

Chairman's Report 2017

This is now our eighteenth AGM and the first without our long-standing Liaison Officer John Holt. We have had a mixed year as we have been adapting to a slightly different way of working but have continued the Focus Groups which inform the way we represent unmet neurological needs. Open meetings on the other hand have been poorly supported which is unfortunate as they do represent an opportunity to hear from local health and social care decision makers and to learn about the services they provide in light of this, regrettably, we have suspended these meetings. With money so tight, especially in social care, it is important that the limited resources available are used to best effect and to this end, we need to be challenging the providers to do better for those experiencing neurological illness.

Since the last AGM we have held 3 Focus Groups, the first two of which were funded by Healthwatch West Berkshire. These covered 'Caring for someone with a rare neurological condition' and 'Technology and the over 75s'. In August our topic for discussion was on 'How people with a neurological disorder can help themselves and avoid emergency admission to hospital'.

Distribution of Carers' Grants continues with increasing numbers of applications for these respite grants of up to £300. The first carers' grant money was received on October 28th 2014 and the second came on 16th May 2015 and the third on 24th September 2015. In total we were entrusted with £14,500 to distribute to carers in need. We have now approved 55 grant applications of which 5 are still to be paid. We are most grateful to the Berkshire Community Foundation for allocating these funds to us and now anxiously await the outcome of their Trustees meeting to see if we are to be awarded a further tranche of funds to distribute, as demand is outstripping supply. There is a clear need to do more for carers to not only give them a much needed break, but in funding them, recognising the invaluable and unsung work that they do.

As we reported last year, we supported local pain Consultant Deepak Ravindran to help fund an App to help Junior Hospital Doctors to manage their patients' pain better. It has been 'live' since January of this year and all junior

doctors are now aware of it and more GPs are becoming aware. There has been a good uptake from patients although feedback from them has highlighted some glitches which are being addressed.

As the principal backer for the West Berkshire Therapy Centre we are delighted to report that it was nominated for, and WON, the Queen's award for Voluntary Service. It is such a well-used service with 250 individual exercise sessions taken up each week, enabling disabled people to exercise safely under supervision using power-assisted machines. The benefits for people affected by neurological conditions has been shown to be significant and in a recent impact report 99% of clients agreed or strongly agreed that attending WBTC had had a positive impact on their health and wellbeing.

Last year I reported that the commissioning of the services needed by neurology patients locally was being improved systematically in NHS Berkshire West. We had a seat on the Berkshire West's Clinical Commissioning Group Federation's Long Term Conditions Board (LTCB) and also on one of its key sub-groups, the Neurology Steering Group, **but** sadly, this group has now been scrapped. The Neuro Steering Group was set up because 10% of GP time and cost is taken up with neurology patients and so problems needed to be addressed. The Group took an early focus on epilepsies and migraine/headache and developed pathways to be set up on the GPs' desktop system known as DXS. The next phase of work was due to concentrate on MS, Parkinson's and MND but discussions never started, although this work would have made neuro-phobic GPs more confident, efficient and effective in how they spend their Neuro-related time. WBNA research indicates consistently that patients who experience generic NHS services cost the NHS about two or three times as much as if they had been able to use suitably specialised services, so the demise of the Neuro Steering group is bad news for patients as well as the NHS itself. We continue to try and promote neurological issues at the Long Term Conditions Board but, without a clinical champion, it is much harder to make an impact. John Holt used to attend a large number of Public Health meetings (Health Watch, Patient Voice etc.) which gave WBNA a well-known presence and some useful introductions for the Alliance. This level of liaison has declined since John's departure and is much missed.

This year has seen changes to our Committee of Trustees, and during the year we reluctantly accepted the resignation on health grounds of Mick Hutchins, a long standing member from the West Berks Disability Alliance who has made a big contribution over the years and also of Joanna Knott, who is having to reduce her workload. On the plus side, we have recruited Julia Powell who has kindly agreed to carry out much of the administrative work of the Committee. However, we do need to recruit new candidates to carry on the work of the Alliance as well as having more support and input from our member organisations. The Commissioners of Services do appreciate our Focus Group reports and do read them, but for these to be effective we need more people able to come and take part in them. Similarly, we would like to hold more Open Meetings but this requires an audience, other than the Committee, to come and attend them and take part in the discussions that follow presentations. We cannot afford to be complacent and we need to keep neurology as high up the health and social care agenda as we can, but to do this, we do need your increased help and support.