

Chairman's Annual Report for 2011

This is our twelfth AGM and changes in health and social care service provision – I wish I could say improvements – have continued at a pace. The recent closure of local day centres has provided the grim reality of the effects of recession and spending cuts. A new hard-hitting report from the Royal College of Physicians and the Association of British Neurologists concluded that, overall, services for patients with neurological conditions are poorly organised and do not meet patients' needs. Our struggling, outgoing PCT, which claims vaguely to spend maybe £16M or £33M p.a on Neurology Services has clearly indicated that it does not regard Neurology a priority and has no plans to action simple, cost-saving ideas. However, Consortium Commissioning will be taking over in 2013 and hopefully will be more forward looking in designing effective and efficient services. On the positive side The Royal Berks Hospital recently has decided to make neurology a Local Priority and we have been invited to take an active part in this key development. So, future improvements in services for people affected by a neurological condition are a possibility. WBNA has consistently argued that much could be achieved without additional expenditure – indeed in the long-term savings could be made – provided commissioned services are rationally-planned on the basis of robust needs assessment, taking account of the views of both patients and professionals. During the year West Berkshire Neurological Alliance has tried to play its part to provide constructive ideas for service improvements by collecting evidence from patients and carers using targeted surveys and focus groups. You hear more about these later this evening. We were delighted and honoured that the Royal College of Physicians new ten year vision for neurology mentions WBNA's model, twice.

Membership in 2011 increased and now consists of 27 charities and 17 individual members, covering some 28 neurological conditions. Our executive is currently 10 strong and has had a very busy year. We were gratified to be nominated for the Queen's Award for Voluntary Service by West Berkshire Council. Although we did not win a national award, some of us attended a reception at St Bartholmew's School 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

During the last year we have cooperated with the West Berkshire Local Involvement Network (LINK) on a major survey to ascertain the views of people with a neurological condition. Patients and carers were consulted with 10 neuro-conditions covered in the survey. We are very grateful to Tony Lloyd of the LINK and John Holt for the huge amount of work they undertook and the final report provides valuable information on the local prevalence of neurological conditions and will inform providers and commissioners of services about the views of patients and carers. The Alliance collaborated with The Princess Royal Trust for Carers, Cross Roads Care and several local groups in a survey of the needs of local carers, with a special focus on respite provision and gaps in services. The results are very revealing with some carers coping very well while others reported being close to breaking point, and all

shades in between. The report makes 10 important recommendations, which were positively received by West Berkshire Council Community Services, and will be presented to its Carers Forum shortly. Since the last AGM we held two Focus Groups. We are very grateful to all those who took part and provided valuable insights into the subjects under discussion. The first was access to therapies and from this it was very clear that commissioners need to ensure that therapy services are restructured around patient needs, with a more extensive range of local services providing personalised packages of holistic care, rather than the 'one size fits all' and narrow range of services currently on offer. The second focus group, on funding and using disability equipment, identified a minefield of problems that patients face when seeking suitably-adapted equipment to allow them to lead normal and independent lives as possible. Both summary reports have been presented to the appropriate bodies for comment and we are involved in detailed discussions with service providers to ensure that appropriate action is taken. Just this week we have followed up with a focus group to obtain views of wheelchair-users. Our next focus group will be held in November on the subject of continence advice and services. Progress continues to be made with the project for a Hydrotherapy Pool and Power-Assisted Gym for Newbury/Thatcham and John Holt, one of the directors, will be providing a brief report. WBNA continues to work with, and support, partner organisations such as West Berkshire Disability Alliance and Independent Living Network.

It was with great sadness that we learned of the death of Joyce Parker. Joyce was a founding member, served as Vice Chairwoman for many years and for a time WBNA Chairman. Joyce was instrumental in writing our constitution and was made a life member in recognition of her loyal services. We shall miss her wise counsel.

In 2011 we have funded all our activities and our reserves are strong, in the context of our forward work plans. We continue to value our relationship with professionals and are pleased that they continue to consult with us on a regular basis. On October 4th we host our 5th biennial conference '*New Opportunities for Neuro*' at Arlington Arts, Snelsmore Common, near Newbury. We are indebted to Professor Christine Collin and Dr Faraz Jeddi for helping us put together a truly exciting programme and once again it has been recognised as an educational event for Continuing Professional Development. We will be exploring the latest positive developments in neurology and neuro-rehabilitation as well as issues such as preventive medicine, self-help and the patient-therapist interface.

Finally, it remains to thank our President and Patrons for their support during 2010/11 and our committee members for all their hard work.

David Roberts (Chairman)

8th September 2011