

*Hello from the Editor*

This edition of the Newsletter follows a series of meetings with different service providers which has all happened in a fairly short space of time. There is a mixed bag of good and disappointing news. Our Executive is in for a busy time in the months ahead as issues develop. If you have the time or inclination to lend a hand, please call the number at the bottom of the reverse side.

*And an apology....*

It was on 10th December that the Alliance's main phone and fax lines began to splutter, and within 24 hours all was silent. Despite every type of pleading with BT this awful interruption lasted up to 2nd January, by when we have no idea how many of your messages to us may have been lost. If you've given up trying to contact us, be assured we're plugged in and switched on, rearing to go and wanting to hear from you.

*Grants make a difference!*

The fund-raising team has had further success, with a grant from the Colefax Charitable Trust, for which many thanks. With 9 grants having been received to date we have been able to upgrade some office equipment which is already proving most valuable in saving time. Our new computer will help in progressing our neurology patients survey, the key to us informing service providers of our members' needs. We plan to invest much time and effort into this survey and are delighted at the

support from Newbury Primary Care Group and the Public Health Consultants in helping us move this along.

*Therapy at the Sandleford Day Room*

Last time we reported how the grants team has put in a big effort seeking grants to fund a team of specialist neuro-physio, speech & language and occupational therapists. The idea is they will work in the already equipped Day Room at Sandleford which has been offered to us for these purposes by the hospital managers. This is a great opportunity for the voluntary sector to work in partnership with the NHS and Social Services. In the event, we were very disappointed to learn that Berkshire Health Authority Partnership Development Fund was over-subscribed by 10 times, and our project alone needed twice the entire available money! Some projects are just too big for their own boots! We are still waiting to hear if the New Opportunities Lotteries group will fund this project and have other feelers out to boost our funds already set aside for therapy provision.

*Newbury's new Hospital*

Alliance members turned out in force at a meeting about the New Newbury Hospital on 8th January. Well done to the 11 neurology representatives who turned out and asked some very searching questions. We made up more than a third of the entire audience!! The project has many attractive features, but also an impoverished feel, only one of the reasons the consultation process has turned out to be so disappointing to so many.

## Health Improvement Programme

One of the big problems we're up against is that central government has yet to place neurology into their Health Improvement Programme (HImp) priorities. We continue to press this point with the national Alliance wherever the opportunity arises. Members might consider reminding their head offices to do likewise.

The West Berkshire HImp is the key document which defines the official view of priorities for change in local health care provision. At our open meeting on 25th January we shared and pooled our knowledge about priorities for neurology patients. The main themes coming from members were lack of support at the time of diagnosis, problems with ongoing medical support, and difficulties in accessing therapies. The Executive will continue the consultation amongst our membership and consolidate the output into one document, to feed into the HImp consultation process. Our thrust follows the theme of confirming the local prevalence of neurological conditions, ensuring the NHS has a register of those affected, sharing knowledge of what constitutes best practice, and encouraging service providers to bridge any gaps in an equitable way.

### *It's time to renew membership!*

At the end of the year our membership stood at 18, embracing 16 medical conditions. We maintain informal contacts with a further 20 or so neurological voluntary groups. Renewal time has arrived already. To tempt you we've lowered the 'Group' subscription rate to £15, so please complete and return your membership form as soon as possible. If you need an application form and don't have one, phone 01635 33582.

## Sharp and to the point!!

Why not join your GP's surgery Patient Participation Group and get neurology on the agenda at the sharp end?

### *Who's who in the Alliance.*

A reminder of who is on the Executive:

Chairman: Joyce Parker 01635 200351  
Treasurer: Patrick McGrath 01635 873454  
Secretary: John Holt 01635 33582  
Executive: Gill Hall 01635 863459  
Executive: Sandra Paget 01494 729373

If you have issues you wish to raise please feel free to approach any Executive member. Better still, come along to any Open meeting, dates as below.

### *Diary dates to note:*

**Please note the venue of future Open meetings has changed, to accommodate the growing numbers. All are welcome.**

**22nd March.** Guest speakers **Mark Charters**, West Berkshire Social Services, and **Jan Evans**, Partnership Manager, Newbury Primary Care Group.

**24th May.** Guest speakers **Dr Elaine Farmery** and **Dr Nicky Cleave**, Public Health Consultants, Berkshire Health Authority.

**Both meetings are at St Joseph's Church Hall, Robin Hood Roundabout, Newbury. Both are on Thursdays, at 1400 hrs.**

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