

## LOCAL MP SUPPORTS MND IN COMMONS



**Newbury MP Richard Benyon**

Following the General Election last May, Newbury gained a new MP, Richard Benyon. This was good news for the branch, as Richard has had personal experience of the effects of MND

His uncle, Admiral Sir David Hallifax, who helped lead the British fleet to victory in the Falklands campaign, died from the disease in 1992. Richard was brought up at Englefield and was living 2 miles away and watched his uncle becoming more disabled as Motor Neuron disease destroyed his ability to move his hands and

arms and eventually took away his ability to speak. Richard's aunt, Lady Hallifax, is President of the MND Association, and his father, Sir William Benyon, is a Patron of our branch.

In June Richard visited our stand at the West Berkshire Community Hospital, for MND Awareness Week, and pledged his support.

So, with all this experience behind him, one of Richard's first tasks on entering the House of Commons was to join the All-Party Parliamentary Group on MND.

The four main aims of the Group are:

- \* To provide a political forum for discussion and debate
- \* To create a core group of supportive MPs and peers in Parliament
- \* To create an additional channel

of communication with the Government

- \* To increase understanding of MND amongst parliamentarians

The Group was set up in January 2002 and has a membership of around 150 MPs and peers. Since then there have been debates on MND in both the Commons and the Lords, and a meeting with the Health Minister.

Richard attended his first meeting in July, which focused on ventilation, at which the Group decided to write to all Primary Care Trusts encouraging them to make non-invasive positive pressure ventilation (NIPPV) more widely available to people with MND.

The latest research shows that NIPPV can both improve quality of life and extend survival. However, it is not currently widely available for people with MND.

*Contributed by Jane Gilbert*

## NEURO NURSE APPOINTMENT

After interviews in late August, a successful candidate was identified and has accepted the post of Specialist Nurse for rare and complex neurological conditions which she will take up at the end of October.

Together with the West Berks Neurological Alliance (WBNA) the branch have raised funds through the Dr Monnica Stewart Appeal for this two year pilot post to provide a community and hospital based specialist nurse for patients affected by MND, Huntington's Disease, late Effects of Polio and other diseases.

The Neuro Nurse will work with Professor Collin,

which means that there should be more rapid access by plwMND and their carers to the specialist knowledge and services they need. This in turn should lead to less stress and anxiety and greater levels of independence and self management.

The new appointee has considerable experience of working in a hospice and with plwMND and an enthusiasm for the role, and she will be welcomed by us all.

We wish her well in her new and exciting role and look forward to working with her.

*Contributed by Margaret Moss*

## PHILLIP RECEIVES GOLD LONG SERVICE AWARD

Phillip Adams received his Gold Long Service Award from Lady Hallifax at the September committee meeting to mark 15 years of service.

Phillip joined the branch shortly after its formation as a result of his mother having

MND. He has been involved for all that time and was our chairman until a few years ago.

This is a fitting acknowledgement of his commitment - the branch can only thank you, Phillip, for all you have contributed.

*Contributed by Margaret Moss*



National President, Lady Hallifax presents the award to Phillip Adams.

## Memories of the Canoe Club Tea Party

One of the earliest events I attended when I first joined the MND Association was the Canoe Club Summer Tea Party held two years ago. I remember how beautiful the river looked in the sunshine. I am afraid to say that the weather this year was not so kind as it rained!

The rain, however, did not affect the mood inside, where the outlook was still warm and sunny. It was good to catch up with old friends.

Some were re-building their lives after losing a family member. One person, who lost his wife to MND a little time ago, was enthusiastic about joining a new art class, and is already planning a small exhibition of his paintings. Another talked about the love of his life, a Sunbeam Talbot. (Colin Moss's article on his car collection will appear in next month's newsletter).

We were also able to welcome someone who has recently been diagnosed with MND. They were able to talk to our Volunteer Visitors and share their concerns in a relaxed environment.

The local MP for East Reading, Rob Wilson, also came as a surprise, but very welcome, guest. He had received letters from his constituents regarding problems in accessing funding from the council. As a result, he had come to meet people living with MND, to hear their views and give them the chance to raise any concerns they might have.

*Contributed by Val Pearson*



## CARDS FOR GOOD CAUSES

Look out for two new outlets for MND Association Christmas cards in West Berkshire this month.

The Cards for Good Causes multi charity shop in Newbury has moved to the United Reformed Church in Cromwell Place (opposite Marks and Spencers) and will be open from October 17 until December 15, Monday to Saturday, 10am – 4pm.

This year in Hungerford Mrs Gilly Burrough has kindly agreed to stock our cards at the branch she runs in Burrough and Co estate agents, 19 High Street, which opens on October 22 and runs through to December 21, Monday to Saturday, 9.30 – 4.30.

All charities represented in the shops receive at least 81p in every £1 from their card sales, out of which they have to pay for the production and distribution of their cards and any applicable VAT.

Card sales also give an enormous boost to raising awareness and the Branch receives 20% of the order value towards funds. Last year, the Branch bought cards directly from the MND Association and offered them for sale in various venues such as Wokingham Winter Carnival, drop-in meetings and open meetings. We are intending to do the same again this year, concentrating on the Wokingham Winter Carnival.

If you cannot make it to any of these events, but want to support the Branch, please contact Val Pearson on 0118 9789063. If the item you want is not in the Branch stock, she can place an order for you with the suppliers or send you a Christmas catalogue, directly, if you would prefer.