

*Let's see more professionalism!*

One of the Alliance's main campaigns has been to ensure local service providers know how many neurology patients there are in the area, so service levels can be properly defined and resourced. Evidence shows more such patients locally than generally assumed. Accordingly we applied to Berkshire Health Authority's Partnership Development Fund for money to be spent across four local Primary Care Trusts to confirm the local prevalence of neurology. The outcome was a rejection, and the basis was this is 'not a priority'.

Some data recently collected by local GPs shows the prevalence of Epilepsy, Migraine, Cerebro Vascular Disease and MS all are distinctly higher in West Berkshire than standard NHS estimates. Knowing the local prevalence of conditions is surely one of the keys to defining the resources needed. We are surprised and more than disappointed to be told this is considered a low priority. We seek a rational and equitable way to allocate hard pressed NHS funds and will continue to press for a more professional approach!

*Health & social care needs survey launched.*

Obtaining the necessary approvals took an awful lot of time but our survey of the health and social care needs of local neurology patients is finally under way! We are in stage one of a multi stage process which is going to take quite some time to complete. Along the way we will be pressing for action wherever the interim data indicates. We are particularly grateful to Dr Sue Rendel and Dr Barbara Barrie, and also to all the other GPs who are now involved in moving the survey forms out

to their patients. The returned forms will be analysed statistically by Berkshire Health Authority, all part of ensuring the data is given objective analysis. We trust readers will encourage everyone they know who is sent a survey form to fill it in and return it.

*Modernising Local Health Care.*

Newbury Primary Care Trust held a very useful gathering at Newbury Racecourse on bonfire night, at which many of our members were present. It was great to see the PCT seeking the voluntary sector's priorities.

The priorities listed for improvement were:

- Applying best practice
- Developing more of a learning culture
- Supporting chronic conditions, e.g. MS, MND
- Quality of life-pathways for patients/carers
- Keeping the patient informed at all stages
- Keeping professionals informed at all stages
- Partnerships with patients
- Better access to information
- More specialist nurses/clinicians
- More physiotherapy

Not a surprising list to us when the local ratio of Consultant Neurologists to patients is 65% below that recommended, the Neurosurgeons ratio is the worst in the British Isles, and many services used by our members are poorly resourced, the worst we know of being Speech & Language which is funded only at about 15% the recommended level.

Call us if you want to see the full notes of this meeting. We have asked the PCT to repeat the exercise annually, and think they are planning to do so anyway. Well done to them!

### *Blackish humour and reddened faces.*

Apparently, after some 40 years of waiting, we might be on course for an opening date 'not too long after April 2003' for our new Newbury Hospital. Chris Tarrant's ambivalent humour seems apt: 'Well done everybody.....'

To be fair, of course, we haven't done much to help this project. We offered to raise half a million for a hydrotherapy pool and were told not to bother, so we didn't. We should be thoroughly ashamed of ourselves for this inertia. Then again, let's not forget that the Alliance's very reasonable questions about this new hospital have not been answered. The architect's plans have changed repeatedly along the way; indeed how many more times since we last looked, we wonder? We'll reserve our judgement. 'Consultation' on this project just seems to result in redness in the face, wherever you are in the process.

### *Setting our priorities.*

Our final Open meeting of 2001 was devoted to a detailed examination of some of the issues we earlier identified as Alliance priorities to feed into the NHS Health Modernisation Programme. We plan to continue this discussion at the next Open meeting on 7th February. The number of issues of common interest and serious concern to members continues to grow, as more new members attend and new information emerges from our relentless research. When we first met informally 3 years ago we had little idea how big an agenda for change is really needed. Do try and get to St Joseph's hall on the 7th February. Non members are always welcome.

### *Membership renewal time.*

Most memberships currently are up for renewal. The Executive agreed at their last meeting to extend the term of membership to 2 years, while keeping the fees the same,

effectively halving membership costs. Please return your forms as soon as possible. Our strength lies in the quality of our wisdom, the way we present, and the breadth of neurology conditions our membership embraces.

### *Just the job!*

The Executive Committee members are:

Joyce Parker, Chairman: David Roberts, Patrick McGrath, John Holt, Gill Hall, Hilary Hinchliffe, Chreanne Montgomery-Smith, and Sandra Paget.

If you have time and feel you can help the Alliance don't be shy. Phone us any time and be sure of the warmest of welcomes! We have many interesting positions!

### *Diary dates to note:*

**Open Meeting** dates for 2002 are as follows.

Thursday **7th February.**  
Thursday **21st March.**  
Wednesday **22nd May.**  
Thursday **25th July.**  
Thursday **21st November.**

Arrive at 1. 45. p.m. for a cuppa. We start at **2 p.m.** All Open Meetings are at **St Joseph's hall**, Robin Hood Roundabout, Newbury.

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

**Note your diaries now! All are welcome at all the above meetings.**

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