavements is massive. Everyone is clapping and cheering. 200 yards to go, all of the training in the sun, wind, rain and thunder seems so worthwhile. 100 yards to go and the Red Arrows fly across the skyline in front of me. Fantastic. I cross the line in 2 hours and 16 minutes and in 22,543rd place. Slightly off the Elite pace but I enjoyed every step of it.

Thank you very much to all those who sponsored me helping me to raise over £500 for MNDA.

Christmas Tea Party



On Sunday 7th December the branch held its Christmas 'get together' at The Ark in Turners Hill. We were delighted that over thirty people could make the party and enjoyed the sumptuous selection of home made cakes and a festive flower arranging demonstration by Shirley Crowther. In the absence of our Chairman, Carol Rieley, who was enjoying a holiday in New Zealand, Chris Sheridan, Vice Chair welcomed everyone and congratulated two young fund raisers on their fantastic efforts. Tom Hopkins raised £60.72 collecting at his school and Shirley Crowther's grand daughter, Hannah Cousins, successfully nominated MNDA as her school form's chosen charity for the past term.

The afternoon finished with a raffle of Shirley's arrangements and other festive fare. We look forward to seeing you at the first of the 2009 social events on Sunday 15th March at The Ark.

Accessible Britain

The Motability Car Scheme and Rough Guides have between them produced a guide for ideas on tried and tested days out across the UK. The guide is user friendly with handy maps to help plan your day out. The guide costs £6.99 (incl P & P) or free to Blue Badge holders who pay £1.99 for P & P and is available on line at www.accessibleguide.co.uk.

Log on for safety advice

The Disability Living Foundation and Tunstall have launched a new website to raise awareness of the benefits of telecare for people living with a physical disability and sensory impairment. Telecare consists of equipment and services that support people's safety and independence within their homes. The equipment can sense risks such as smoke, floods and gas, can remind people to take medication and can also call for help in the event of a fall or accident. The website address is: www.telecaremadeeasy.com.

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.org.uk gives useful information about accommodation with ceiling hoists, including hotels, guest houses, self-catering accommodation, motor homes and caravans.

Wheelchair accessible toilets

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.



Walk to d'Feet MND – July 2008

(Apologies for missing this out of the last newsletter – Ed)

It was good to see so many people turning out to join our walk – 24 in all plus 2 dogs! Many were our usual “stalwarts” but it was also good to welcome new faces. The walks are always friendly events with plenty of chatter and this year’s was no exception. The location this year was Horsted Keynes – a circular walk as usual but with just one stile! We walked for approximately two hours and, despite a dismal weather forecast, the rain held off until the last twenty minutes or so.

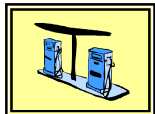
Many thanks to all who supported us. We raised £210 in total. We look forward to seeing you all again next year.
Chris Sheridan

Monitoring the financial situation

By Kirstine Knox, Chief Executive

You may have seen or heard recent coverage in the media of the news that the financial reserves of some charities have been put at risk by the collapse of banks in Iceland. I am pleased to say that we do not have any investments in Icelandic banks and have therefore not been directly affected by developments in the Icelandic economy. We will be continuing to monitor the current financial situation carefully, including its impact on people affected by MND who, of course, remain at the centre of what we do at the Association.

Paying at the pump – know your rights



Disabled drivers can find it difficult to get out of the car to use a chip and PIN terminal. Banks can still provide you with a chip and signature credit or debit card if you are unable to use PIN. The technology used at the point-of-sale will recognise the fact that it is a chip and signature card and will print off a receipt for you to sign. Your bank should inform you of any consequences of not having a PIN-enabled card; this could mean that you may not be able to use a cash machine.

On the forecourt, after indicating that you need assistance, a member of staff will fill your car with the required amount of petrol, ask for the card you wish to pay with, then return from the shop with the paper slip for you to sign. You can find out more at www.bankingcode.org.uk.

Step towards equality



European Union legislation is a significant step towards equality for disabled people. The first stage of the legislation came into effect in July 2007 making it unlawful for airlines to refuse bookings from disabled people. The second part of the legislation came into effect in July 2008 and covers assisted travel, compensation for damaged mobility equipment and disability equality training for airport and airline staff. The Civil Aviation Association will enforce the legislation in the UK. For further information visit: www.disabilitynow.org.uk.

New stem cell clinic opens

The treatment offered in Cologne is unproven.

Over the last few months, the MND Association has become aware of a new stem cell clinic that has opened in Cologne, called ‘X-Cell’, that is offering stem cell treatments to people with MND. Currently, there is no scientific basis for how this treatment may help motor neurones affected by MND on a cellular level and therefore no evidence for how it may help people with MND. In addition, the side effects of receiving a stem cell treatment are unknown. Thus, the treatment offered in Cologne is unproven.

We would encourage anyone with MND who is considering embarking on an unproven treatment to discuss all the implications with their neurologist before making a decision. More information is available in the Association’s Research Information Sheet U.

If you would like to talk this over with someone, please contact the Research Development team on 01604 611880 or, alternatively, by email at research@mndassociation.org.

Keep Warm and Save Cash



If you receive certain benefits, you could be entitled to FREE home insulation from British Gas and access to British Gas’s lowest standard rates. To qualify, you must be receiving one of these benefits:

- Disability living allowance
- State pension credit
- Attendance allowance
- War disablement pension
- Disablement pension
- Child tax credit where relevant income is £14,600 or less.
- Working tax credit, where the relevant income is £14,600 or less.
- Council tax benefit
- Housing benefit
- Income support
- Income-based job seekers allowance
- Carers allowance
- Severe disablement allowance.

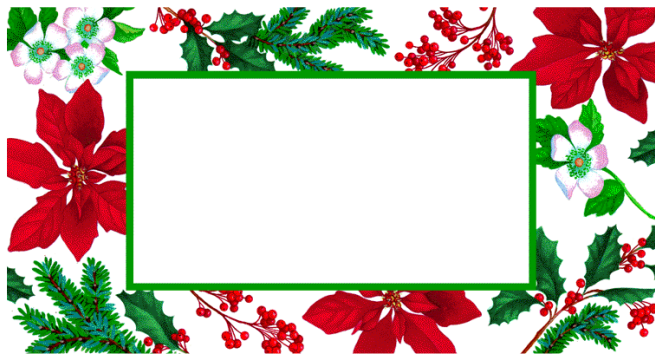
For more information call **0845 8502207**.

MONIES RECEIVED



Anna Shaw – Bewl Water Walk	£ 297.00
Tim and Stevie Roberts (Bridge Drive etc)	£1,200.00
Lindfield Street Collection	£ 265.00
Haywards Heath Quiz Night	£ 867.00
Jenny Rimmer’s Hat Hire	£ 610.00
In Memoriam MS	£ 885.00
East Grinstead U3A	£ 537.00
Mrs McDonald - donation	£ 50.00
Mr D J Julian - donation	£ 100.00
Raffle at Branch Meeting	£ 55.00
Tom Hopkins Collection	£ 60.72

**Christmas Card Design
Competition 2009**



Have you ever thought you could design a better Christmas card than the ones you've seen for sale? Well here's your chance.

As 2009 is the 30th anniversary of the foundation of the Motor Neurone Disease Association, they are offering promising artists and budding photographers the chance to demonstrate their talents by designing a charity Christmas card for 2009. Designs should be creative and original, incorporating a Christmas or winter theme. Entries must be presented as artwork or photography (20cm x 20 cm) and can be traditional or contemporary. There are no restrictions on style. The winning designs will be reproduced into 12.7cm x 12.7cm cards.

The different categories for entrants are:

- *Person with MND*
- *MND Association Members and people affected by MND*
- *MND Association Staff and Volunteers*
- *Aged 10-17*
- *Aged under 10*

The deadline for entries is 27th March 2009, judging will take place on 6th April 2009 and the winners will be notified by 30th April 2009. Their designs will be mass produced and sold as part of the MNDA Christmas 2009 Collection.

To enter, ask Liz Carter (01444 232099) for an entry form, complete it and send it with your design (carefully packaged) to Liz Watkins, MND Association, PO Box 246, Northampton, NN1 2PR by the deadline of **27th March 2009**. Copies of the entry form can also be obtained from Liz Watkins on 01604 611688 or by emailing her on liz.watkins@mndassociation.org.



MOTOR NEURONE DISEASE ASSOCIATION

HELPLINE – 08457 626262
(all calls charged at local rates)

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NORTHAMPTON, NN1 2PR

Reg. Office: David Niven House
10-15 Notre Dame Mews
NORTHAMPTON, NN1 2BG

Telephone: 01604 250505

Fax: 01604 624726

Reg. Charity No. 294354-Reg. Co. No. 2007023

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