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Reading and
West Berkshire
Branch

HEAVENLY HARPS FILL THE AIR

In this issue

<i>Wokingham Winter Carnival</i>	1 & 2
<i>Thinking and Behaviour Patterns in MND—Paul Wicks</i>	2
<i>Carol concert and readings at Purley</i>	3
<i>A Prayer by Ivan Mann</i>	3
<i>Building Society boosts funds</i>	3
<i>Invitation to Open Meeting</i>	4
<i>Shameless Thieves swipe charity boxes</i>	4
<i>Forthcoming Events</i>	4
<i>Contact Details</i>	4



Young harpists Anna Brown (8), Jessica Robinson (11) and Keirsten Davis (10) with Jack Hayward at the Tadley concert.
Bottom right—the harpists in action.

The heavenly sound of harps filled the air and helped to raise £400 at a carol concert in Tadley.

Seventeen harpists of all ages provided free entertainment with a delightful programme of traditional carols followed by refreshments.

Funds for the MND Association were boosted thanks to a raffle and the sale of some harp strings – donated by the

London-based company Salvi – to an anonymous benefactor from Padworth Common.

The popular event has been held for the last nine years, initially at the Burghfield home of harp teacher Jack Hayward, and it moved to the United Reform Church venue last year.

Jack's wife Pat is a member of the branch management committee and was our secretary for several years.

Contributed by Jane Gilbert



DIARY DATE

Open Meeting	18th Feb
Silver Jubilee Races	Thurs 1st July
Newbury Racecourse	1979-2004



Wokingham Winter Carnival

We were lucky with the weather at the Wokingham Carnival this year, in spite of the bad forecast. The threatened rain held off until late in the afternoon, so Gill Cheetham, Sandie White and I were able to enjoy the atmosphere, with the help of some warm, mulled wine. The carnival is held in the old market

place and surrounding streets and attracted a good crowd.

We were able to sell most of the remaining bric-a-brac left over from the stall in Reading market in October.

Val's account is continued page 2.....

Thinking and Behaviour Patterns in Motor Neurone Disease

How you could help the King's College Research

There are three main areas into which research is conducted at the King's College MND Care and Research Centre. One of these, clinical research refers to a wide range of research that involves people with MND, their carers, family members and other volunteers giving time and information about themselves.

Paul Wicks is a PhD Research Scientist who graduated from the University of Durham in 2002 with a degree in Psychology. He joined the MND team later that year, after being awarded a PhD Prize Studentship at the Institute of Psychiatry, funded by MND. He is currently involved in research looking at cognitive and behavioural change in people living with MND. He also attended the 14th International Symposium on MND/ALS in Milan, where his group presented a paper.

The team at King's are carrying out a thorough battery of tests investigating memory, language, mood, anxiety, emotional and behavioural changes of people living with MND in order to give a better understanding of any changes that may occur and shed light on questions such as:-

Do people with different types of MND experience different psychological changes?

What is the prevalence of anxiety and depression in people with MND?

Do carers feel there are any personality changes associated with MND?

As a control set, Paul needs to interview people who are **not** suffering from MND. Paul is especially keen to see carers or friends of people living with MND; preferably

right-handed men between the ages of 35 and 75 who did not attend university and who are not suffering from a major medical condition. These include diabetes, hypertension, history of severe head injury, stroke, heart bypass surgery, current psychiatric condition or colour blindness. He would also prefer it if you were not a first-degree relative of a person with MND (i.e. child, parent or sibling).

This group would be asked to carry out the same tests as those performed by the people living with MND. The results would then be compared as a control set. The study will preferably be carried out at King's MND Centre, but they could be carried out at home if you prefer. Participation in this part of the study involves an interview during which you will be asked to do a series of tasks, similar to word games and puzzles. In addition, you will be asked questions on how you have been feeling and your mood recently. The interview will last approximately 4.5 hours, but there will be frequent breaks and a lot of variety in the tasks, many of which are computer-based.

If you are interested in taking part please write to Paul at PO 78, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF or contact him either by phone on 020 7848 0715 or by the internet : p.wicks@iop.kcl.ac.uk

Contributed by Val Pearson

The Branch have also asked Paul to make a presentation at the Open Meeting to be held on Wed 18 February—see detail on the back page.

Wokingham Winter Carnival cont from p1.....

I will always remember the young boy who had set his heart on a camera on the stall. His mother refused to buy it for him and he left the stall, heart-broken. So that, when he reappeared with dad in tow, we offered the camera to him for nothing. But, in true Christmas spirit, his father insisted on giving us more than we had originally

asked! His son's face, as he walked away clutching his prize, was a pleasure to see.

Packing up in the darkness to the sound of favourite old carols, we felt the effort was particularly worth-while as we had raised £205 taking the combined takings from the Reading Market stall to a total of £431. Thanks to all of you for your contributions.

Contributed by Val Pearson



Coffee Morning Funds

A series of Coffee Mornings held on the lead-up to Christmas raised £190. Special thanks to Gill Howgego, who lives with MND, who raised £141 of that total.

Thanks also to Sonning Common NWR women's group, who put their hands in their purses at their National Telephone Quiz night. They didn't win the quiz, which was all about movies with single titles, ("Barbarella" was a dead cinch) but they were happy to support their favourite charity.

Carol Concert and Readings at Purley Church

St Mary the Virgin is a beautiful little church, hidden away in Purley. Our Christmas tea was held there in the church hall which is only separated from the church itself by red curtains, hanging from floor to ceiling. Our guests were welcomed with a glass of warm, mulled wine.



Margaret Moss delivers one of the readings

We moved into the church for carols and readings from poems and prose connected with Christmas. My particular thanks to Kitty Gilbert, Jane's young daughter, who delivered her reading with more composure than many an adult would have done. We also heard an account of the Cratchits' Christmas dinner from 'A Christmas Carol'; about the carol-singers calling on the Mole and the Rat from 'The Wind in the Willows'; John Betjeman's view on the real meaning of this old festival; and an old favourite, 'The Night Before Christmas'. They were read with style and panache. We finished by listening to a beautiful prayer, written by Ivan Mann, an Anglican priest whose wife, Jackie, had MND, and which we have reproduced here for you. Having sung our hearts out, we moved back into the hall for conversation and cake, before trooping home.

I would like to thank all those involved for their efforts, but particularly for those not directly involved with MND who generously gave their support free of charge. These include the church, for allowing us to use their beautiful building; the organist, David Jordan, who accompanied our singing; and Brenda Jenkins who gave her readings with such expression.

Contributed by Val Pearson

A Prayer *by Ivan Mann*



Father,

*I cry to you in prayer -
Help me to live my life to the full,
To find the things I can do and do them joyfully.*

*To give my family and friends some sense of achievement
- a job well done.*

*Help me to meet people,
Those who are embarrassed by my disease.*

Those who are too busy to listen to my voice.

Those who are very willing to help but cannot find a role.

*Help me to say 'No' tactfully,
Or, when anger speaks on my behalf,
May others realise the pain inside
That sometimes must be heard -
and not take offence.*

*Father hear our cries, each one of us,
Who knows something of the frustration,
And give us strength, courage and humour*

Amen

(Written by Ivan Mann, an Anglican priest whose wife Jackie suffered from MND and died in 1989)

BUILDING SOCIETY BOOSTS FUNDS

The Hungerford branch of Newbury Building Society has raised £300 from raffles and collections in the town.

Hard-working staff left their normal places behind the counter to collect cash mainly from a Victorian Extravaganza held in the High Street.

They chose the MND Association as charity of the year after a close friend of one

of them was diagnosed with the disease.

Office manager Sandra Smith presented the cheque to Jane Gilbert, the branch publicity officer, and treasurer Barry Clouting.

Contributed by Jane Gilbert

(Picture courtesy of Newbury Weekly News chief photographer Geoff Fletcher.)



Mrs Smith is pictured with two of the main fund-raisers, Sue Carey and Val Troke, presenting the cheque to Jane Gilbert.

SHAMELESS THIEVES SWIPE CHARITY BOXES

A heartless thief has swiped one of our charity boxes from Ladbroke's in Pangbourne.

And a bid was also made to snatch a similar MND Association box from Bateman's opticians but the thief was spotted and fled empty-handed.

Another box – for the Thames Valley Air Ambulance – disappeared the same day from a counter at the post office in the town.

Thames Valley Police are investigating the thefts but fund-raisers with collecting boxes are urged to be on their guard.

The branch management committee will consider issuing more boxes that can be chained to premises.

On a more positive note the thefts did result in widespread local newspaper coverage for the Association and its work.

Contributed by Jane Gilbert



Commiserations to Anne and Jennifer who battled through the snow, lightning and horizontal sleet to get to last week's committee meeting, only to realise it had been cancelled!

Charity Auction

at
Newbury Racecourse
on **Sat 28th February**
6.30—10pm approx.

West Berkshire
Neurological
Alliance

£5 entry fee

Call Chris on 01635 275302 (day) or
01488 658540 (eve) for more details

Contact Details

Branch Contact	Secretary	Events
Beth Thorpe	Val Pearson	Coordinator
0118 9421600	0118 9789063	Gill Cheetham
Chair	Publicity	01344 423440
Margaret Moss	Jane Gilbert	Reg. Care Advisor
0118 9470871	0118 9714172	Carole Kingston
Treasurer	Newsletter	0118 9462057
Barry Clouting	Mary Watson	
0118 9410186	0118 9722506	

Forthcoming Events

You are warmly invited to our
Branch Open Meeting
on

WED 18 FEBRUARY 2004

7.30 - 9.30 pm

at

Courtyard Marriott Hotel,
Padworth Lane, Bath Rd.,
Near Reading

We are delighted to welcome
our speaker for this evening:

Paul Wick
**King's MND Care and
Research Centre**

'Thinking and Behaviour in MND'
plus highlights from the Milan Conference,
Including developments in clinical, patient-centred
research, recent clinical trials, stem cells and the use of ven-
tilation & peg.

*(If you have any request for information on a specific sub-
ject, he would be glad to address that also, so please let
him know in advance.)*

Light refreshments will be served
The venue has wheelchair access and toilet.
There is a car park on site.

*If you have any queries or need a lift, please contact
Val Pearson, Secretary, on 0118 9789063.*

**A special "Thank you" to the manager and staff at
Kall Kwik in Reading who support the MNDA and
print this newsletter for us free of charge.**

**Kall Kwik Printers,
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Reading.
Tel. 0118 9571256**

For all the latest news and information:

www.mndassociation.org