

Charitable Status

With a great fanfare we can announce that the charity Commissioners have approved us as a registered charity, number 1081021. This milestone is due to Joyce Parker's great perseverance and is a big step forwards. Well done, Joyce, and many thanks.

More new members

Membership now stands at lucky 13, representing 10 neurological conditions. This includes groups representing Cerebral Palsy (SCOPE), Huntington's Disease, Learning Difficulties (Mencap), Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease, Polio and Stroke. Individual members also represent the interests of Ataxia and Charcot-Marie-Tooth Disease.

This is great progress and more members are expected to join before the AGM. Anyone who needs a membership form, can phone John Holt on 01635 33582.

Please remember that it is only members who may vote at the AGM.

More Success on the grants front

It is great to report that, further to the grant from West Berkshire Council, the Greenham Common Trust recently also awarded us a grant of £1000. Many sincere thanks to them. It is planned to use this to sort out some improvements to our office equipment. Watch out for some publicity on this in the press in the weeks ahead.

Neuro rehabilitation

Our guest at our open meeting in May was the Consultant in Neuro-rehabilitation at the Royal Berks. and Battle Hospitals Trust, Dr Christine Collin. She gave us an excellent run down on how she envisages things will shape in the future. This helps us to see where to place the emphasis in our activities, in support. Her parting comment was to confirm her welcome of the emergence of the Alliance. Let us not disappoint her!

Newbury Community Hospital.

Several members of the Alliance attended a presentation of the plans for the new Newbury hospital. The architects were present, along with Project Manager Sue Howson. Projects like this always raise many concerns, so we were delighted that Sue subsequently attended our July open meeting to update us further and to outline how we could continue to make input. Some financial aspects of the hospital remain a concern. The redrawn plans, due shortly, are expected to show a better shaped building with less distances to walk within the out-patient areas. We have requested further detailed information as soon as it is available, and will monitor progress closely.

Better all round

Sue Howson is also responsible for service redesign within the new hospital. She will shortly announce a timetable for the next round of services to be reviewed. This next round will include ophthalmology. We have registered with Sue a full list of the services used by neurology patients, so she is aware of our interest and concern. If any individual is a regular user of one of the hospital services and has an interest in service redesign they can contact John Holt on 01635 33582 for more information.

Hydrotherapy

As most of us know, hydrotherapy is a greatly beneficial treatment for many of our members. We have been assured there is plenty of space for a hydrotherapy pool in the new hospital, but the authorities do not seem keen to write the words in black and white. Maybe they wish us to write them in our own blood? Maybe we will! If we are to get the right facilities for this in the new hospital we need to get the right team together to ensure we bring as much expertise into play as possible. Anyone who knows of someone with specific skills or knowledge in this area, and who is able to get involved, please contact our Chairman, David Roberts on 01488 608647.

Combined therapies project

From previous neuro newsletters you will be aware that we have been offered the use of the elderly rehabilitation day room at Sandford, in the afternoons, for the provision of physio and other therapies if we can provide the staff. How to find and finance this has been the subject of much discussion, but unfortunately, to date, little progress. We are still seeking funds, and there are still a number of administrative matters to resolve before we could start. We remain determined to take up the offer of this well equipped room and the potential it offers to our members to benefit from therapy they could not otherwise get.

Health improvement programme

Berkshire Health Authority have updated their Health Improvement Programme (HImp), as has the local Primary Care Group (PCG).

Shamefully, the same as last year, the word neurology or its derivatives does not appear once in either document despite our best estimate that there are 5000 neurology patients in West Berkshire! This omission is, to a considerable degree, a reflection of neurology not being a national HImp priority. What it means is that little or no priority will be given to improving existing services used by our members, such as physiotherapy, hydrotherapy, speech and language therapy, occupational therapy, Orthotics, continence advisory service, specialist neurology nurses and so on. We have been informed that, in future HImps, 'care of the elderly' may come more under the spotlight, which, by default, will cover neurological conditions. Oh to be a teenager again! These unappetising crumbs of comfort must be replaced with something focused and of tangible help to our members. It is imperative that we get national government to specifically recognise neurology as a priority. Members are all encouraged to urge their respective national headquarters to demand this, and similarly we will be pressing the national Neurological Alliance to do the same. Footnote: the reply we got from the Health Authority to our letter on how some of this year's extra funding could and should be spent on services used by neurology patients was to the effect that our requests had 'been noted', but that attention was on 'assessment of the priorities which the government expects us to take action on'.

See how the cookie crumbles?

PCGs out; PCTs in!

The Health Authority has published proposals, the main effect being to combine Newbury Primary Care Group with Newbury Hospital into a single Primary Care Trust, with similar changes elsewhere in the County. If anyone needs a copy of the proposal, or feels there are issues for us, please contact John Holt on 01635 33582.

What's up at the NHS Executive?

At the top of the NHS structure sits the NHS Executive. One of their projects is the production of a 'Compendium for PCGs on commissioning neurological services'. This is to include an appendix with actual working examples of good practice in commissioning of neurological services. To date they have been unable to find any such examples! Not too many of us will be surprised by that revelation! At least they are trying. Can't wait to see what this document says!

CoFA raffle tickets

We have now received our year 2000 CoFA raffle tickets, sales of which last year raised us a useful sum. Anyone able to sell these tickets, please contact John Holt on 01635 33582.

Diary Dates

Wed. 27th September at 1930 hrs. **AGM** at the Mencap Centre, Enborne Road, Newbury. Guest speaker **Peter Cardy**, Chairman of the national Neurological Alliance. **All are welcome.**

Wed. 4th October. Meeting of all **regional neurological alliances**, West Bromwich. Theme 'Forging Links'. For details contact John Holt.

Thurs. 2nd November at 1400 hrs. **Open meeting** at 11, Croft Lane, Newbury. Guest speaker **Helen Taylor. Head of Adult Services**, West Berkshire Social Services. **All are welcome.**

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