

Special neurology nurses.

Discussions continue with our local Consultant Neurologists about their very keen interest in creating a general neurology nurse for the West of Berkshire. There are still several issues to overcome before anyone can be appointed. It remains a top priority for the Alliance to help make this post a reality, and the positive encouragement we have from members on this could not be any clearer.

And where's the money coming from?

Motor cycle time trialling is an exacting activity, especially in the cool and damp of night. Riders can, and do, put themselves to great discomfort while 'doing their thing'. To raise money for charity, as part and parcel, takes a very special breed of person.

We must therefore most heartily thank Newbury & District Branch of the AJS & Matchless Motorcycle Club for adopting us as beneficiaries of their 2002 time trial, the 'Westward Ho!' run, which raised a magnificent £4,500 towards our specialist neurology nurse fund appeal. Riders from all over the country took part in this annual event.

Clad in leather they may have been, but their hearts of gold shone brightly in the dark, to see them safely through. Our warmest thanks to them all for their support and for the real difference their efforts will make in future to the well-being of local people affected by a neurological condition.

Their support means we now have £10,000 available to help create a neurology nurse post.

Survey results show need for changes.

The results of the first round of our Health and Social Care Needs survey, which we initiated in January, have finally been published. Some important findings include: confirmation of the need for more information and support at the time of diagnosis, the problems which occur when patients have to see more than just a small number of clinicians, the clear benefits experienced by those in contact with specialist neurology nurses, opportunities for improvements in several services, notably Contenance Advisory and Occupational Therapy, denial of access by patients to certain drug therapy, and a general lack of access to several services.

We plan to continue this research, embracing a larger group of patients. We are most grateful to Newbury PCT, East Berkshire Clinical Development Unit, and Berkshire Community Foundation for their help and support in this.

Chronic number fatigue?

We were intrigued that the Government's Chief Medical Officer recently reported the prevalence of Chronic Fatigue Syndrome (CFS), also known as ME, as 0.4%, while a Berkshire NHS Committee quoted the local prevalence to be only 0.1%. Assuming both parties are correct it is vital to investigate, understand and publish the reasons. Is there something magic in Berkshire's environment that amounts to a protection against CFS/ME?

And why is some other local neurology prevalence data at variance from the norm? We must have better local prevalence data, and better understanding as to what it means.

West could be best!

28 representatives from 7 of the 12 Regional Neurological Alliances met in Newbury on 15th October, sharing their experiences and ideas. Sadly, many of the frustrations experienced by our local members, when seeking the health and social care services they need, seem common to other parts of the UK. West Berkshire Alliance stands out for its breadth of activity and research based approach, and West Berkshire service providers seem among the most responsive to ideas for improving, so well done to them for as long as they maintain such a reputation!

Mandy Williams enthuses at AGM.

David Roberts, started our third AGM as Vice Chairman, and closed it having been re-elected to Chairman. He reported a further steady increase in membership and praised a year of solid teamwork by the Committee and others, with many achievements delivered.

Mandy Williams, Director at Royal Berks. & Battle Hospital, updated members on developments there in patient and public involvement, noting there remains much still to do, but enthusing how patient centred care is becoming ever closer to reality.

The new committee is : David Roberts, Joyce Parker, Patrick McGrath, John Holt, Bob Cray, Mollie Davison, Gill Hall, Hilary Hinchliffe, and Chreanne Montgomery-Smith.

Canoeing partners ?

We are flattered and delighted to have been approached by West Berkshire Social Services to be their voluntary sector partner in a bid for a Euro grant for 'A water based adventure programme'. The concept certainly sounds a good way for Alliance members to make a splash! Let's hope the bid is successful, and we're not left up the creek without a paddle!

Partnership Experts.

We are also delighted that Newbury PCT have found the resources to run an 'Expert Patient' pilot for people with neurology conditions. They have asked if we will help in publicising the scheme once details are finalised. The pilot seems likely to be of particular interest to some members and we will keep readers posted.

Neuro conference, Friday, 28th March 2003.

We have a superb line of speakers signed up for our 'Experts Together' Neurology education conference to be held next March at Newbury Racecourse. Most surplus income from the day will go towards our neurology nurse fund. The event will carry education credits for professionals, and will also be of interest to sufferers, carers and others. To register your preliminary interest telephone Hilary Hinchliffe on 01635 42775.

Diary dates to note:

Open Meeting, Thursday 21st November.

Guest, **Kendall Bird**, Specialist Commissioning Director, TVStHA.

1: 45. p.m. for **2 p.m.** at **St Joseph's hall.**

Open meeting, Thursday 6th February 2003.

Speaker to be advised.

1: 45. p.m. for **2 p.m.** also at **St Joseph's hall.**

All are welcome at the above meetings.

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