

**Reading and
West Berkshire
Branch**

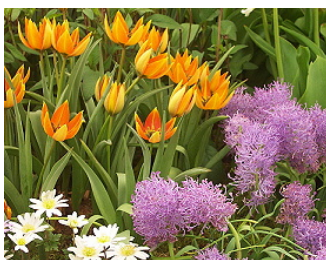
Train ties take the strain to raise charity cash

In this issue

<i>Alan's brave walk for MND</i>	2
<i>Super fit gran's pedal power</i>	2&3
<i>Local Branch spends more on local patient support</i>	3
<i>Training to be an Association Visitor</i>	4
<i>Forthcoming Events</i>	4
<i>Contact Details</i>	4

DIARY DATES

Next Drop-in Meeting	Sun 6th June
Charity Fishing Match	Sat 3rd July
Silver Jubilee Races	Thurs 1st July
Newbury Racecourse	1979-2004



A Berkshire man is letting the train take the strain out of raising cash for charity.

Bill Veloz, a fleet controller at Reading station, produced a limited number of special ties to mark a shake-up in the rail industry. And he has sold them to railwaymen all over the country with a built in donation to the Motor Neurone Disease Association in the price.

The father-of-two from Priory Road Newbury is pictured (with beard) on the platform handing over a cheque for £300 to Barry Clouting from Calcot who is treasurer of the Reading and West Berkshire branch.

Bill chose the charity to benefit from sales as the disease had claimed the life of his father 25 years ago – the year the MND Association was founded.

He had the ties specially made to mark the change in April from Thames Trains to First Great Western Link Trains. Bill, aged 57, works in the station's control



Bill Veloz hands over the cheque to Branch Treasurer, Barry Clouting,

office and has the important job of deciding whether the trains run or not.

He said: "Tie collecting is a big hobby in this industry where special limited edition ties are produced to suit every occasion.

"I have been dealing with some collectors who have more than 800."

Contributed by Jane Gilbert



The management committee would like to thank all those people who took part in the Englefield Walk (see our article page 2) - and are collecting cash for the branch.

AND A REMINDER....Please sign a gift aid declaration.....

If you are a UK taxpayer do you realise that your £5 donation becomes £6.20 if you sign a gift aid declaration? Just give your house number and postal code with your donation to our treasurer and we can claim the tax back.



ALAN'S BRAVE WALK FOR MND

Courageous Alan Hankin, who has MND, took on the challenge of the Englefield Walk inspiring others along the way.

The West Reading history expert believes he will have raised £500 in sponsorship for his brave Walk to D'feet MND. But it was also a personal triumph for 46-year-old –Alan who stepped out with his walking stick.

Afterwards he declared: "It took me longer than anyone else but I did it. I am pretty pleased with it.

Alan, who lives in Kensington Road, also became something of a celebrity after his picture appeared in the Reading Chronicle. He agreed to be interviewed to publicise the three-and-a-half mile walk which was held jointly with the Duchess of Kent House Trust in the grounds of Englefield House thanks to our patron Sir William Benyon..

Soon after, several people turned up at the desk in Reading Central Library where Alan works to pledge cash for his efforts.

"When I saw Alan's picture in the paper he inspired me to walk as well. In one week I have collected £300. People have been so kind and supportive.

"Alan was determined to walk right to the end. It took him two hours – he did fantastically well."

Linda Green

He also inspired Mrs Linda Green to walk as well as rekindling a relationship they had several years ago



Linda Green and Alan Hankin take a well-earned break at the Englefield Walk

when Mrs Green sought Alan's help when she was researching the history of Mill Lane, Calcot, where she lives.

Linda said: "We found out so much that our little pamphlet turned into a book. He was so helpful and so wonderful. We had a book launch at our local hall and Alan came along.

Linda is no stranger to MND – her father suffered from the condition 24 years ago. She said he was the image of David Niven whose "thumbs up" sign remains the MND Association's symbol of hope.

Contributed by Jane Gilbert

SUPER FIT GRAN'S PEDAL POWER

Super fit gran Sylvia Hemmings will be using pedal power again this Summer to raise money for MND.

Since 2000 she has clocked up the miles on the big Paris to Hayling Charity Cycle Ride and she has no plans to put the brakes on.

Originally Sylvia raised money for a cancer charity in memory of her late husband but now she cycles for us thanks to her great friend John Austin, who has MND.

"I decided to do it for John," says Sylvia, formerly of Tilehurst, Reading. "I have known John and Mavis for years – we used to go water skiing together."

Sylvia, who is in her sixties, met so many friends through the annual fun ride that she has now settled on Hayling Island.

Continued on facing page 3....



Barry Clouting, Reading and West Berkshire Branch Treasurer, is pictured at the presentation evening at Hayling Island receiving a £250 cheque from Sylvia Hemmings, cycle ride organiser Jenny Phelps and Chairman Paul Fisher.



Your Letters

Local Branch Treasurer Barry Clouting provides a summary from his report at the April Branch AGM and gives us a clear picture of how and where our Branch funds are raised and spent.

This was another successful year in which both the income and expenditure were maintained at or above the average of recent years. The Branch spent more on providing local patient support than at any time in the past five years and the income, even without a major fund raising event, enabled a small surplus to be carried forward to 2004/05.

Total income during the year amounted to £32700 compared to £35400 in 2002/03, (which included £10000 from the Sir William Benyon Trust); £30800 in 2001/02 and £40684 in 2000/01 ('Walk for Us' raised £14300).

Outgoings during the year totalled £27600, which includes £5000 to the David Hallifax Appeal, compared to £32600 in 2002/03 (£10000 to David Hallifax Appeal) and £29700 in 2001/02 (£20700 to the Research Project).

Our bank balance at the year end was a healthy £35300, which also includes an additional £10000 set aside by the Committee for the appointment of a neurological nurse. This brings to a total of £20000 set aside for this purpose, of which, if the scheme does not proceed, £10000 will be forwarded to National Office).

Contributed by Barry Clouting

Super Fit Gran's Pedal Power continued.....

The three and five day rides this year start on July 11 and 13 and clock up 221 and 416 miles respectively.

It is probably too late to register for this year but for entry information for 2005 contact Jenny Phelps on 023 9226 9311 or look on the website www.hayling-cycle-ride.org.uk.

The total amount raised through Ride 2003 was more than £45,000 and all of it goes to charity.

Contributed by Jane Gilbert

Local Branch spends more on local patient support

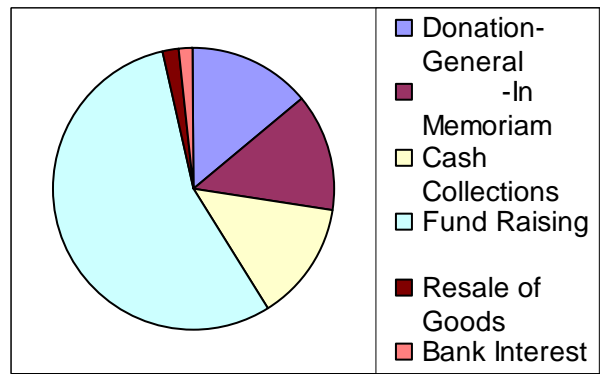
The Branch spent more on providing local patient support than at any time in the past five years

Including the contribution to the David Hallifax Appeal, 63% of all Branch expenditure is committed to Patient Care

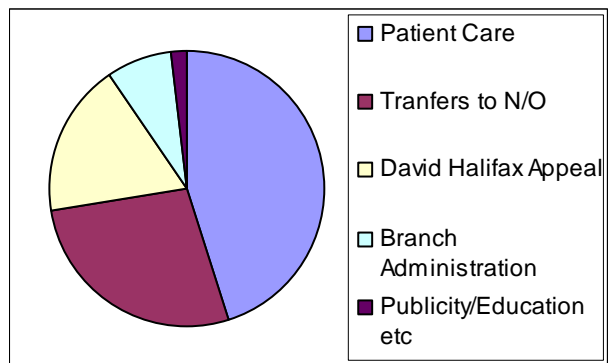
A further 27.5% supports the work of National Office including funding of Research.

Administration costs account for just 6.2% of Branch income.

INCOME



EXPENDITURE



Are You
 • a good listener?
 • caring?
 • practical?

Could you be an association visitor with us?

Association visitors offer caring, practical support to people with MND and their families... Could you be an association visitor with us? (See Joanna Knott's article on back page)

Tel: 01604 250505 or

Training to be an Association Visitor

Having worked in a professional capacity with a number of people living with MND, I was enormously impressed with the work of the MND and the very real help and support it is able to give. So when I retired from the NHS, I decided to try and train as an Association Visitor to do what I could in a voluntary capacity to further the aims of the MND in supporting people affected by the disease.

To be accepted for training, I first had to fill in a form about my background and reasons for applying, and provide 2 referees. Once these formalities were completed, I was invited to attend a Course in Winchester to be held at a local hotel, which would be spread over 2 months and would consist of: an introductory day, a 2-day residential weekend and a follow up day.

There were 13 of us trainees and a team of 3 running the Course, with extra speakers brought in for specific topics. All of us had had personal experience of MND and most had had the experience of a close relative living with the disease. During the Introductory day, we learned more about the nature of the disease and current research into it, and the role of the MND and its Staff and Visitors. By the end of that day there was an opportunity for us and the staff, to assess our suitability

for the Association Visitor role, and in fact, at this stage one person did decide that she was not yet ready to pursue the training.

The Residential weekend seemed a fairly daunting prospect at first, and I must confess to not looking forward to it, but in the event it turned out to be great fun as well as a very worthwhile learning experience. Although we ranged in age from early 40s to over 70, we really began to gel as a group in that time. During the weekend, we gained more insight into the personal experience of living with MND, developed and practised skills in active listening, discussed issues surrounding loss and bereavement and learned about the roles of various Health and Social Care Professionals involved with people with MND. We also considered situations relating to the issue of confidentiality and confirmed the responsibilities and boundaries of the role of Association Visitors and the resources available to enable volunteers to fulfil the role.

It was a very full but stimulating 2 days and well worth the effort put into it. In the month that followed, we were expected to do some 'experiential learning' i.e. doing some directed reading and trying to gain some practical experience with either a qualified Visitor or the local Regional Care Adviser. When we all met up again for our final day, it was like meeting old friends and it

was noticeable how much more confident we all were in contributing to the different discussions. Dealing with important questions, role playing situations together with telephone training, were all highlights of the day.

Altogether, I was most impressed by the money, time and resources allocated by the MND towards this training, and it made me appreciate how important the role of Association Visitor is to the work of the MND. It now remains for me and my fellow trainees to try and fulfil the aims of that training and to justify the faith placed in us.

Contributed by Joanna Knott

Forthcoming Events

DROP-IN MEETINGS

Next Meeting:
Henry Street Garden
Centre



Next meeting:
Sun 6th June

Contact Val Pearson for details

MND AWARENESS WEEK

12th–20th June

CHARITY FISHING MATCH

Run by Justin Watkins
Contact Val Pearson for details

Sat 3rd July

SILVER JUBILEE RACE MEETING

Newbury Race Course

Thurs 1st July

CHARITY GOLF DAY

Marlborough Golf Club

Fri 10th Sept

DINNER AND SPEAKER

Courtyard Marriott hotel
To raise funds for the
neurological nurse

Sat 6th Nov

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	

Congratulations !!
To Graham Hodgetts
on winning the Easter
Wordsearch



www.mndassociation.org