

### Neuro nurse revving up

We are delighted to report that the post of Rare Conditions Neurology Nurse for the West of Berkshire has been offered and the nurse should be operational shortly.

She will support people affected by Motor Neurone Disease, Huntington's Disease, Myasthenia Gravis, Late Effects of Polio, Multiple System Atrophy, Ataxia and PSP. We are £7.5k short to fund the post and to research its impact. Offers to help complete the £90k funding package will be much appreciated!

### Conference news

We are pleased to report the final profit from our 2005 conference, 'Action in Neuro-rehab', was £2,462. This is in addition to the truly rich educational experience provided for the 150 who attended. Thanks to everyone who organised, sponsored or took part. With two excellent conferences behind us we shall soon start planning our 2007 event. We are therefore canvassing readers for ideas for suitable themes.

Once again we shall aim to produce a conference of outstanding quality. Let us know if you want to help shape our '07 conference.

### Projects update

There have been setbacks in both our 'hydrotherapy pool' and 'active therapies' projects since we last wrote, but nothing that time and application should not be able to overcome. We are considerably in the hands of others, but everyone appreciates the value these projects will deliver, and we will move things forward just as soon as circumstances allow.

### Neurosciences: building the regional network

The National Service Framework for Long Term Conditions recommends that each Health area establishes a Neuroscience Network to oversee the necessary changes to deliver the services needed by neurology patients. The Alliance is in active discussion with several key people in the Strategic Health Authority about the establishment of one for Thames valley and momentum is beginning to build.

Linked to this we have held discussions with the Bucks. Neurological Alliance and set up Thames Valley Neurological Alliance Partnership with John Holt in the Chair. With over 30 charities under this umbrella we are well organised to ensure a strong and well researched voice for patients and the voluntary sector at regional level in addition to our involvement within the West of Berkshire.

### Neuro rehab review lifts off

The three PCTs and three Community Care Directorates of the West of Berkshire have charged Margaret Goldie, Corporate Director of Community Care, with leading a review of neuro rehab services for the area. The review will commence with a one day workshop in September, and many Neuro Newsletter readers are likely to be present. This is the first time the statutory sector has ever organised any neuro specific event of this type locally, so this is a remarkable milestone. There are many issues for this review to grasp and it is critical that the patient perspective is listened to. We will report in more detail next time, hopefully with some good headlines and some substantive, worthwhile proposals for action.

## *Patient patients*

The NHS's West of Berkshire 'Long Term Conditions Collaborative' has commenced a broad review of services for local neurology patients. Accordingly we submitted to them the full set of the Alliance's agreed local priorities for change and we await a reaction. Our main themes are greater levels of preventive services that are easy to access, with a higher proportion of specialist and sub specialist staff, everything being patient-centred. In other words more effective and less costly services! We understand this group is considering how to involve patients in its work. Great idea!

## *Healthcare Commission's jaded stars*

The Healthcare Commission, which awards stars to PCTs and Trusts, has added to its miserable record by awarding Royal Berks. Hospital (RBH) a 'top' 3 stars again. RBH does many things very well, but it doesn't deserve 3 stars for the way it has not planned services for neuro patients. Is it OK for NHS Trusts to keep improving the so called 'priority' services the Healthcare Commission monitors, paying for this by cutting non assessed services? Is it OK for NHS Trusts to deny there will be cuts in beds, then cut them, then announce an immediate review, and then take months to start one? Of course not! No marks from neuro patients to RBH for that!

But the Healthcare Commission looks at things with blinkers on. NHS Trusts get stars only for what they are assessed upon and stars are not an indicator as to whether Trusts provide a balanced, all round or good service. We have once again written to the Commission and reminded them of the folly of their audit system. If we knew no better we would award them zero stars, but we shall simply award them a rating of 'inadequate, unaware of the whole picture'.

## *Boost from 'Change Up'*

We are currently negotiating to benefit from some 'Change Up' funding, money originating from the government for use in developing the voluntary sector's infrastructure. We should soon be benefiting from some paid secretarial/admin support. In turn we hope this will encourage someone to step forward to become the Alliance's Secretary, a post that has been unfilled in the last year. Indeed this resource should liberate Executive Committee members more generally. Does this news tempt you to stand as a candidate for the Executive? We are always seeking new blood and new energy, and there remains much to be done as the NHS's National Service Framework kicks in.

## *AGM change of date*

Please note the **new venue** for the AGM, Stockcross Village Hall, and the **changed date**, Friday 23rd September. Please try to get along, as this will be a super opportunity for everyone to hear from and to brief the Executive Committee on any of the many issues currently in hand. Our speaker, Dr Peter James is leading the development of the Thames Valley Neuroscience Network.

## *Diary dates to note:*

Friday 23rd September. AGM.  
7.15 for 7.30 p.m. at Stockcross Village Hall.  
Speaker: Dr Peter James, Thames Valley H A  
Neuroscience Network Champion.

Thursday 17th November. **Open meeting.**  
1.45 for 2.00 p.m. at St Joseph's.

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