

Good news for those with rare and aggressive neurology conditions.

We have the green light from all involved to raise the rest of the funds needed to pay for the first two years of the Specialised Neurology Nurse, who we've been trying to establish for so long. There's well over £30k already lined up and about £50k more needed to complete the package. The Motor Neurone Disease Association, (Reading & West Berkshire) and the Alliance have committed big sums, and we hope that other benefactors will now wish to join in. The nurse will focus on patients with rare, aggressive neurological conditions, in what will be a unique and demanding post.

Anything you can pledge?

It is timely that Newbury's Rotary Club have announced they are hosting a pledge auction at Newbury Racecourse on Saturday 28th February, to benefit local charities, including our own. We are seeking pledges to auction on the night, to boost our nurse fund. Any reader with anything that may seem suitable to pledge, please contact the Editor, speedily!

Dark sky for the star makers

The Commission for Health Improvement (CHI) has announced the topics it will audit in 2004. Their audits result in the 'Star Ratings' given to NHS Primary Care Trusts. Despite them being sympathetic to submissions that there is a need for meaningful targets in neurology, they have done nothing about it. So our official award to CHI?

ZERO STARS FOR 2004 FOR CHI!

National Service Framework (NSF).

The time gets closer for the Secretary of State for Health to make his announcement on the National Service Framework for Long Term Conditions which will focus on neurology. Readers are urged to write to Dr John Reid, Secretary of State for Health, PO Box 3040, London SW1A 2HS to inform him of the need to fund fully both the NSF and all the services that are needed to meet the future health and social care needs of all neurology patients.

Congratulations to Dr Ralph Gregory, Consultant Neurologist in Reading, on securing one of only eight grants from the 'Action On Neurology' fund, which finances research specific to the implementation of this NSF. Dr Gregory's project will consider the IT links needed between GPs and Neurologists. He has approached the Alliance for patient input to the project and Len Middleton and Alan Scott have offered to take that role.

Stirrings on the bench.....

Executive Committee members are in regular touch with colleagues in other regions. Constantly we hear about similar problems across the country, of under resourced or unavailable services for neurology patients. At the same time we hear about local neurology patients who have found a specialised service they need, by travelling out of our region.

The Executive Committee therefore announces that a benchmarking study will be conducted later this year, to see how well services in Thames Valley Strategic Health Authority compare. Anyone interested in getting involved in this, please contact the Editor.

December open meeting.

Councillor Phil Barnett, Executive member responsible for Community Care, and Jayne Brinkworth, User & Carer Development Officer, both from West Berkshire Council, were the speakers at our well attended December open meeting. In a wide ranging discussion the issues which particularly concerned those present included: the health & social care co-ordination of services for people who live in areas with non-aligned Council and NHS boundaries, the 'out of hours' Forest Care service, standards within Home Care, the general need for investment in preventative services, and the lack of consultation about a range of issues, particularly the changes needed to improve the Council's star rating. Councillor Barnett has since offered to meet with Executive members again, to see how to take forward these and other issues.

Time for an uplifting experience.

The voluntary sector in West Berkshire is to be invited to consult on the criteria used to decide the eligibility for people who need Disabled Facilities Grants. These grants pay for, among other things, stair-lifts and the more major home adaptations. We understand that West Berkshire applies the rules in a less generous way than that enjoyed on average elsewhere. It is important for those interested in taking part in the consultation to register their interest.

Epilepsy group forms.

We are delighted that a support group for people with epilepsy has formed, covering West Berkshire and surrounds. Anyone affected by Epilepsy can contact Debbie Walker on 01635 866 560.

The group came about because the Alliance invited people affected by epilepsy to attend a focus group, as the first step in a research

project with Newbury PCT. The aim of the research is to assess the effectiveness of local epilepsy services. The focus group was a riveting experience for those who attended. Our research now moves into its next phase.

Neuro Conference 2005.

In consultation with Dr Christine Collin, Consultant in Neuro Rehabilitation in Reading, our conference team is negotiating its line-up of speakers for our Spring 2005 conference. We are delighted that Fred Davison has offered to lead our conference team.

Snippets.....

The Out of hours GP services are under review at present, and will change. We have assurances that everyone needing to contact a doctor out of hours will be able to do so.

Neuromyelitis Optica (Devic's Disease). Anu Jacob of Liverpool University is seeking to establish a database of people affected by this condition. For details contact the Editor.

Diary dates to note:

Thursday 12th February. **Open meeting.**
1. 45 p.m. for 2. p.m. at St Joseph's, Newbury.
Speaker: Annette Leach, Neurology Nurse.

Tuesday 20th April. **Open meeting.**
1. 45 p.m. for 2. p.m. at St Joseph's, Newbury.

Friday 25th June. **Open meeting.**
7.15 for 7.30. p.m. at St Joseph's, Newbury.
Speaker: Dr Collin, Neuro-rehab Consultant.

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West Berkshire Neurological Alliance,

2, Clayhill Crescent, Newbury,
Berks. RG14 2NP

Tel: 01635 33582 Fax: 01635 569177

www.wbna.org.uk

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