

South Bucks Branch

Next Open Meeting

An informal social
event on **Wednesday
20 January** at **The Hit
or Miss, Penn Street**

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Diary dates



24 December – don't
forget to leave out
sherry, mince pies and
carrots when you go
to bed!

December 2009

Happy Christmas to everybody!



**The Committee send their very
best wishes to you all for a very
Happy Christmas**

An enjoyable and successful fundraising evening with the BBO Big Band

Many thanks to those of you who joined us at the Winter Hill Golf Club on 26 November for an evening of big band music, and our sincere thanks also go to the Band who played in order to raise money on our behalf. Not only was it an enjoyable evening, it also raised a very welcome £525!

Thanks to Waitrose!

You might recall that in the October edition we reported on our having been selected as one of the local charities to benefit from Waitrose's "Community Matters" scheme in their branch in Beaconsfield. We can now report that this resulted in the Branch Chairman collecting a cheque for the excellent sum of £491. This is one of the largest amounts collected for a local charity in that Branch, and our thanks go to the store employees for

selecting us from the charities that had been nominated, and to those customers who dropped their tokens into our box.

Our next Open Meeting

Our next Open Meeting, which will be the first of the New Year, will be held on Wednesday 20 January. It will be an informal social event, and will be at The Hit or Miss, Penn Street, HP7 0PX. If you want to come along just for a drink, please do, and food is also available until 9:30pm. Members of the Committee will be there from 7pm – please come and join us!

Difficulties with the supply of Rilutek

The Association is aware that some people with MND are still experiencing difficulties in getting supplies of Rilutek (you may know it as Riluzole).

If you are having difficulties, the arrangements mentioned in an earlier Newsletter are still in place: you should ask your pharmacist to arrange for a supply to be sent direct by phoning the manufacturers, Sanofi Aventis, on 0800 854430.



Would you like to take part in a carers' study?

Would you like to influence change in services that allow carers to take a break? If the answer is 'yes' then King's College London would like to hear from you. The Department of Health has commissioned King's College to find out about carers' needs for, and experiences of, replacement care services (also known as respite care). If you are interested in taking part in this study, further details are available on the Association's national web site at www.mndassociation.org/life_with_mnd/for_carers/carers_study.html

Alternatively, please contact David Williams by phone on 020 7848 5418 or by email at kclcarestudy@kcl.ac.uk

Early Day Motion on MND

Mark Todd MP, who chairs the All-Party Parliamentary Group on MND and who is Chairman Elect of the Association's Board of Trustees, has tabled an Early Day Motion (EDM) in Parliament calling for the Government to produce a National Strategy for MND. A National Strategy would set standards for the coordinated care of people with MND in order to improve quality of life as much as possible. The Association is encouraging as many MPs as possible to sign the EDM and it would be appreciated if you would write to your MP asking them to sign up to the EDM (Number 198 – National Strategy for Motor Neurone Disease). A suggested template letter can be found on the Association's national web site, or can be obtained from Alison Railton by email at alison.railton@mndassociation.org or by phone on 01604 611842.

New driving assessment centre

As part of the forum of mobility centres, offering assessments and advice for people who have a medical condition that may affect their ability to drive or access a vehicle, a new centre, operated by the Regional Driving Assessment Centre, has opened in Northampton – there is already one in Eynsham, near Oxford. The centre is staffed by a team of dedicated and experienced professionals including driving instructors and Occupational Therapists. There is access to a wide range of adapted vehicles to cater for a wide variety of needs. The fee for a driving assessment is currently £80 and a passenger

assessment is £20. More information and application forms can be downloaded from their website www.rdac.co.uk or by calling 0845 337 1540.

National raffle is a success

The Association's first national raffle was a great success and raised more than £120,000 – well above the initial target. The winner's sister has MND, and she plans to use the money as a travel fund and possibly to go on holiday with her children and grandchildren.

Major boost for research

A major new £4.6 million research initiative involving leading MND researchers has been announced by the Wellcome Trust and the Medical Research Council.

It has long been suspected that similarities exist in the way nerve cells degenerate in different neurological diseases. MND researcher Professor Chris Shaw, based at King's College London, is leading an international group of researchers to develop a series of new disease models that will help add to the understanding of what initiates the degeneration of nerve cells in MND and will be used to accelerate the discovery of effective drugs. Professor Colin Blakemore, the Association's President and one of the UK's most respected scientists, welcomed the announcement: "This major grant from the MRC and the Wellcome Trust is another indication of the recognition of the importance and broader relevance of research on MND. It is wonderful to see this concentration of funding aimed at understanding the origins of this terrible disease."

Branch and National Office contacts

If you wish to contact the Branch, please call Richard Coleman (Chairman) on 01494 713861 or Roger Curry (Branch Contact) on 01494 715732 or visit our web site at www.mndasouthbucks.org. The National Office number is 01604 250505, and MND Connect is 08457 626262.

