

March 2004

ISSUE NO 25

Reading and
West Berkshire
Branch

‘I NEED YOUR HELP’, SAYS MND RESEARCHER

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at cognitive and behavioural change in people living with MND.

The team at King’s are carrying out tests investigating memory, language, mood, anxiety, emotional and behavioural changes of people in MND.

Paul explained that the tests are the same tests as those carried out on people living with MND. The results would then be compared as a control set.

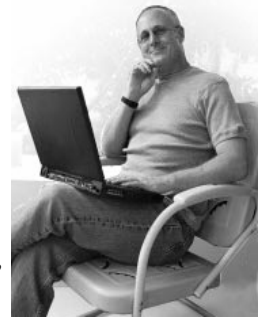
During his Power Point presentation, Paul used the powerful wartime appeal poster (above) to ask for controls for the research, which should ideally include spouses, friends, in-laws or cousins, but not 1st degree relatives. Paul would particularly like to interview right-handed men between the ages of 30 and 75 who

did not attend university and who are not suffering from a major medical condition.

The tests include pen and paper tests, word games and puzzles, computerised games and questionnaires. The test procedure is long—4.5 hours—but there are frequent breaks, and travel expenses to the Kings College Hospital site will be reimbursed. Alternatively, tests can be carried out at the volunteer’s home.

If you think you can respond to Paul’s appeal, you can contact Paul direct and his contact details are listed below.

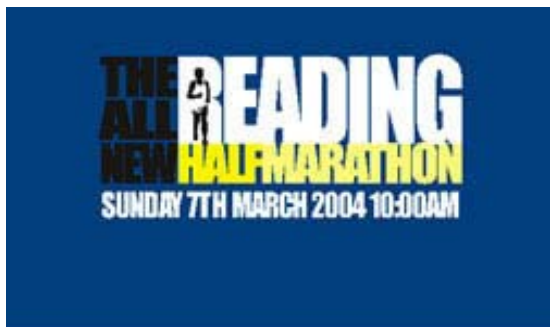
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DIARY DATES

AGM	28th April
Silver Jubilee Races	Thurs 1st July
Newbury Racecourse	1979-2004



Please sponsor
Christine and friends who
are running for MND—see
letters page 3
for more details.





SILVER JUBILEE RACE EVENING



RACING fans will be keen to hear that we have our very own evening meeting at Newbury Racecourse on July 1 dedicated to the MND Association.

The high profile evening is to be the summer highlight in a programme of national events to mark the charity's silver jubilee. Its aim is to raise funds and to help continue the ongoing development in research and in the care and support for people living with MND.

The six-race televised card – including one named after the Association – will also give a huge boost to raise awareness of the disease.

MND Association members will be offered race badges at half price – that works out at £9.50 each. Details of how to apply will be published in Thumbprint nearer the time.

Behind the scenes a committee has been working to plan the glittering evening that includes a lavish dinner for 250 people with an auction and celebrity speaker. Already the tables of ten have been sold – mainly to corporate buyers – and there is a reserve list should seats become available.

Four of the six races have been sold to sponsors but there are still buyers to be found for two key

races at £12,000 and £10,000 respectively. We also need a sponsor for the Champagne reception (£5,000) and the auction (£3,000).

If Newsletter readers know of a company who might like details of the sponsorship packages please contact Jane Gilbert, branch publicity officer, on 0118 9714172.

An important part of the

CAN YOU HELP?

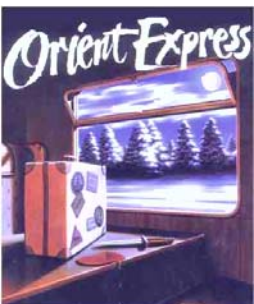
evening will be a silent auction and tombola set up by the branch out among the racegoers. We need volunteers prepared to do a stint on the stand and/or to donate a prize – the more unusual the better for the auction. We already have a morning's mole catching instruction so beat that!



We also need collectors on entry and exit points at the racecourse so if this is more your bag PLEASE sign up. Volunteers will be offered free entry and refreshments on the night.

Contributed by Jane Gilbert

If you are willing to help please contact branch vice chair Jennifer Hay (tombola/silent auction stand) on 01923 720198 or branch secretary Val Pearson (collecting at gate) 0118 9789063.



Not at all "Murder" on the Orient Express!

Even if you are not a regular rail user you will no doubt have seen reports on television and in newspapers regarding the problems of rail travel owing to the old rolling stock still in use. Well I was part of a group who recently had a trip in carriages even older. Decades older, in fact. So you may be forgiven for thinking that our trip must therefore have been even worse than the average commuter's. Wrong, for this was the Orient Express, from an era when things were built to last and to a high standard of luxury.

We arrived at Victoria Station in time for photographs to be taken and then

boarded and took our seats – extremely comfortable armchairs - to the accompaniment of a musical ensemble who followed on board to provide entertainment on the journey. I understand that the carriage in which I was seated was a favourite of the Queen Mother. (I looked under the seat but didn't see a gin bottle!). At this point we were served with champagne which set the standard for the rest of the journey.

The train left at 12.50 travelling through Brixton, Catford and Beckenham Hill. Along the way we were served the first course of Terrine of Salmon and Halibut with a cauliflower and caviar sauce. Travelling through London the view tended to be the backs of tenements and brick walls

with graffiti. However on leaving London behind the view improved greatly as we passed through Swanley, moved into Kent and headed south towards the South Downs. We passed over the M26 at Otford before turning east through Wrotham and Maidstone, past Leeds Castle and over the Great Stour River, whilst enjoying the second-course of Pumpkin Soup. With so much glorious food and wine on the table it was sometimes difficult to tear ones eyes away to look out at the scenery.

Alec Jenkins rediscovers some of the charm and luxury of steam travel—on the Orient Express through "the garden of England"!

Alec's story is continued on the back page.



Your Letters

Laura Clintworth, whose granddad has MND, talks about the Charles Clore Centre in Newbury, and suggests we pay a visit.

A few months ago when my granddad had to give up full time work, we started wondering what sort of things he could do and looking at places where he could go or be taken. We heard of a day care centre in Newbury, called the Charles Clore unit. Here, people with all kinds of severe illnesses have the opportunity to get out of the house for a few times a week, meet other people and learn fresh hobbies.

The Charles Clore Centre seems to be inspiring and offers opportunities we thought my granddad would never have. As I said before, this unit isn't just for people with MND, but for people with other different illnesses as well and it would welcome lots more people to come along.

There are a variety of activities going on, for example glass painting, photography, card making and flower arranging. My granddad is particularly good at the last. All the activities are run by experts who have come from Newbury College or the Newbury Weekly News (for photography).

There is a lot of professional help too, from doctors, Macmillan nurses and therapists, such as a masseuse or physiotherapist, if you need their skills or just for a chat. If there is any trouble getting to the centre, they do arrange transport, even for people in wheelchairs. There will never be a time when you can't take part in things as there is always help with the activity making.

I hope this inspires more people to come along and enjoy the experience, as my granddad does.

Laura Clintworth

Drop-in Meetings



A reminder to all carers and those living with MND in the area that the local Branch organises "Drop-in" meetings at various local venues. These sessions offering the opportunity for those living with MND to come out for a chat over a cup of coffee with others who have also lived with or are living with MND.

Details of the forthcoming Drop-in meetings will shortly be posted in our Forthcoming Events session, so make sure you make a note of the one nearest to you, and come and have a chat and a break.

Contact Val Pearson for details

In her moving letter, Christine Mercier explains why she is running the Reading Half Marathon for MND this month

Just a year ago, I turned on the radio in my car on my way back home from work. My daughters had changed it and it was, unexpectedly on a local radio. It was a few days before the Reading Half Marathon and I heard interviews of people ready to run it for various charities.

Andrew Bickerton, a friend of mine, was suffering from Motor Neurone Disease and I had been impressed by the way Andrew and Chris, his wife, were facing this awful disease. I was, at the time, just starting to exercise a little bit harder after several years of suffering from the consequences of a bad fall and I thought "Had I started exercising earlier, I would maybe have been able to run the Half Marathon and raise money for the Motor Neurone Disease Association".

Sadly, the day before the 2003 Reading Half Marathon, Andrew died. I then decided that I would try to get ready to run the 2004 race for Andrew and Chris. I kept it secret as I was not sure I could get fit enough and be ready within a year (I work full time, have a family and don't have a lot of time available for running). Nevertheless, I explained my project to my husband, Yves, who regularly runs. He encouraged me but pointed out the hard work I had ahead.

I started by running 3 miles, and gradually increased the length. I also started going swimming two to four times a week from 6 to 6:30 am before going to work. By the end of the summer, I thought that it would be hard but I could do it. As a test, I registered for the Henley Half Marathon (last October). Mark, my daughter's boyfriend, kindly offered to run it with me. Thanks to his support all along the 13 miles (it was very hard!), I managed to run it. I then started to speak out a little bit more about my project. My husband, daughters, friends and neighbours have all been very supportive.

I am close to achieving my goal and I think I am ready. Mark will run again with me and today, Helen and Becky, two friends of my daughter's who have registered to run the reading Half Marathon (just for fun!), offered to help me raise money for the MND Association. I have to say that the support of these young people means a lot to me.

I know it will be very hard, but what are painful legs and tiredness compared with what Andrew has suffered and with what Chris and her children have had to face ?

Christine

If you would like to sponsor Christine's Half Marathon run, even after the event, you can contact her on 01491 572190.

Not at all "Murder" on the Orient Express!...continued

Heading south east towards Ashford alongside the Channel Tunnel Rail Link the third course of Fillet of Wild Scottish Venison Wellington was served with yet more wine.



Outside the view was very picturesque as we were travelling through hop fields, orchards and what appeared to be vineyards. At Ashford International Station we headed north, crossing over the Great Stour River again before veering east. We travelled through Wye, Canterbury – with a view of the cathedral in the distance - past Minster Abbey and Ramsgate harbour. We then looped around the end of the Isle of Thanet before travelling through Broadstairs, where Charles Dickens wrote *The Old Curiosity Shop*, *Barnaby Rudge* and *David Copperfield* and then heading west on the homeward leg of our journey. At times we could see tantalizing openings in between the houses which seem to indicate the sea beyond but we were not quite close enough to see it. Along the way we had been served the fourth course of cheese and biscuits with Home-made Chutney.

Travelling through Margate, Herne Bay and Whistable – famous for its oyster beds - we enjoyed the fifth course of Coffee Parfait with Coconut Pannacotta before the line turned inland through the sheep grazing land of Graveney Marshes. At Faversham we roughly followed the M2 through Sittingbourne, Rainham, Gillingham, Chatham and Rochester, passing alongside Chatham Docks.

After Rochester we passed over the M2, and soon passed close to the Bluewater Shopping Centre, whilst enjoying the sixth and last course, coffee and liqueur.

At Swanley we rejoined the outward track before branching off again at Shorlands Junction, returning via Croydon, Penge, West Dulwich and once again through Brixton. All too soon we were drawing into Victoria at the end of our journey and I had to go through a reverse metamorphosis from Lord Muck to plain old Alec Jenkins. I could get used to living like that.



Rheingold - Pianowagen

Perhaps if I could win the lottery !!!!

Contributed
by
Alec Jenkins

Forthcoming Events

READING HALF MARATHON Sunday 7th March
Contact Christine Mercier on 01491 572190 for sponsorship details.

DROP-IN MEETINGS During March & April
Contact Val Pearson for details

AGM Wed 28th April

WOKINGHAM FAYRE Mon 3rd May

GRAHAM HODGETTS CHARITY SHIELD TBA

MND AWARENESS WEEK 12th–20th June

ENGLEFIELD WALK Sun 16th May

SILVER JUBILEE RACE MEETING Thurs 1st July
Newbury Race Course

Once again, our thanks to Kall Kwik in Reading for printing this issue.

For all the latest news and information:

www.mndassociation.org

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Treasurer	Newsletter	
Barry Clouting	Mary Watson	
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FIGHTING MOTOR NEURONE DISEASE