

**Reading and  
West Berkshire  
Branch**

[www.mndrdgwberks.freeuk.com](http://www.mndrdgwberks.freeuk.com)

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**Dan's back-up crew celebrate at The Last House in Scotland!**

## DAN COMPLETES 850 MILE CYCLE RIDE

The death of his cousin from MND at the age of only 28 led trainee solicitor Dan Pearson to complete a gruelling cycle ride in his memory.

Determined Dan finished the solo 850-mile ride from Land's End to John O'Groats in just seven days – a day earlier than planned.

He spent 50 hours in the saddle averaging 120 miles a day with the hills of Dartmoor proving the most punishing.

Now Dan, aged 25, hopes to collect about £3,000 in sponsorship for the Motor Neurone Disease Association.

Afterwards he said: "I took the whole week off work to recover but I feel absolutely fine and don't know what to do with myself".

Dan was followed by his parents Roger and Liz Pearson, from Whitchurch Hill, who drove with their two dogs Trevor and Wesley to help publicise the challenge. He rode solo after his cycling partner was forced to drop out.

The Pearson's eldest son Charlie has already run several marathons for MND in memory of father-of-three Chris Pearson who died in 2001.

Mrs Pearson said: "We are all very aware that Dan will soon be the age that



Dan and bike at John O'Groats

Chris was when he died.

"The ride was a massive challenge for Dan but he had been training for a long time. He doesn't get much time off work in London and I am just amazed.

"He did it for Chris."

For the record Dan's route from Land's End included seven

stops at Exeter, Leominster, Lancaster, Galashiels, Pitlochry, Inverness and John O'Groats. Some of the days were wet and windy and the gradients were gruelling. After the tough first day he wondered if he would keep up the pace.

Most people take two weeks to complete the ride but he was lucky to have his family support team following with the luggage.

Dan set up an online website for sponsorship and there is still time for you to pledge your support on [www.justgiving.com/lejogsept06](http://www.justgiving.com/lejogsept06)

*Contributed by Jane Gilbert*

It may have rained at the **Reading Canoe Club Summer Tea Party** but inside all was bright, with English afternoon tea, lots of laughter, exchange of experiences and watching the boats and canoes go by amidst the sun and showers. See insert for more...

## FAREWELL TO CHARLES CLORE



Our picture shows Sam Brown, who has MND, with Charles Clore team leader Maria Heron and (from left) branch representatives Maureen Hodgetts, Joanna Knott, Val Pearson and Margaret Moss (chair). Maria was presented with a herb planter for the unit.

*Thank you to Barry Hopperton of BMH Photography for the picture.*

Charles Clore Macmillan Day Unit has re-opened in a much smaller new location following a year of campaigning against NHS cash cuts.

Whilst patients are pleased that the staff and facilities, such as occupational therapy and recreational classes have remained the same, they are uncertain that the move to its base at West Berkshire Community Hospital is for the better.

The highly regarded palliative care unit in Newtown Road was finally closed in August to cover debts elsewhere in the NHS region. A campaign enabled the unit to continue to operate but at a different much smaller base in the hospital environment.

Before the move a group of branch volunteers marked the occasion and said a fond farewell to the unit which opened in 1990 as a joint project

between the Clore Foundation and the Macmillan Cancer Care Appeal.

People living with MND who visited the old unit for regular drop-in meetings run by the Reading and West Berkshire Branch of the Motor Neurone Disease Association expressed concern that the new facilities might not be suitable for the social drop-in sessions, particularly as the new unit is next to the wards. Staff have, however, worked hard to convert a ward into a day area and to make the new base more homely and they are keen for it to be used for drop-ins again.

Branch secretary Val Pearson, who runs the sessions with Association Visitor Joanna Knott, said: "We will give it a try for a drop-in meeting in the New Year to see how it goes. It all depends on the response of our users."

*Contributed by Jane Gilbert*

## Thank you Debenhams!

Thanks to enterprising supporter Laura Clintworth the branch has been invited to raise awareness of MND by Debenhams in Newbury.

Student Laura, who works at the store on Saturdays, was given a stand during a shopping event after she told bosses about her grandpa Graham Hodgetts who died from MND.

Graham's widow Maureen was joined on the night by her daughter Nikki Clintworth, Lady Hallifax, branch secretary Val Pearson and Alec Jenkins, who is living with MND.

One of the perks of the job was that all the women got to have a free face make-up!

Afterwards Maureen said: "It was a very good night and the staff has asked for a collecting box for their canteen."

The volunteers have also been invited back to do more awareness raising at one of the store's big shopping days before Christmas.

Val added that Debenhams staff went out of their way to make us welcome.

## Ironman Will's ultimate challenge



**Caversham soldier Will Richards**

Caversham soldier Will Richards became an Ironman champion in his biggest endurance test yet.

The super fit 30-year-old took part in the gruelling UK Ironman triathlon this summer in aid of the Motor Neurone Disease Association.

Will says the charity is very close to his heart as his mother has been living with MND for 18 years. So far he has collected £3,500 in sponsorship for the massive challenge.

He is now serving in Afghanistan for six months. For the past two years he has been based in Reading, training and preparing T.A. soldiers to go to Iraq and Afghanistan.

To claim the title of Ironman Will had to swim 3.8k, cycle 180k and run 42.2k. Next year he plans to "slightly raise the bar" and complete two Ironman challenges in 14 days.

*Contributed by Jane Gilbert*

## Cards for Good Causes



Cards for Good Causes has allowed us to sell our Christmas cards again this year at its shop in the United Reformed Church, Newbury (down alleyway opposite Marks and Spencer) and St Mary's Butts Church, Reading.

The multi-charity shop is now open for cards and gifts from 10am-4pm, Monday to Saturday. It is manned by volunteers and more than 80p in every £1 goes to the charity. Please tell your friends about it.

## LADY HALLIFAX RETIRES AS PRESIDENT

Lady Hallifax has retired after nine years as President of the Motor Neurone Disease Association.

The announcement was made at the AGM and annual conference in September where her successor was named as Liberal Democrat MP Lembit Öpik.

Lembit Öpik first became involved with the Association in 2005 after his father died from the disease.

He passionately supports the charity's vision of a world free of MND and has devoted time and energy towards raising the profile of MND both inside and outside Parliament.

Millions of TV viewers watched him on the celebrity edition of "Who Wants to be a Millionaire" when he donated his winnings of £32,000 to the Association.

### And at The Association AGM....

The Association Annual General Meeting in Birmingham in September precedes the Annual Conference. This year the conference was back to two days so as to make it easier for people travelling from afar. And do they come from afar! Northern Ireland, Channel Islands, West Country, NE and NW and others; so Berkshire seems like it's just next door.....

The branch had a display along with others showing events during the year. But our most significant moment was the presentation and thanks given by the Chair of the Trustees to our own Lady Hallifax. Anne was stepping down from being President of the Association and Alan Graham acknowledged her dedication and hard work over the years. He presented her with a bouquet as a token of the Association's gratitude.

Kirstine Knox, Chief Executive for the MND Association, paid tribute to Lady Hallifax's hard work and dedication.

She said: "Lady Hallifax made an enormous contribution to the work of the Association during her nine years in post. She will be a very hard act to follow but we feel privileged to have found such a worthy successor."

Lady Hallifax, who lives at Englefield, near Reading, has accepted a newly created position of honorary Life Vice President.

She became involved with the charity when her late husband, Falklands War veteran Admiral Sir David Hallifax, was diagnosed with MND.

Lady Hallifax will continue to work tirelessly for the Reading and West Berkshire Branch where she is an Association Visitor supporting people living with the disease and their families.  
*Contributed by Jane Gilbert*

Reading and West Berkshire Branch along with several neighbouring branches were proud to be associated with this presentation. This photograph, or a similar one, will be appearing in several branch newsletters around this time!

Not only has Anne worked hard for the Association nationally, she does, at the same time, do sterling work for our branch. That work of course continues and we join with all those at the AGM in wishing her well in this retirement.  
*Contributed by Margaret Moss*



Anne receives her bouquet and the thanks and gratitude from the Association for her hard work over nine years as President



Lady Hallifax and Lembit Öpik at the Annual Conference in September

## Alex's Tribute to Grandma



A teenager organised a football match, raising £1,000 for charity, as a tribute to his late grandmother.

Trainee electrician Alex Tucker, aged 19, arranged the game at Padworth, near Reading, in memory of Pam Harman, who died last year from MND.

The cash will be given to the Duchess of Kent House palliative care unit where Pam was cared for in the last months of her life.

Medals were presented to the winning team by Lady Hallifax, who supported Pam as an Association Visitor.

*Contributed by Jane Gilbert*

## “DREAM AS IF YOU’LL LIVE FOREVER”



Rachael Marsden, the MND Care Centre Co-ordinator based at Oxford, addressed a recent Open Meeting on the subject of Advance Directives. Rachael has a wealth of experience in dealing with motor neurone disease and its effects on people, and started the potentially difficult subject by quoting from James Dean, ‘Dream as if you’ll live for ever. Live as if you’ll die today’

### What exactly is an Advance Directive?

It is a way of making an individual’s views known regarding medical intervention, if he/she becomes incapable of giving consent to treatment. Rachael stressed that it is a specific wish to refuse some, or all, forms of treatment, although that cannot preclude basic care, such as warmth, shelter, pain relief and food and drink taken by mouth; it cannot be used to insist that a particular treatment should be given. Also, requests cannot be made for anything illegal, e.g.; euthanasia or assisted suicide.

An Advance Directive is legally binding. It is valid if the individual is over 18, not under any duress and fully capable of making a decision and understanding the consequences. Also, it must not have been altered verbally or in writing since it was made, unless signed, dated and witnessed. If these criteria are met, it must be recognised and upheld under common law until April 2007, when the Mental Capacity Act 2005 will become the legal basis for advance decisions to refuse treatment.

It is advisable to have a written, signed, dated and witnessed copy of the Advance Directive available in the house. A good idea is to use the Lions Club scheme, ‘Message in a Bottle’. This means that the directive is put in the special bottle provided, placed in the fridge and a green sticky cross stuck to the inside of the front door and on the outside of the fridge door, where any ambulance crew can find it quickly. Make sure that a copy is held by the GP, the next of kin, and is attached to medical notes.

Rachael finished by saying that an advance directive can remove the burden from family members in decision making, provide an opportunity for open, honest discussion and, most importantly, provide a degree of control for people with MND. If you want to know more, please contact Rachael directly on [rachaelmarsden@noc.anglox.nhs.uk](mailto:rachaelmarsden@noc.anglox.nhs.uk)

Rachael handled the presentation and discussion with honesty and sensitivity, lightened by the occasional glimpse of humour. It has given me, at least, food for thought.

*Contributed by Val Pearson*

## Forthcoming Events

### Pangbourne Christmas Fair

Church Hall, Pangbourne

Sat  
4th November

### Drop-in Meeting

St Luke’s Church Hall  
Englefield Road  
Theale

Mon  
13th November  
11.30-2.30pm

### Debenhams Newbury Gala Day

Kennet Centre, Newbury

Wed 15th and  
Thurs 16th  
November

### Wokingham Christmas Fair

Sun  
26th November

### Duchess of Kent House Trust

Collection at The Oracle, Reading

Mon 11th–  
Sun 17th  
December

If you can help,  
please contact Gill Cheetham

### Christmas Tea Party

St Luke’s Church Hall  
Theale

Mon  
11th December  
2.30-4.30pm

A very Merry  
Christmas  
and Happy  
New Year to  
you all



A special Thank you  
to The Courtyard  
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**FIGHTING MOTOR NEURONE DISEASE**