

Neuro nurse post re-advertised

Sadly we report no joy yet in finding a suitable candidate for the specialist nurse post we are funding, for those affected by rare, complex neurological conditions. We are advertising the post for the third time! The good news is we have received grants for the project from The Ammco Trust and Berkshire Masonic Charity (£1,000 apiece), and from the EBM Charitable Trust (£2,500). This leaves us with just £7,500 to go out of the £90k needed to fund the post and to research its impact. We are most grateful to all who have sponsored the project.

The nurse will support people affected by Motor Neurone Disease, Huntington's Disease, Myasthenia Gravis, Late Effects of Polio, Multiple System Atrophy, Ataxia and PSP.

Conference 2005: a huge success

Everyone has been congratulating Fred Davison and his team for the huge success of our second conference. Building on the reputation of our brilliant 2003 event they knew they needed to produce something special. With Professor Collin and Penny Lilley as advisors they found a truly superb line up of speakers who delivered a riveting set of lectures ranging from stem cells to cybernetics and functional electrical stimulation to drugs and brain recovery. It is now very apparent that the National Service Framework for Long Term Conditions needs a conference in its own right! The final session, a debate on 'Intermediate care is it working?', got the audience very worked up, and a vote at the end showed less than unanimity, suggesting there is much still to be done to get things right there.

We are most grateful to Greenham Common Trust, Newbury Town Council, Medtronic, West Berkshire Disability Alliance, Berkshire Community Foundation, Ipsen, Publicity Projects Newbury and Cephalon who all sponsored the conference, and to all those who paid to attend with Trade stands. We're still calculating the financial profit, but we know the educational profit was very great.

Hydrotherapy really bubbling

Our research into the demand for hydrotherapy services in the area has shown a clear need for a pool, and AFC Newbury Football Club are very keen to site such a facility within their new stadium complex. Greenham Common Trust are indicating interest in funding the capital costs. In no time at all we are seeing partners come together to make this dream a reality. A stakeholder meeting is to be held at AFC Newbury's ground on 29th June at 10 a.m. Any organisation with an interest in any aspect of hydrotherapy is welcome. Please phone John on 01635 33582 to say if you are intending to be at this meeting.

Sponsorship flows in

We are very grateful to West Berkshire Council for their grant of £1,200 towards our core running costs. We appreciate this recognition and the value the Council places on our work, and we appreciate the way they increasingly ask for our involvement.

We are also very grateful to Newbury Building Society for their grant to us of £400 to cover the costs of our Newsletter for a year, and are delighted to acknowledge their vital support.

Yes, Minister!

The National Service Framework for Long Term Conditions (NSF) is the government's blueprint for future service provision for people affected by neurological conditions. Apart from the ten year implementation period the recommendations are so good we can only ask readers to study them, rejoice, and join everyone else in helping to implement them!

One key recommendation is to set up Neuroscience Networks, generally one for each Strategic Health Authority. These Networks will determine local ways of implementing the NSF. Logically there will be sub Networks looking at needs at the most local level. We have already had responses from Thames Valley, Royal Berks. Hospital Trust and 'West of Berkshire' leading professionals about the need to get organised. It will no doubt take longer than we would like, but we are ready!

Based on 6 years of being together we have a very good dossier of ideas ready to table, and we are comparing notes with the Bucks. Neurological Alliance to see where there may be differences within the region that need to be taken into account, so we avoid a 'one fits all' solution across Thames Valley Region.

Sarah Cox, Manager of the West of Berkshire Long Term Conditions Collaborative couldn't make our last open meeting but will be at our July meeting to share on the subject, and everyone is most welcome to attend.

Healthy hearts, never mind your brains!

The Healthcare Commission, the organisation that awards star ratings to NHS PCTs and Trusts, has gone back on its plans for 'cross cutting reviews' and 'local priorities' and is continuing to focus on so called 'national priorities'. What a let down and what a serious

mistake! With this approach people affected by neurological conditions will continue to find themselves ever less likely to get the services they need. The annoying thing is that the Healthcare Commission had some good ideas and then ditched them. Our message to them is this. It is better to assess all parts of the NHS on all aspects of their work from time to time, rather than assess some parts on a narrow range of issues repeatedly. This is basic stuff and the Commission is well out of tune with the way things should be done.

The dangerous lack of thought surrounding the loss of rehab beds at Royal Berks. is further evidence of 'national standards above all else'.

Stimulating the old grey matter

The Alliance is one of three Foundation Partners working with others to secure lottery funding for a range of 'therapies for the brain', as headlined by 'singing for the brain' pioneered locally by West Berkshire Alzheimer's Society. Keep your fingers crossed we can get funds, but more important, keep **your** brain in good working order!

Diary dates to note:

Monday 11th July. **Open meeting.**
7.15 for 7.30 p.m. at St Joseph's, Newbury.
Speaker: Sarah Cox on Long Term Conditions.

Thursday 15th September. **AGM.**
7.15 for 7.30 p.m. at Stockcross Village Hall.
Speaker to be confirmed

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