

Good news for Epilepsy.

With Ethics Committee approval under the belt, the drive is on to find local people with epilepsy to take part in our latest health and social care needs survey. We want to hear from local individuals with epilepsy, or their carers, to contact us and register an interest in taking part in an epilepsy focus group. Newbury & Community PCT are our professional partners, providing advice and support. Phone John Holt on 01635 33582 for more information.

CHI must do more than just change their name!

We congratulate our three local NHS Primary Care Trusts in Newbury, Reading and Wokingham for their positive and constructive responses to the audits they had from the Commission for Health Improvement (CHI), resulting in them being awarded their recent 'star' ratings. The audits have been accepted by the Trusts as useful, and perceptive in their recommendations. The lack of 'stars' awarded to the Trusts is set against a similar pattern of a lack of 'stars' awarded nationally. Not surprisingly, the perceived need among NHS staff to be awarded more 'stars' next time around is strong, to say the least!

Largely unnoticed, but surely more important, the scope of CHI audits is such that neurology and allied services are simply not audited. CHI's recommendations for improvements are general and certainly not specifically relevant to filling the gaps in the services needed by neurology patients. The focus remains firmly off neurology. CHI's written response to our concerns confirms this without directly saying so. They have promised to forward our concerns

to their successor organisation, CHAI. We recommend that readers write to CHI, at: Performance.Indicators@chi.nhs.uk

A forest of eyes on the balance sheets.

Working with the local Disability Alliance and MS Society Branch, September 30th saw West Berkshire Neurological Alliance at West Berkshire Council chamber, asking Councillors to confirm that all is well with Disabled Facilities Grants and the minor equipment and respite budgets, subjects of particular interest to our members. This headlines a series of actions we have taken to raise awareness of the importance of several services provided by the Council. We are particularly grateful to Councillor Phil Barnett for his interventions.

We have heard broad assurances that the budgets should be sufficient to meet local needs in future. There remains a need for us to follow through as a result of the interest our probing has raised. We look forward to more joint working with voluntary sector colleagues and West Berkshire Council on these issues.

National neuro perspective at our AGM.

Diane Newman, Chair of Cambs. Neurological Alliance, addressed our AGM in September. She stressed the significance of the developing National Service Framework (NSF) for Long Term Conditions which will focus on neurology patients. The national Alliance has played a leading role in providing information and encouraging others to take part in the consultation. How to fund extra services and the long time-scale to implementation are major ongoing concerns. For more, look up www.doh.gov.uk/nsf/longterm

Another good year

In his annual report, given at the AGM, Chairman David Roberts noted that membership has grown to 34, which includes 14 voluntary groups. Our conference was an organisational and educational success, adding £5,700 to our specialist neurology nurse fund. Our agenda is now widely known and our health and social care needs survey has helped generate service improvements. Extra local NHS funding has been put into neurologists, neuro-surgeons and some allied services.

Molly Davison and Chreanne Montgomery - Smith stood down as Trustees, with thanks from David for their contribution towards our progress. We hope that both will stay in close touch. The newly elected Executive is:

David Roberts, Chairman. Joyce Parker, Vice Chairman. David Woodhead, Treasurer. John Holt, Secretary. Bob Cray, Leila Ferguson, Gill Hall, and Hilary Hinchliffe complete the team.

Consult, prevent and self refer!

On 30th July, at our open meeting, Clare Stafford, Public Partnerships Facilitator at Reading PCT, updated members on Reading's vision for improving services. The main thrust is to establish GP networks and bring as many services as practicable into these, allowing Royal Berks. & Battle hospital to focus on specialist work. There will be more emphasis on preventative intervention. Anyone interested in contributing to the ongoing consultation should contact Clare on 0118 982 2898.

At the same meeting Phil Prynne, Continence Advisor, West Berkshire, disclosed the good news that her staff complement is being increased. This will help shorten waiting times for assessments, although historically waiting times have not been excessive. A survey of the views of her service users is nearly complete and the results may help to clarify the findings

of our Alliance's earlier survey which identified some concerns among our members. Self referral is welcome, and Phil is pleased for us to publicise her number; 0118 949 5148.

Neuro Conference 2005.

Our conference team is already making plans for our March 2005 event. The team will need to adopt a new leader, as Hilary Hinchliffe is seeking a lower profile this time around. Any person interested in contributing should contact John Holt on 01635 33582 for an initial chat.

Link Up recycling

Local charity, Link Up, which provides employment to a number of people with neurological conditions is currently expanding and in the next 15-18 months is planning to have a large recycling facility in operation. Anyone with an interest in this development should contact Patrick Slater on 01635 41464.

Jam, but no cake?

The NHS is consulting on 'Patient Choice', i.e. 'choose where you get your NHS treatment'. What if there's no service in the first place? Let's get the priorities right, Secretary of State!

Diary date to note:

Thursday 4th December. **Open meeting.**
1. 4.45 p.m. for 2. p.m. at St Joseph's, Newbury.
Speaker: West Berkshire Councillor Phil Barnett, Executive member, Community Care.

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