

West Berkshire Neurological Alliance

Representing all West Berkshire people with a neurological condition.

Annual report 2003

Membership increased to 34, covering 20 neurology conditions and embracing 14 charitable groups. We continue to be indebted to our Patrons and thank all who gave us support in another year of clear progress. Mr and Mrs Puxley of Welford Park allowed us to collect at the annual Snowdrop Walk, bringing in over £2000 and the Sobell Foundation provided recurring financial support of £1000. We have designated a further £5700 towards our specialist neurology nurse fund, and remain solvent.

Our dossier of health and social care priorities is promoted wherever possible. We challenge the low number of Consultant Neurologists, and specialist neurology nurses, while welcoming the planned increase in Neuro-surgeons. It is disappointing there is not sufficient attention given to reducing the amount of time neurology patients spend in hospital, due to lack of investment in preventative measures and therapies. It is pleasing to note that professionals now consult with us on a more regular basis, as our ability to make a contribution becomes more widely recognised and accepted. We were delighted to assist in publicising the Expert Patient programmes of three Berkshire PCTs, each aimed at neurology patients, and to be asked to contribute to the new Newbury hospital's information centre.

Our survey of the health and social care needs of patients with MS produced several recommendations to which local health professionals are responding. We are now embarked on similar research in the areas of Stroke and Epilepsy, in close partnership with Newbury PCT. We input to the draft National Service Framework for Long Term Conditions, and look forward to how this standard develops and is implemented. We contributed to the Commission for Health Improvement's review of the three West of Berkshire PCTs. Having been asked to pump prime a specialist neurology nurse post, it is frustrating that local NHS budgets are now so overspent it is proving difficult for the Royal Berks. & Battle Hospital Trust to co-fund any new development work. We shall need to look for creative solutions to progress this important nurse post. Our representation on the Royal Berks. & Battle Hospitals Trust Patient Panel has allowed us to register a number of proposals for review, although it has been disappointing this Panel has taken time to find momentum.

Our open meetings continue to be well attended, and are a useful forum for exchanges with senior health and social care professionals. We observed again at many PCT Board meetings in Newbury, Reading and Wokingham and continue to submit questions to these Boards. We strengthened our contacts with the Thames Valley Strategic Health Authority, where there remains a lack of structured thinking in many areas of their service provision for neurology patients. We hosted a meeting of the regional Neurological Alliances in Newbury in October and continue to work closely with them and with the national Neurological Alliance which is making an increasing impact in its central role. Our Website is a now fully operational and an excellent source of information. We produced and widely distributed a Website directory pamphlet to help neurology patients find reliable information.

We are very grateful to Awards for All, Charles, Lucas & Marshall, the Berkshire Branch of the British Polio Fellowship and Publicity Projects (Newbury) for sponsoring our 'Experts Together' conference in March, and to Newbury PCT for setting aside a training day, which allowed so many of their staff to attend. The day was attended by 150 delegates, of which 100 were professionals. Baroness Susan Greenfield and Penny Lilley, both Alliance Patrons, were among several other speakers of national standing, and the day was a great success in every sense. Thanks go to Dr Collin for her clinical input, and to Hilary Hinchliffe and her team of organisers and helpers. Over £5700 was raised as a result.

We thank Patrick McGrath who stood down as Treasurer during the year. We co-opted and welcome David Woodhead who now looks after that role. Finally, my thanks go to all the members of the Executive Committee who have worked solidly, and so productively, as a team throughout the year.