

**Reading and  
West Berkshire  
Branch**

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[www.mndrdgwberks.  
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## OUR SPECIALIST NURSE STARTS WORK

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### Thank you!

Our sincere and heartfelt thanks to the Courtyard Marriott Hotel, Padworth Lane, Bath Road, Newbury for their warm welcome and excellent service at the Open Meeting and Committee Meetings.

Also to Kall Kwik Printers in Reading, for their generosity and support in publishing this Newsletter.



**Carol Allen visits Mrs Anne Smith, who is living with MND, at her Thatcham home.**

**A specialist nurse for people with rare and complex neurological conditions has begun her pioneering work in Berkshire thanks to hard-working charity groups.**

Carol Allen is poised to transform the way services are provided for people affected by complex conditions such as Motor Neurone Disease, Late Effects of Polio, Huntington's Disease, Ataxia, Multiple System Atrophy, Myasthenia Gravis and Progressive Supranuclear Palsy.

Voluntary groups, led by West Berkshire Neurological Alliance, have raised nearly £90k to pay for the post for two years and to research its impact. The Reading and West Berkshire branch of the Motor Neurone Disease Association, believes a specialist nurse is so desperately needed it is funding half the cost.

Carol Allen will be largely community based, helping people to manage their conditions at home as much as possible. This will involve training of patients, family

carers and professional staff and providing emotional and palliative support. Patients will have rapid access to the specialist knowledge and services they need, leading to less stress and anxiety and greater levels of independence. These are outcomes that follow from other neurology nurses already providing for local people affected by MS and Parkinson's disease.

Margaret Moss, our branch chair, described Carol's launch as wonderful news. She said: "To know that all is in place for the next two years is such exciting news and in time for Christmas too."

The initiative to raise funds for this important post was led by the late Dr Monnica Stewart of Kintbury, a stalwart supporter of the MND Association, who, as an association visitor, knew how badly a specialist nurse was needed.

The branch appeal to raise funds for its share of the cost was named after Monnica as a tribute to her dedication and drive.

Maureen Hodgetts, whose late husband Graham inspired a huge amount of fundraising, spoke about the vital role of a specialist nurse in a New Year interview on Meridian TV and Publicity officer Jane Gilbert thanked them all for being so supportive and helpful with TV, radio and newspaper reports on the appointment especially during such a busy time of year.

Carol is the latest member of Professor Christine Collin's pioneering neuro-rehabilitation team based at the Royal Berkshire Hospital covering Newbury, Reading and Wokingham districts.

Her job is thought to be unique in this country in its profile and aims. Initial referral to Carol is through GPs.

*Contributed by Jane Gilbert*

## WHAT A CORKER!

The national chain of Majestic wine warehouses has chosen the MND Association as its charity of the year for 2006.



It will be raising money through staff activities, charity tasting weeks and collection boxes in each store. The current Spring catalogue also raises awareness and highlights the work of the Association which was nominated by a member of staff whose father has MND.



Managing director Tim How says: "With your help we can help to make a serious contribution to this fantastic organisation."

[www.majestic.co.uk](http://www.majestic.co.uk)

## KARAOKE CALLING!



Calling all budding karaoke stars in the Newbury area!

Paggies Bar in Thatcham is offering you the microphone and a chance to raise funds for the Motor Neurone Disease Association.

Owner Piero Pagliaroli has entered the bar in the Pub Stars National Karaoke Competition and heats will be held every Thursday night during February and March. The eventual winner of the national final stands to win £2,000 prize money and a day in a recording studio.

Our own Maureen Hodgetts will be one of the judges and will also be urging punters to dip into their pockets for branch funds.

Piero has been a great supporter of the branch since Maureen's late husband Graham was diagnosed with MND. He organised the Graham Hodgetts Charity Football Shield and has held regular collections in the bar.

For an entry form call **01635 871805**

*Contributed by Jane Gilbert*



## TV Fans Watch out!

Both Holby City and ER will have story lines featuring MND in the near future.

## Tribute to Molly Kerswill

*The following tribute to Molly, who died on 14th October 2005, has been contributed by her sister, Moya Wallis.*

Molly was a fiercely independent person, who loved gardening, travelling, art, and driving fast cars!

She did her nurse training at the Radcliffe Hospital, Oxford, and after qualifying, specialised in nursing head injuries – her fiancé having been killed in a motor cycle accident just before her 21<sup>st</sup> birthday. Years later, after she had married and the children were at school, Molly worked as a District Nurse for the local GP in Twyford. She then took a management course at Durham University, and subsequently moved to Greenwich and became Director of Nursing for Kent and the Medway towns. After her retirement from the NHS she worked as a Relate counsellor. She returned to Berkshire in 1998.

When she was diagnosed with Bulbar Palsy three years ago, she was determined to remain independent for as long as possible. She immediately wrote an Advance Directive which her doctor was given, stating there should be no resuscitation under any circumstances. She decided not to have a PEG as she wanted to enjoy the act of eating food, and she also took no medication. The only aid that she did use was a respirator at night, which was very helpful.

During 2005 she had three objectives: to support her son through his divorce, to look after me as I recovered from 2 hip replacements, and to baby sit whilst her daughter and husband went on a cruise in September. She met all three objectives.

The MNDA Drop in Centre was a source of great support and encouragement to Molly, as was her association with Anne Hallifax. Also invaluable was the advice given by Dr Kevin Talbot and Speech Therapist Rachael Marsden, both at the Radcliffe Hospital.

Molly died at the Duchess of Kent Hospice on the 14<sup>th</sup> October 2005. I think that the following comment from Rachael Marsden sums up her final years perfectly: "Neither Kevin nor I could think of anyone who has been more in control of their destiny. She knew exactly what she would do & how she would cope with the difficult times". Molly wished that her body be used for research—she was a very special person.



## CHRISTMAS TEA PARTY

By Val Pearson

They say that the older you get, the faster time seems to pass, and I am living testament to that. St. Luke's Church in Theale was once more the venue for our annual Christmas Tea Party and the church went out of their way to make us welcome. The branch committee also pulled out all the stops to provide the buffet. I am a particular fan of Joanna's asparagus rolls and Gill's savoury canapés. To top it all, even if I am supposed to be on a diet, I cannot resist Margaret's chocolate roulade!

We were pleased to welcome John Brearley, who provided an entertainment in words and music to keep us amused. It really began to feel like Christmas, reminding me of the Joy to the World concerts at the Royal Albert. Does anyone else remember those? I hope so, otherwise I shall feel even older than my sixty-three years!!

We also had a birthday to celebrate. Sue Watson, who is living with Motor Neurone Disease, had a birthday two days after the tea party, so we all sang 'Happy Birthday' and embarrassed her by insisting she blew out the candles on her birthday cake (i.e. Margaret's roulade).

On a more serious note, we missed quite a few of our regulars who have died during the last year. Their absence was felt, but we were pleased to welcome their partners, who have formed their own support group and gathered round a table to exchange the latest gossip and Christmas cards.

*Contributed by Val Pearson*

## READING GOLF CLUB SUPPORT FOR LOCAL BRANCH

Reading Golf Club has chosen MND as their charity to support this year. Mr. Ian Durie, who is the current Co-Chair of the Golf Club for a 1 year term wrote to us recently to give us the good news. (Mr Durie's first wife died of MND in 1992 and he remembers Grace from the local branch).

The Golf Club hold a Charity day in August and then a "Swan Song" in January, when they present a cheque for the money raised.

Mr Durie is keen that the money is used locally. The Golf Club regularly raise around £10,000 each year and any funds would be split between the Branch and the Duchess of Kent House, who they are also supporting.

What a wonderful gesture and a great start to the New Year!

*Contributed by Beth Drury*

## LIBRARIAN ALAN WINS NATIONAL AWARD



Alan Hankin, who worked at Reading Central Library until the day he died from MND, has been recognised nationally for his work.

The brave bachelor was awarded the accolade posthumously for his "commitment, dedication, flair and innovation" in local studies work.

Alan's award was made by CILIP, the institute for librarians and information professionals and it is named in memory of Dorothy McCulla, who founded the local studies group within the institute.

During the last two years of his life Alan was determined to carry on working as long as he could be of service. His positive frame of mind despite adversity was an inspiration to his colleagues.

When he collapsed and died, aged 47, at his new specially adapted home in Tilehurst last April the library closed its doors to allow staff to attend the memorial service.

Colleagues and former colleagues later sent a submission to CILIP proposing Alan for the award which was announced in December. They had collected testimonials from library customers and from local history societies many of whom saw Alan as a good friend and adviser.

Local Studies manager, David Cliffe, said: "Alan will be remembered by many for his enthusiasm, his forthright Lancastrian manner, his helpfulness, and the range and depth of his knowledge of the history of Reading and Berkshire."

Typically in what proved to be his final months he spent much time training younger members of the library staff and he left his collection of books and pamphlets about Reading and Berkshire to the library.

A native of Lancashire, Alan came to Reading in 1975 to study linguistics at the University. The town became his second home and, as a frequent user of the Central Library, he went on to work there in 1988. A loyal Reading FC fan, he rarely missed a home game.

Alan's ambition was to help develop and promote the local history collections in Reading's public libraries. Eventually his post was designated Local Studies Specialist.

Many useful projects were initiated and carried out not the least of which was his computer "Megafile" of local history resources for future generations

*Contributed by Jane Gilbert*

## From "The News": Benefit Changes

From April 2006, more people should qualify for Income Support, Housing Benefit and Council Tax benefit. This is because the capital limits will increase for these benefits, allowing people to have more savings when they claim.

At the moment, capital below £3,000 is ignored, but from April 2006 only capital above £6,000 will be taken into account. Currently you are unable to claim Income Support if your savings are over £8,000, but from April 2006 the upper limit will be £16,000.

*Contributed by Jennifer Hay*



## SUCCESS OF CARDS FOR GOOD CAUSES

Thanks to all who took part in raising money by selling Christmas Cards last year.

Special thanks to Chris Bickerton and Kerrie Pearce for charming people into parting with their hard-earned cash. Also to Gill Cheetham, Sandie White and Mari Lewis for their sales efforts in a cold and windy Wokingham market place and to Laura Clintworth and the headmaster at Kennett School in Thatcham for allowing us to have a stall at the school Christmas fair.

Our thanks also go to The Cards for Good Causes multi- charity shop in Newbury for their support in selling MND Association cards. The profits from these sales go to National Office, not the local branch, but what really matters is the level of awareness-raising achieved.

Both Jane Gilbert, our publicity officer, and Barry Clouting, our treasurer also both gave up a considerable amount of their time to help in the shop.

Thank you all for your time and commitment to the charity. We covered our costs with the cards and will be looking to repeat this performance next year!!

*Contributed by Val Pearson*

## Forthcoming Events

<b>AGM</b> MND Association Brightwell Room Courtyard Marriott Hotel	Tuesday 4th April 7.30pm <b>NOTE CHANGE OF DATE!</b>
<b>Drop-in Meetings</b> St . Luke's Hall, Theale	Mon 27th Feb 11.30- 2pm
Charles Clore Centre, Newbury	Mon 27th March
<b>Spring Conferences</b>	10.30am-4pm
Thorpe Park and Spa, Leeds	9th April
Solent Hotel and Spa, Fareham, Hampshire	23rd April
The Grand Hotel, Torquay	7th May
Hilton Puckrup Hall, Tewkesbury, Glos	21st May
<b>Concert - The Farley Singers</b> (MND Awareness Week—Ticket only) St. Marks Church Englefield	Saturday 15th July

### The Benefits of Visiting - a 2-way Street! Can you...

- Help someone to smile, even laugh, when they are depressed by their physical decline?
- Get practical or financial support to help them stay at home?
- Take them shopping when they can no longer drive?
- Interpret for them when their speech has gone?
- Show you care by a simple phone call?

**With these little efforts on your part, your own life could be happier too!**

*Contributed by Lady Halifax*

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**FIGHTING MOTOR NEURONE DISEASE**