

## **Chairman's Annual Report for 2013**

This is our fourteenth AGM and we have had a good year. The NHS restructured and we are pleased the PCT administration was replaced by a doctor-led CCG, focused on patients. The four Berkshire West CCGs act as a Federation and have set up a Long Term Conditions Board. This discusses neurological need regularly. It has found funds to establish an epilepsy nurse specialist, and a first-ever service for people with ME/CFS, also bringing the nurse specialists into one team. Encouraged by this, we have pressed for reinstatement of the Neuro Implementation Team to ensure neurological need can be reviewed systematically and comprehensively. On the down side, we remain confounded that the JSNA, Joint Strategic Needs Assessment for Neurology, that was due to be issued for consultation in December 2010 has been quietly shelved. We have maintained a campaign to get the Neuro JSNA completed.

We welcome that the ineffective Strategic Health Authority has been replaced by NHS Thames Valley. This change establishes of a much-needed Neurological Clinical Network and neurological leadership for the first time. Meetings have been held with the Alliance in Oxfordshire to ensure patients can influence the Network's agenda and we look forward to the Bucks Alliance also becoming involved.

We continue to enjoy a loyal and supportive membership. This is due to the relevance of the meetings we hold and our needs-orientated research that inform the representations we make on behalf of neurological patients and carers, which we do in as many scenarios as possible. We were disappointed not to take forward the project to support a GP to specialise in pain management, something seen by the PCT as 'too difficult'. More positively, we followed up our Focus Group on 'Living with Incontinence' with a survey, funded by West Berkshire LINK. The report had a mixed reception from the NHS: acceptance where there was praise from patients and dismissal where the opposite applied. Healthwatch is now following matters through. Since our previous AGM we held Focus Groups on 'Living with Communication impairment' and 'Living with co-morbidity', and there are various matters for us to follow through. It is good to report that every priority identified in our focus group on epilepsy nurse specialists has been incorporated into the new nurse's job role.

We continue to act as Friends of West Berkshire Therapy Centre whose project to develop a Hydrotherapy Pool and Power-assisted Gym for Newbury/Thatcham, has picked up pace. There are positive discussions about a suitable site and it is likely that the gym will be commissioned ahead of the pool, to get some therapy provision in place as soon as possible. We continue to work with West Berkshire Disability Alliance and Independent Living Network where opportunities arise, helping us to maintain a dialogue with the three local Unitary Authorities, particularly with West Berkshire. We value all our links with Healthwatch, the Patient Panel and many other organisations.

We had our Newbury Race Course Collection on 20<sup>th</sup> September 2013. We raised a magnificent £1113.18. The weather was kind. My thanks to all those who helped us on the day and also to Newbury Race Course for allowing us to be there.

We were very sad this year that one of our stalwart volunteers, Mick Amor, died. She is much missed. Our executive is 8-strong. We functioned without a Secretary throughout the year, the Committee covering business seamlessly. We funded all our

*West Berkshire Neurological Alliance*

Representing all people in Berkshire West affected by a neurological condition.

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activities without difficulty, our reserves are strong and planning for our next conference is on-track. I would like to thank everyone on the committee for their hard and effective teamwork and dedication and to thank our Patrons for their support.

Irene Waters (Chairman)

26th September 2013