

**MOTOR NEURONE  
DISEASE  
ASSOCIATION**

**WEST SUSSEX - NORTH BRANCH  
NEWSLETTER**

**MAY 2009**

*Diary Dates*

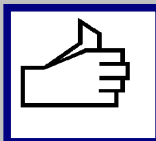


Please note:

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

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|---|---|--|
| <b>Social Get Togethers</b>               | <b>Sunday 28<sup>th</sup> June</b><br>We will celebrate the lives of our loved ones who have passed away (not just due to MND)  | <i>The Ark, Turners Hill</i><br>3 pm to 5 pm   |
|   | <b>Sunday 27<sup>th</sup> September</b>   | <i>The Ark, Turners Hill</i><br>3 pm to 5 pm   |
|   | <b>Sunday 6<sup>th</sup> December</b>   | <i>The Ark, Turners Hill</i><br>3 pm to 5 pm   |
| <b>Street Collections</b>                 | <b>Saturday 6<sup>th</sup> June</b><br><b>Saturday 4<sup>th</sup> July</b><br><b>Saturday 28<sup>th</sup> November</b>  | <i>Horsham</i><br><i>Haywards Heath</i><br><i>Sainsbury's, Haywards Heath</i>  |
| <b>Walk to D'Feet MND</b>                 | <b>Sunday 5<sup>th</sup> July</b><br>3 miles (approximately 1½ - 2 hours)<br>Bolney recreation ground - behind the church.<br>Entrance is off the A272 immediately west of Bolney nursery – sign-posted for Church and School.<br>Dogs are welcome but will need to be on a lead for part of the walk. Eight Bells pub in the village serve very good lunches.<br><br>This is not intended to be a sponsored event, but a donation of at least £5 to branch funds would be welcome.<br><i>For further details, contact Chris Sheridan on 01444 245486 or email <a href="mailto:christine.sheridan@virgin.net">christine.sheridan@virgin.net</a></i> | <i>Bolney</i><br>10.30 a.m.<br><br> |
| <b>Quiz</b>                               | <b>Saturday 17<sup>th</sup> October</b>   | <i>The Social Club, Princess Royal Hospital,</i><br>7.30 p.m. <i>Haywards Heath</i>                                      |
| <b>Bridge Drive</b>                       | <b>Monday 28<sup>th</sup> September</b><br>£6 per person including a delicious tea<br>For more information Tel: 01342 301684  | <i>Warnham Village Hall</i><br>2 pm  |
| <b>Annual Conference and National AGM</b> | <b>Saturday 12<sup>th</sup> September</b>   | <i>Park Inn Hotel, Heathrow</i>  |

*Fighting*  
**Motor Neurone Disease**



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

## Report of AGM

The AGM at the Age Concern Hall in Haywards Heath on 21st April was well attended. In her report, Carol Rieley, Chairman, reflected on the past year. She said the weekend meetings with tea, cakes and chat at the Ark had been enjoyable and she had been pleased to see some members who found it difficult to attend the evening meetings in the past. The street collections had raised almost £2,500 and Carol warmly thanked all the stalwart collectors. Other highly successful fundraising had been by Alf Bodimeade who raised £11,000 with his city quiz, Liam Dwyer, who organised a bike ride from which we benefited by £4,802 and Tim and Stevie Roberts who raised £1,200 from their annual bridge drive. The money raised and donated had been put to good use helping people living with MND. Carol thanked all the committee and also her husband, John, for all their hard work during the year. Longstanding awards are to be presented to Nick Cottom, Alf Bodimeade, Lorelei Hilson and Carol Rieley.

In his Treasurer's report, Alf Bodimeade told us that our income was £35,000 which was up from £26,000 last year. He stressed that this money was for the benefit of people living with MND and, if anyone knew of a need for it, to let Carol know.

Most of the committee were willing to stand again but Lorelei Hilson was standing down as Newsletter Editor after 8 years and Anna Shaw, Publicity Officer, was leaving after 4 years. Carol said that Lorelei had been a dedicated and thoroughly professional editor and the newsletter had grown into an excellent production. She thanked both Lorelei and Anna for all their support and hard work and they were presented with a lovely floral arrangement and a WHS gift card. There was an appeal for a new Publicity Officer. The newsletter will be taken over by Natasha Newton, a health professional who had benefited from funding by the branch to attend courses and had kindly said that she would like to give something back by helping in this way. Carol expressed everyone's gratitude to her.



When the business had been completed, Carol introduced our speaker, David Arscott, a former newspaper journalist and BBC producer/presenter who has for some years worked as a freelance author, broadcaster, publisher and editor. David regaled us about a Sussex gardener called Bert Winborne who was born in 1905 and was a champion gardener. Bert did a weekly radio broadcast for David in his broad Sussex dialect which is now long gone and David explained that this dialect differed in East, West or Mid Sussex. Bert started work with a team of 15 gardeners in a large Sussex garden at the age of 14. It was very strict and the vegetables had to be presented properly to the demanding and fearsome cook. He loved the life and was a stickler for doing things properly. He entered many local shows and, in 1952, the Daily Mail put on a national vegetable show which he entered and won, having only half a point deducted and that because nothing could be deemed perfect. After he stopped showing vegetables, he became a judge. He still wanted to help make a vegetable patch at around the age of 90. After David's talk, there was a discussion about regional accents. It is hard to preserve them because people move around so much now. On a show of hands, only 4 people were Sussex born and bred! After the talk, we enjoyed wine, a delicious buffet and a good chat.

### Support through funding maze

A NEW guide to support people through the care funding maze and establish whether or not their loved one may be eligible for NHS continuing healthcare has been published by Counsel and Care, the national charity working with older people, their families and carers to get the best care and support. Stephen Burke, chief executive of Counsel and Care, said: "We are concerned that access to the right advice and information about the assessment process and eligibility for NHS continuing healthcare remains extremely patchy. While the introduction of the new National Framework was a welcome development, in order to ensure that decisions on continuing healthcare are fairer and more consistent across the country, older people and their carers must be able to easily understand why they may or may not be eligible. The confusion which reigns shows how complicated and unworkable the current system is in practice, and reinforces the need for a radical new care and support system, that includes universal access to high quality information, advice and advocacy for all who need it." More information is available at: [www.counselandcare.org.uk](http://www.counselandcare.org.uk)



### Know your rights and entitlements

HEALTH and social care is currently going through a period of great change. Personalisation and integration are high on the national agenda, both in health and social care. Because of these ongoing changes, The MND Association has withdrawn their rights and responsibilities information sheets.

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. The Disability Alliance produces a range of informative fact-sheets. They include useful information about your rights and entitlements and what you can do when things go wrong. Contact the Disability Alliance, Universal House, 88-94 Wentworth Street, London, E1 7SA. Phone 020 7247 8776, Email: [office.da@dial.pipex.com](mailto:office.da@dial.pipex.com)

The MND Association's Standards of Care document sets out minimum standards for the level of care we believe everyone living with MND should be able to expect.

For further information contact MND Connect, Tel: 08457 626262, Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### Worth a look

[disabled4disabled.co.uk](http://disabled4disabled.co.uk) is a new website which is exactly as the name suggests and has lots of interesting information and tips for disabled people.

**Exciting new cycle challenge**

The MND Association is thrilled to announce that back by popular demand is the legendary London to Paris Cycle! Set your wheels in motion and pedal your way through the streets of London and on to the boulevards of Paris, celebrating your success at the city's most famous landmark, the Eiffel Tower! With a challenging 300km to cycle in just three days, this will prove to be a long weekend pedal you'll always remember. The thrill of magical Paris awaits you! Reserve your saddle with pride of place from the 18-21 September 2009. Registration fee £99 and a minimum sponsorship £1,250. For more information or to register, please contact Trudi Willis, Community and Events Fundraiser on 01604 611834 or email [trudi.willis@mndassociation.org](mailto:trudi.willis@mndassociation.org)



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**FANCY** a different way of fundraising? How about fundraising through a restaurant - you and your friends eat while the MND Association earns pounds!



How? You just have to book your table in a restaurant through Whichtable online and they will make a donation to a charity of your choice. Whichtable rewards the charity with a number of points for every person who books in one of the member restaurants. You can exchange the reward points for a donation to charity. Each reward point can be exchanged for 1p donation. Many restaurants will earn you 50 reward points per person. The reward points can alternatively be exchanged for prizes such as free meals. So, check out the website [www.whichtable.com/eatforcharity.asp](http://www.whichtable.com/eatforcharity.asp) and let your friends and family know so that you too can earn pounds for our funds whilst enjoying good food.

**MONIES RECEIVED**

Liam Dwyer Cycle Rid	£4,802
Sue Charman Tribute Fund	£1,136
Commission on Christmas Cards	£ 20
Mrs Holloway	£ 30
Mrs Robinson	£ 20
Mrs Setford	£ 35
Mr and Mrs Hinton	£ 60
Mitsui Sailing Day	£ 325
Mrs E Wolstein	£ 10
Marion and Tony Ashby	£ 382
Brighton Road Baptist Church	£ 21
Mrs D Coombe	£ 19
City Quiz (to date)	£8,573
Mrs C Eyre	£ 15
Hannah Couzens	£ 96

**A MEMORABLE EASTER STROLL!!**

*Written by Alice Robson*

Marc was diagnosed with MND in November of last year and has, since that time, received wonderful support from the MND Association. So – how to make a contribution to them was a question posed to his family. His sister and her husband organised a sponsored family walk to take place over the Easter weekend, so 22 family members, aged 7 – 74, and a few very close friends met up at Kingston Station in SW London at the start of the 45+ mile walk which was due to end on Sunday afternoon in Marc's home village of Ardingly.

All who started managed to finish the walk and others who had to work joined in for the Saturday and/or Sunday. Apart from a nasty drizzle on Good Friday, the weather was ideal for walking although not without some members suffering very sore and blistered feet and aching limbs – but all was worthwhile!

The route took the party through some wonderful countryside and UNDER the M25, over Reigate hill with fantastic views, on down through Horley and finally into Ardingly and the very welcome sight of the South of England Showground, next to where the walk terminated.

One of the relatives who did not walk provided coffee and cold drinks mid-morning on Sunday and then a huge buffet picnic lunch in the area of Gravetye Manor. There were approximately 35 for lunch!

Finally, on reaching the cricket pavilion at Ardingly, refreshments were served, certificates and badges distributed and one of the grandchildren, who was 18 the next day, enabled the event to have a lively conclusion by way of an early birthday cake as part of a short celebration.

The original financial target was £1,500 but, at the last count, it is expected that a figure including Gift Aid will exceed £6,000 which will be donated to the MNDA West Sussex North Branch.

A very memorable Easter indeed in so many ways and such a wonderful experience for all concerned. The photo says it all.



**FREE TELEVISIONS**



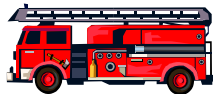
W4B (formerly Wireless for the bedridden Society) is a national, UK-wide television and radio charity. It aims to provide radio and/or television sets for people who can't afford a set for themselves. In all cases, priority will be given where help will significantly relieve isolation. W4B offers a range of televisions and radios free of charge, all of which are covered by a maintenance agreement or warranty. Applications have to be made by a sponsor, ie a health and social care professional or charitable organisation, on behalf of a potential beneficiary. More information can be found on the W4B website at: [www.w4b.org.uk](http://www.w4b.org.uk)

# Advance in stem cell research

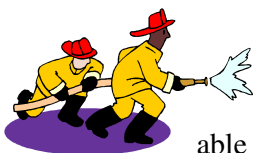


In January, heart researchers discussed a recently published advance in stem cell research on the Today programme on Radio 4. Below, is a brief description on what this development means and what it may mean for the future of MND research.

Normally, your bone marrow (which is where stem cells are produced) has a build up of chemicals that stop stem cells from migrating into the blood stream to be used around the body. When things go wrong in the body, stem cells (which can be thought of as emergency service vehicles) are sent to repair the damage caused. Therefore, depending on what the problem is, a different service is sent out.



However, the number of 'emergency service vehicles' sent out in a disease situation are simply not sufficient enough to repair the system. This can be related to a roaring fire, where one fire engine is not able to subdue it. By manipulating this system, researchers have found a way to select which 'service' they require and send out a much larger number to tackle the situation. In theory, this means that in a disease situation, 'fire engines' may be chosen to effectively put out/subdue the roaring fire. For MND research, this means that a proof of principle has been found that it is possible to dramatically increase the number of (selected) stem cells in your body, which could (if developed further) lead to an effective treatment for MND.



However, this research is still at a very early stage and requires evidence that the selected service sent out would be able to repair the system as there is no point sending a fire engine to fight a fire without any water!

**MOTOR NEURONE DISEASE ASSOCIATION**

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

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