

### **Chairman's Annual Report for 2008**

Membership has remained more or less steady, consisting of 21 charities and 16 individual members, covering some 23 neurological conditions. We were delighted to see the revival of the local Huntington's Disease Branch and to have repaid the donation from the previous Branch with interest. Our executive has been 10 strong with a busy year and progress in some areas. It is heartening to have funded all our activities and to note our reserves are strong, in the context of our forward work plans.

We contributed to the Darzi review of the NHS, 'High Quality Care for All', whose theme aims to transform the NHS to provide clinical-led, patient-centred and locally-determined care. South Central SHA has published its own 10-year vision, full of ambitions for improving the quality and the safety of healthcare and making patient choice a major determinant. We welcome this but during 2008 our experience has been that real progress is perpetually hampered by continual reorganisation of NHS structures, budgetary problems and staff changes.

All has not been doom and gloom in 2008, for we have seen progress in West Berkshire. The transfer of 5 neuro-rehabilitation beds to West Berkshire Community Hospital and the establishment of a Community-Based Neuro-Rehabilitation Team are welcome. One of the high points of 2008 was when Carol Allen, our specialist nurse for rare neurological conditions, had her post made permanent and was honoured with a Leadership for Improvement Award at the South Central Strategic Health Authority Health Social Care Awards ceremony. The award recognised Carol's leadership and sustained impact on patients, service users and staff. Your chairman was proud to attend the NHS Health and Social Care Awards Ceremony at Wembley Stadium in July when Carol was nominated for a national award, alongside Professor Christine Collin of the Royal Berkshire Hospital Foundation Trust and West Berkshire Neurological Alliance. Sadly, we did not win but it speaks volumes that the role of Specialist Neurological Nurse makes such a positive impact on the national stage. Congratulations to all involved who supported the Specialist Nurse project, particularly the Motor Neurone Disease Association amongst other charities, and thanks for the tireless commitment of John Holt. Carol's impact so impressed the Department of Health that it has cited her post as an example of a 'Top Ten Quick Win' to be considered for every health area in England.

Progress continues to be made to make a Hydrotherapy Pool and Power-Assisted Gym for Newbury/Thatcham a reality. The Alliance helped fund the feasibility study into the gym and is supporting the Social Enterprise with banking and other arrangements during their start up phase. The Board of the emerging Social Enterprise has issued a prospectus and the early response has been very positive. A business plan has been prepared and a legal constitution is being prepared. Critical meetings to secure land for the project are ongoing but there still remains much to do.

We remain concerned at the slow progress of implementing the National Service Framework (NSF) for Long-term Neurological Conditions and the devolving of responsibility for developing the NSF to local health bodies. These bodies have a duty to listen to the views of patients when planning and commissioning services. With this in mind, WBNA has worked with Buckinghamshire and Hampshire NA as the South Central Neurological Alliances Partnership to provide a patient voice on the South Central Neuroscience Network. After several meetings leading to some progress, we now find that the South Central Board of Commissioners has ordered a review of the network structure, with responsibility for neuroscience being devolved to Specialist Commissioning. Such tactics are immensely frustrating and destroy the goodwill and working relationships we have taken time and effort to build, involving commissioners, professionals and patient representatives. At present we do not even know if there will be a South Central Neuroscience Network and if neurological patients will have a voice there.

The committee has tried to represent your views and take an active part on advisory bodies, attend patient panels, hospital board meetings 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 have engaged with representatives of patients in other regions, supporting new Neurological Alliances in Hampshire and Oxfordshire. We have continued to play our part at a national level with representatives going to 10 Downing Street and the House of Commons. One of the committee serves on the national Neurological Alliance Board of Trustees.

Before I end this report I want to express our great sadness at the passing of Hilary Hinchliffe MBE, who died in July aged 89. Hilary was a founder member of the West Berkshire Neurological Alliance and an immense support in so many our activities and initiatives. Hilary showed great vision and a remarkable empathy with, and compassion for, the plight of any individual facing difficult circumstances. She identified the need for specialist nurses to support sufferers of the rarer neurological conditions, and tirelessly promoted the idea. As we make plans for our 2009 conference we remember it was through her dynamism and determination that WBNA hosted its first conference in 2003, which was such a success. Hilary will be greatly missed by all of us, as a mentor and great friend. We expressed our condolences to her family.

Finally, it remains to thank our President and Patrons for their support during 2008 and our committee members for all their hard work.

David Roberts (Chairman)

11th September 2008