

Chairman's Annual Report for 2009

This year is the tenth anniversary of the West Berkshire Neurological Alliance (WBNA) and I would like to begin by thanking all our members for their loyal support over the decade. WBNA was established by a far-sighted group of people who recognised the need for co-ordinated campaigning for improved services for people living with a neurological condition. Their vision was that better information and improved services can bring great benefits in quality of life for patients, and their carers, as well as reducing the need for acute stays in hospital. By co-ordinated working as an Alliance, representing a wide range of neurological conditions, our founders saw that there was greater likelihood our voices being heard. More practically, WBNA was able to work with others to raise funds to 'pump-prime' the post of specialist nurse for rare neurological conditions. The value of this post was demonstrated by a Strategic Health Service Award and is now permanent and funded by the Primary Care Trust.

Since the inception of WBNA much has changed and several reorganisations of health bodies have occurred. The Health and Social Care Act (2001) requires Health Authorities and Trusts to consult patients and the public on the provision and commissioning of services. The National Service Framework (NSF) for Long-Term Neurological Conditions with its 11 quality requirements was introduced in 2005. Most importantly, commissioning of services is now devolved to a local level, so WBNA has an even more important role to play as an informed and united third-sector partner.

Membership in 2009 increased and now consists of 23 charities and 14 individual members, covering some 28 neurological conditions. We are delighted to have the newly-formed Berkshire Dystonia Support Group join us. We are currently supporting the emergence of a new support group for those affected by brain tumours, the fifth support group we have helped into being since our inception. Our executive is currently 10 strong and has had a very busy year, particularly because of our fourth successful neurology conference in July. In 2009 we were gratified to be nominated for the Queen's Award for Voluntary Service by the Mayor of Newbury. Although we did not win a national award, some of us attended a reception at Windsor to receive a certificate from the Lord Lieutenant of Berkshire. During the year we have funded all our activities leaving our reserves healthy and able to support our forward plans.

The 2009 one-day conference, *Brains, Pains and Gains* on the management of pain was held at Arlington Arts. We are indebted to the sponsors: Greenham Common Trust, Berkshire West PCT, Newbury Town Council, The BG Trust and the British Polio fellowship for making the event possible. We were delighted to work with pain specialist Dr Stephen Allen, Neuro-Rehab consultant Professor Christine Collin and neuro-physiotherapist Penny Lilley in organising a superb programme, which attracted over 120

delegates with 12 speakers. The event including lunchtime 'taster' sessions for complementary therapies and was generally considered to be a success with very gratifying feedback from delegates. As part of the conference we carried out an internet-based Pain Survey to determine the unmet needs of people in Berkshire West who suffer from chronic pain. The results will be reported later in the meeting and shortly will be published on our website. These provide invaluable material to help us formulate our policy on provision of local pain services.

In December 2008, WBNA gave evidence to the Royal College of Physicians review on services for neurology patients. From this we have developed a position statement on local primary and secondary health services needed by people affected by a neurological condition in Berkshire West. This has been circulated to our member organisation for discussion and, when finalised, will be published. The committee has continued to represent your views and take an active part on advisory bodies, attending patient panels and PCT meetings. We continue to value our relationship with local professionals and are pleased that they continue to consult with us on a regular basis. We are represented on the Local Implementation Team concerned with implementing the NSF. WBNA continues to engage with representatives of patients in other regions working with Neurological Alliances in Buckinghamshire, Hampshire and Oxfordshire as the South Central Neurological Alliances Partnership. In this way we provide a patient voice at Strategic Health Authority level. Last year South Central Neuroscience Network was unilaterally disbanded and nothing has been put in its place, despite us pointing out to the Chief Executive that considerable savings can be made by the effective partnership working between patients and professionals. We are also playing our part in the national level Neurological Alliance with one of the committee serving as the Regional Neurological Alliance Trustee.

Progress continues to be made with the project for a Hydrotherapy Pool and Power-Assisted Gym for Newbury/Thatcham. The Board of the emerging Social Enterprise has issued a prospectus and 16 local groups have signed up their support. A business plan and legal constitution have been prepared and meetings with district planners and local developers are taking place.

Finally, it remains to thank our President and Patrons for their support during 2009 and our committee members for all their hard work.

David Roberts (Chairman)

10th September 2009