

West Berkshire Neurological Alliance

Representing all West Berkshire people with a neurological condition.

Annual report 2004

Membership has stabilised at around 32, covering 20 neurology conditions and 14 charitable groups. We remain indebted to our Patrons and thank all who gave us support in another year of progress. Proceeds from an auction organised by Newbury Rotary Club were £808. Grants were received from the Foyle Foundation, the Institute of Our Lady of Mercy, Orion Pharma, Eli Lilly and the Mary Webb Trust for our specialist nurse project, and from Newbury Town Council (£500) for our 2005 conference. We designated further funds towards our neurology nurse fund, and remain solvent.

Our dossier of health and social care priorities is promoted wherever possible. We challenge the poor resources available to provide Neurologists, neurology nurses, physiotherapy, counselling and a range of other services. It remains disappointing that insufficient attention is given to reducing the amount of time neurology patients spend in hospital, due to lack of preventative measures and therapies. We are pleased that the local PCTs have launched their Chronic Disease Collaborative initiative, and look forward to making some input. It is pleasing to note that professionals continue to consult with us on a regular basis. We provided the publicity to set up an epilepsy focus group, took part in clinical audit review, and we contributed towards the new Newbury hospital's information centre. We were delighted to grant £500 to the local Speech & Language service towards the purchase of S&L software.

We had a strong response to an event we organised for people with ME/CFS, and a good turn out at a meeting we publicised to start a group for people with Aphasia. Our plans to survey more local neurology patients about their health and social care needs were held up, but we shall continue this work when permitted. Following our earlier input to the National Service Framework for Long Term Conditions we have now submitted ideas for Neurology Performance Indicators, and have secured a seat on the Research Strategy Group. We challenged the way that the Commission for Health Improvement audit process had a damaging effect on services for neurology patients, and expressed our concerns to their successors that their proposals will have similar damaging effects. We were pleased to send representatives to Dr Gregory's 'Action on Neurology' IT project team. We await the outcome of the consultation on the possibility of establishing a local Care Trust with optimism.

We have been strongly encouraged by the statutory sector to fund a specialist nurse for people affected by rare and aggressive neurology conditions, and are pleased to be leading the fund raising consortium which has now secured almost all of the £90k needed to pump prime a specialist nurse post for 2 years. Our open meetings are well attended, and a useful forum for exchanges with professionals from health and social care. We observed at several PCT Board meetings mainly in Newbury, but also in Reading and Wokingham. We continue to submit questions to these Boards. We strengthened our contacts with the Thames Valley Strategic Health Authority, where there are more signs of structured thinking about service provision for neurology patients. Our representation on the Royal Berks. & Battle Hospitals Trust Patient Panel has again allowed us to register a number of proposals for review, although it remains disappointing that this Panel appears to have little momentum, and consultation results are generally disappointing. We continue to take an active part in meetings of the regional Neurological Alliances and continue to work closely with the national Neurological Alliance. Our Website attracts increasing interest and is an excellent source of information. We have worked closely with West Berkshire Disability Alliance on a range of health and social care initiatives, and this relationship is something we intend to continue to nurture.

Molly Davison and Chreanne Montgomery-Smith stood down at the last AGM and we appreciate their ongoing work outside of the Executive Committee. My thanks go to our President, the members of the Executive Committee and the Conference Team, who all worked solidly together throughout the year, and to everyone else I may not have mentioned but who has helped us to have another excellent year.