

Neuro nurse fund nears £50,000!

Let's waste no time in offering our huge thanks to The Foyle Foundation for pledging £10,000 towards our fund for a Specialist Nurse for Rare and Aggressive Neurological Conditions for the West of Berkshire. This adds to the stretching financial commitments already made by the Motor Neurone Disease Association (Reading & West Berkshire), and by the Berkshire Branch of the British Polio Fellowship. The Alliance began raising its contribution to the specialist nurse fund some time ago, topped up most recently by income from February's pledge auction (see below). Adding everything together, an impressive £49k is now pledged to the project, leaving only a further £41k still to track down. We are beavering furiously away to secure this balance, and would love to hear from anyone who can lend their weight to the final push.

Dr Collin shows her worth.

Thanks to everyone who donated pledges, made winning bids, and otherwise helped to make February's pledge auction such a success. 'A day in the life of Neuro Rehab Consultant, Dr Collin', raised a rapid fire bevy of bids which topped out at a brilliant £90. In complete contrast 2 lots of horse manure raised £102 between them!

The 15 pledges auctioned for the benefit of the Alliance raised £808, a great result, meaning that we are now able to commit nearly £18k towards the specialist neuro nurse fund. Most important, our thanks go to Newbury Rotary Club for organising this major event, which helped about 20 charities in all that evening.

In pursuit of excellence.

Interest in our proposed Neurosciences benchmarking study looks as though it might snowball. Colleagues in other Regional Neurological Alliances, and in the national Alliance, have welcomed our call for partners to take this forward. Benchmarking is also now on the agenda of the team that will lead the research needed to underpin the National Service Framework for Long Term Conditions, which will focus on neurology.

Thames Valley Neurosciences are keen to meet with us to explore the issues. The Alliance's Executive will be reviewing how to bring together all the interested parties and see how all this pent-up interest might best be harnessed. Anyone with experience or an interest in Benchmarking and wishing to make a contribution, please contact the Editor.

Easier access to better local services.

The transfer of services to the West Berkshire Hospital has resulted in an environment that is welcoming and recuperative. We congratulate all those involved. We understand that negotiations are in hand for a Consultant in Neuro- rehabilitation to hold clinics in the locality for the first time. We look forward to this as just one element of a more local and more accessible health service. The Patient Information Point is also well worth a visit. On a different note, many report feeling sick just at the thought of having to pay to park at hospitals, so we were pleased to find the local ticket machines have been 'out of order', giving patients and visitors free parking. This simple

lapse surely prevented much illness.

New money for neuro.. (Maybe.....)

We welcome a new NHS initiative, called the Chronic Disease Collaborative, but which will in fact cover all chronic conditions, not just diseases. One patient group to be covered is **neurology!** The proposal tackles the core of issues raised by our members on a daily basis, aiming to improve things by better preventative interventions. This is good news, especially as there could be new funds for PCTs aiming to be 'Case Management Demonstration Sites'. Without many clues as to what one of those is, we encourage the West of Berkshire PCT consortium to bid for these funds and have offered our support to help things along.

April open meeting highlights.

It's perhaps not well known that 10% of the resources of Newbury Cancer Care Trust, based at Sandford's Charles Clore Unit, are available to help people with life threatening conditions other than cancer. Some neurology patients may qualify, and the capacity is there right now. Thanks to Suzanne Oliver and Marie Heron for their informative presentation.

Catherine Mountford, Commissioning Director for Thames Valley Neurosciences, updated members on a range of developments. These include a recent review of the access pathway to Neurosciences, mapping of all the neuro services and oiling of the links between the local neuro and cancer services. Neurosciences will move to the John Radcliffe site in 2006, and members expressed interest in helping to shape the outcome of this, and to have stronger patient involvement generally in service design.

Star wars.

The Commission for Health Improvement, CHI, have now responded constructively to our CHiding of their work by inviting us to suggest a performance indicator for neurology, to be

considered for use in the NHS star rating assessment system. When we have CHI's ground-rules we shall set up consultation groups, locally and around the regions.

Snippets...

Speakability plans to set up a group for local people with Aphasia (speech difficulties), to build confidence in communicating for those in need. If you know anyone who has need of such support please contact the Editor.

National news. Welcome to Judith Kidd as the first ever Chief Executive of the Neurological Alliance, driving neuro issues at national level.

Cerebral Palsy. National line 0808 800 3333
For local support, Tel: 01959 564 686

Diary dates to note:

ME/CFS. We've booked Newbury Town Hall for 2 p.m. on 12th May, International ME/CFS Awareness Day, for anyone affected by ME/CFS to meet up. Please spread the word!

Friday 25th June. **Open meeting.**

7.15 for 7.30 p.m. at St Joseph's, Newbury.
Speaker: Dr Collin, Neuro-rehab Consultant.

Thursday 30th September. **AGM.**

7.15 for 7.30 p.m. at Mencap Centre, Newbury

Tuesday 12th October. **Open meeting.**

1.45 for 2 p.m. at St Joseph's, Newbury.

Thursday 9th December. **Open meeting.**

1.45 for 2 p.m. at St Joseph's, Newbury.

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