

**Reading and
West Berkshire
Branch**

July 2005

ISSUE NO 36

www.mndrdgwberks.freeuk.com

ZORRO TO THE RESCUE!

In this issue

<i>The Englefield Walk— and the rain!</i>	2
<i>Drop-in with bells</i>	2
<i>With a little help from George's friends</i>	2
<i>Drop-in success</i>	3
<i>Gill receives long-service award from new Chief Executive</i>	4
<i>Forthcoming Events</i>	4
Insert	
<i>MND Awareness Week</i>	1
<i>Marian gives £6000</i>	2
<i>Holiday Wordsearch</i>	2



Lady Halifax visits Graham Hodgetts during MND Awareness Week. More on page 1 (Insert)



Rotaract West Berkshire's super heroes in the annual crafty craft race at Newbury.

Rotaract West Berkshire, aka Zorro, bravely joined in the canal capers for this year's annual crafty craft race from Hungerford to Newbury.

The team of super heroes took up the cause of MND and paddled the eight-and-a-half miles in their home-built vessel.

Publicity officer Jonathan Hoare said the toughest part was having to pull the craft out of the water and carry it around all 11 locks including a swing bridge.

After more than five hours the final straights towards home were reached to be greeted by the usual hail of eggs, flour and water from local residents on the

penultimate bridge.

Vice-president Tim Wood said there was a great atmosphere and the team raised £200 to be split between our MND Association branch, its charity of the year, and the Round Table organisers.

Rotaract West Berkshire welcomes new members aged between 18 and 30 for fun, socialising, charity support or community involvement.

To find out more visit www.rotaract.org.uk

Contributed by Jane Gilbert

The crafty crafters paddle their way to run the final floury gauntlet!



And it rained and rained and rained ... at the Englefield Walk!

Following the reports from last year of the idyllic walk through the grounds and gardens of Englefield House, we were looking forward to our annual walk for MND recently. A summer stroll, admiring the beautiful gardens and lake beckoned—with maybe a deer or two to delight our view—followed by a leisurely cuppa.

And then the heavens opened! But the intrepid walkers carried on apace, with a wonderful collection of colourful umbrellas and hoods and dogged in our determination to support the cause and enjoy our day out.

The poor sodden polo ponies looked on as we tramped on regardless up the hill past the old church, but the rain slackened slightly as we approached the wonderful gardens, and we were able to slow our pace to take in the view of house and lake from the rise, and breathe in the heady aromas of the freshly watered shrubs and flowers.

But it was every man for himself down the soggy hill to a quick once round the lake, where even the deer were bolting for shelter and away from these mad humans advancing! The cuppa and biscuit, served by those sensible enough to stay in the dry in the old fire station, was welcoming as was the chance to remove the puddle-filled shoes of those of us who had dressed for dry weather! But it was, nevertheless, a wonderful day out, and it will be even nicer to do it again next year in beautiful sunshine!



Contributed by Mary Watson

Drop-in with Bells delights all

We were very lucky to have a performance at a recent drop-in meeting given by The Newtown and Burghclere Handbell Ringers.



Library Picture

A long-term member of MNDA, Gillian Shillito, arranged the concert for us and it proved to be a real treat. I have never heard handbells before, but was struck by the silvery tones, the delicacy of the sound (can a sound be delicate?) and the skill and concentration of the performers!! We were all very impressed. I might add that the staff from Charles Clore were also fascinated, asking to be put in touch with the group for a repeat performance.

Our sincere thanks go to the group for giving us such a pleasurable experience.

Contributed by Val Pearson



Slightly bedraggled after the rain at Englefield are Sandie White (it will be dry next year, Sandie!) with Branch Chair Margaret Moss and Secretary Val Pearson.

WITH A LITTLE HELP FROM HIS FRIENDS

Friends of popular former carpet fitter George Pearce have been inspired by him to raise cash to help fight MND.

Lorry driver Diane Loveridge and her husband Vince decided to donate their share of the funds to the Association when their club, the Thames Valley Truckers, folded due to dwindling membership.

Diane, aged 50, of Moore Lane, Newbury, has known George, who has MND, and his wife Claire for many years.

She said: "George is marvellous. He is so positive."

The couple's £527 branch donation has been collected by the truckers, from Newbury, Basingstoke and Reading, in a variety of ways including truck pulls.

Another friend of George, father-of-four Mark Sutton, decided to run the London Marathon to help raise funds for people living with MND in West Berkshire.

Mark, aged 45, of Sidstrand Road, Newbury, runs Rainbow Carpets in Reading's Caversham Road.

He told the Newsletter: "George taught me everything I know about carpets. I wanted to do something for him and he inspired me to run the marathon."

Mark finished the 26 miles course in an impressive 3 hours 14 minutes and has donated £476 to branch funds.

Contributed by Jane Gilbert



Branch Drop-in Meetings

By Margaret Moss

Some 13 months ago, our Committee dithered!

For months we had intermittently bounced an idea around.....apart from our Open Meetings we had no opportunity to meet those living with MND; was there a need to have daytime informal 'meetings', would people want them, should they be in neutral settings, what would we 'do', should we, could we, etc.

So, we at last decided! Being a long thin branch geographically, we arranged a venue at each end of our area in order to test it out.

Since then, a lot has been learned, things have changed and the format has settled down. A monthly 'Drop In' now occurs only in our westerly area and usually in a Day Centre (at a time when it's not already in use)

One of our members and Visitors, Dr Monnica Stewart, was particularly keen that these meetings should get going and came to almost every one. It was her presence, humour and common sense approach to the condition that encouraged plw MND to give it a go.



Monnica at "her birthday party"

When she reached her 80th birthday, it was very pleasing for all of us that we could surprise her by celebrating with her and afterwards, calling it 'her birthday party'.

It so happened that it was her last branch event as she died shortly afterwards. Monnica was instrumental in our current project of funding a Specialist Neurology Nurse in West Berkshire (in conjunction with West Berkshire Neurological Alliance) for two years as a pilot to improve the service and care of people with MND in our area. (We launched the Monnica Stewart Neuro Nurse Appeal in her memory and the nurse will be in post in the near future).

One person with MND was particularly surprised and delighted when her 'best man' from many years

earlier, arrived to visit her for the first time since her diagnosis – the neutral territory was what convinced him he could cope with a visit!

Several funny stories and anecdotes are swapped and give much pleasure, fun and laughter – especially the man who told of hypnotising a chicken.....and the other who had a running (sic) battle with the squirrels!

In addition to people with MND and their carers, it has become a place of security, understanding and support for those who have been bereaved.

Conversation is animated, the atmosphere is friendly and welcoming and our Secretary and an Association Visitor who make it happen, also make the most delicious sandwiches!

People with MND compare notes "what happened when you were diagnosed?" "what do you do about.... (personal physical matters)?" "how do you manage to...?"

Ex-carers know they can talk about how they are feeling "that's exactly how I felt when.." "I'm going back to work this afternoon for the first time and am feeling very nervous but... (I thought I'd come & see you before I go)"

Other committee members often drop in & on one occasion everyone felt useful when they helped to get the latest newsletter in envelopes for the post out (with much hilarity on the way!!). Local Health Professionals have also been known to drop in because they know we are there.

There is a room charge and, if there are transport difficulties, the branch pays for a taxi but it is generally agreed that the benefits far outweigh the costs!

Our original reluctance has proved unfounded! Attendance has increased, there are distinct benefits from this – where and when else is there time or opportunity to ask such questions?

"I wish we'd come sooner – months ago" "I really look forward to the Drop Ins"; "I haven't been to a Drop In yet but X says she finds it really supportive"

(We know there are other Branches who have similar events that run under other names, at different times of day, so if you want information, encouragement or help, it is worth asking! It's all free and we're glad to share our experience).

Contributed by Margaret Moss

Gill receives long-service award from new Chief Executive



Gill Cheetham, our Events Coordinator, receives her long-service award from Dr Kirstine Knox

Dr Kirstine Knox BSc PhD became the new Chief Executive for MNDA, taking up her post on the 4th July 2005.

Dr Knox is an immunologist by training, working at the Department of Health. She became the Deputy Director of the National Translational Cancer Research Network at the Department of Clinical Pharmacology, University of Oxford. NTRAC was established by the Government in 2001 with the aim of building a national network of fourteen centres at the cutting edge of cancer research and patient care. She has brought with her a wealth of health management, communication, scientific and business experience and expertise, which includes extensive access to relevant government ministers, civil servants and the educational and research sectors.

Before taking up her post, Kirstine wanted to talk, and listen, to as many people involved with the association as possible to get a real sense of the work the Branches do. The committee was therefore lucky enough to have the chance to meet Kirstine when she attended one of our normal monthly committee meetings. Margaret Moss had already told her that we occasionally heard comments along the lines of 'that's something the Association could (or was it should?) be doing' at the monthly drop-in meetings. This was therefore an ideal opportunity to pass on those ideas. It was also the chance to give Gill Cheetham, our Events Co-ordinator, her well-deserved long-service award!

We all enjoyed and appreciated meeting Kirstine and having the opportunity to talk about the Association. In her e-mail, thanking the committee, she says 'I went home tired and inspired by your group's energy, commitment and achievements.' She promised to pick up the points we raised with her and, on her first day in post, she sent an e-mail to Margaret with the follow-up to the suggestions made on your behalf.



Thank you Kall Kwik!

With sincere thanks to Kall-Kwik Printers, St Marys Butts, Reading, for their continued help and support in printing this Newsletter.

Forthcoming Events

Tea Party Summer afternoon tea party Reading Canoe Club	Wednesday 24th August 2.30-4.30pm
Drop-in Meeting Charles Clore Centre	Monday 26th September 11.30am-2.30pm

Get Wheelchair Wise!

Find out how to get the best from public transport or brush up on the Highway Code for Wheelchair and Electric Scooter users—information booklets are available FREE from BHTA Publications, tel. 01732 458868.

Vitalise Holidays

Formerly the national disability charity, The Winged Fellowship Trust, Vitalise provides holidays for disabled people and breaks for their careers, based on individual need. There are 5 accessible UK Centres and care is provided on-call 24 hours a day by qualified staff.

Vitalise Holidays: Tel. 020 7017 3420
www.vitalise.org.uk

*Happy Summer Holiday
to all our readers.*

Contact Details

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