

*Special neurology nurses.*

Following discussions with Drs. Collin, Gregory and Hyman about their interest in appointing a general neurology nurse for the west of Berkshire we seem close to agreement on what the role will be, and how we can help with the initial costs. This exciting opportunity is at the very top of our agenda. We know readers will be delighted at this news.

*Health Improvement moving forward.*

We polished our reading specs, sat down in our comfy chairs and carefully read what, from the title on the cover, seemed a sure fire bet to be a very dull document. Far from it! Newbury and Community PCT's draft HIMP (Health Improvement and Modernisation Programme) 2002-5 may lack the drama and plot of an Agatha Christie, but shows what a long way this new Health Trust has come in a short time. We are delighted that the needs of neurology patients attract several mentions. The PCT recognise a number of the Alliance's concerns and proposals, and we thank them for this.

*Rolling on.*

Steadily expanding our activity, the Alliance has attended every Patient Panel meeting of Royal Berks. & Battle Hospitals (RBBH) Trust this year. The Panel is still finding its feet, and we can see a number of issues it could, and should, address. We have asked for these to be introduced into the Panel's agenda and priorities. We have fielded three alternate representatives to the Panel, matching the expertise of our members to the subjects under discussion. If you have a subject for the

RBBH Patient Panel, or have expertise in a particular field which could help us make better impact there, please make contact.

*Rolling on further.*

We've also achieved a goodly slice of contact with Wokingham PCT this quarter. That said, we could do with further help in consolidating our contacts there. We raised the subject of neurology services with the Board, who took a positive interest in our concerns. In current draft, Wokingham PCT's HIMP makes only limited references to the needs of those with neurology conditions. We expect to see this change as we prompt further awareness.

*Rolling right on.*

We are delighted to inform that a Neurological Alliance in Buckinghamshire is now up and running, with 20 members and a Steering Group in place. Well done to all involved, particularly Sandra Paget and Lynsey Harrison for their pioneering work. We expect to share and work with our Bucks. colleagues on many issues, not least those at Thames Valley Strategic Health Authority (TVSHA) level.

*Talking of which.*

Mr Kendall Bird, who is responsible for planning Specialist Commissioning in TVSHA, will join us at our November Open Meeting. His responsibilities include planning the commissioning of specialist neurology services at regional level. We hope as many as possible, including colleagues from the Bucks. Alliance, will come along to find out about how things will develop at TVSHA.

### *Rolling on to Whitehall.*

On 12th June Health Minister, Jacqui Smith, updated the position on the National Service Framework for Long Term Conditions. The Minister said 'This NSF will enable us to tackle unacceptable variations in the quality of care across the country for people with neurological conditions and brain and spinal injury. We know that people need help not only in the context of managing their medical condition, but also in the light of their social, educational, employment and family lives. Their views and those of their family and carers are really important in helping improve their independence and quality of life.'

Fine words, but hold on! The plan is to publish the NSF in 2004. Implementation will commence in 2005, taking 10 years. Yes, folks, things should be OK by 2015, and they don't mean quarter past eight! So if the Minister doesn't mind we'll keep on plugging away about what needs to be done NOW!

### *Eager Expert Patients.*

You may recall our lead article last time was on the 'Expert Patient'. We are pleased to learn that Newbury PCT has secured funding for an extra pilot group, and they are particularly keen to involve neurology patients in the programme. We'll keep you 'experts' posted.

### *Open meeting on 22nd May.*

Our May meeting welcomed guest speakers Jay Ellis and Sarah Robinson from the local Speech & Language NHS service. Jay described a service which differentiates the individual needs of patients, but questions and comments from members present revealed a spectrum of problems in accessing the service and in securing sufficient treatment to meet real needs. How these shortcomings will be addressed remains unclear for the time being.

### *Open meeting 25th July.*

Our July meeting had such a full agenda it's probably a good thing our guest speaker couldn't make it! Call if you need the minutes.

### *Neuro conference 2003, 'Experts together'.*

On Friday, 28th March 2003 we will hold our all day 'Experts together' neurology conference at Newbury racecourse. Note your diary **now!**

### *Editor's thanks.*

Sadly, Richard Long was unable to continue as Newsletter Editor. Thanks to him for editing issue 10. Issue 11 is edited by Boris Todd, and we expect to appoint a permanent Editor soon.

### *Diary dates to note:*

Our **AGM** will be on Thursday **26th September, 7.30 p.m.** at the **Mencap Centre**, Enborne Gate, Newbury. Guest speaker: To be confirmed.

Meeting of **Regional Neurological Alliances**. Tues. **15th October** from **10:30 - 4:00 p.m.** at **St Joseph's Church Hall**, Robin Hood Roundabout, Newbury. £5 for lunch. Meet other Alliances from around the UK.

**Open Meeting Thursday 21st November.** Guest, **Kendall Bird**, Specialist Commissioning Planning Manager, TVSHA. 1: 45. p.m. for **2 p.m.** also at **St Joseph's hall.**

**All are welcome at all the above meetings.**

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