

### WBNA conference 2016

Our 2016 neuro conference on integrated services for neurology attracted over 70 delegates and included sessions on the patient experience, pain, and innovative ways of delivering services that make a real difference. DVDs of the event are available by emailing [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com)

### Migraine and Headaches

We are working with Berkshire Healthcare NHS Foundation Trust and will host an informal gathering for local people affected by Migraine or Headaches to drop in, with a view to setting up a local support group for those affected by these debilitating conditions. Local NHS services are in the process of being improved for Migraine and Headache sufferers and the importance of being able to meet with others in a similar situation can be particularly helpful in understanding, coping and managing. This will be the first ever opportunity for Migraine and Headache sufferers to come together locally and we look forward to a successful and independent support group emerging. The meeting will take place at the Regency Park Hotel's Paris Room on Thursday 4<sup>th</sup> August from 2.30-5 pm with light refreshments available. Anyone with an interest is welcome to call in. For further information contact John on 01635 33582 or [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com)

### WBNA focus group 'Neuro Carers'

The report on our Focus Group 'Caring for someone with a neuro condition' is about to be issued. Findings included:

- The caring role is often unwanted.
- Carers and their cared-for often do not recognise the term 'Carer'.
  - The caring experience is often challenging and difficult.
- Relationships can be affected in several ways, with feelings of resentment, abuse, lack of gratitude, loss of sharing, guilt, irritability, loneliness, exhaustion, not coping, worry, low self-esteem, etc.
- Carers appreciate being able to continue to work, lead their own lives, have breaks and maintain dignity and self respect.
- Some are unclear about benefits.
- Social Services and Carers Services provision are of mixed quality.
- The unreliable quality of care from care agencies is a major concern.
- Bereaved Carers face their own, extra problems.

We are delighted that Healthwatch West Berkshire has agreed to sponsor three of our focus groups this year. Their representative role will add to our own ability to inform the work of the local NHS Long Term Conditions Board, the Neuro Steering Group, and the two Thames Valley equivalents, on which we represent the local neurological voluntary sector. To see the report contact John on [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com)

## Grants for carers' breaks

Grants of up to £300 are available for carers take a break from caring. Applicants must live in West Berkshire, Reading or Wokingham and provide care for at least fifteen hours a week. Details are on the application form. Apply to [johnmholtb@sc@aol.com](mailto:johnmholtb@sc@aol.com)

## West Berkshire Therapy Centre

West Berkshire Therapy Centre is fully settled in its new premises in Thatcham and now provides 200+ therapy sessions every week, helping people with disabilities to keep mobile. See [www.westberkshiretherapycentre.org.uk](http://www.westberkshiretherapycentre.org.uk)

## The National Neurological Alliance

The Neurological Alliance has launched its second neurological patient experience survey. This will collect vital information about the experiences of care received by people affected by neurological conditions and help understand progress in provision of neurological services. The survey is for anyone with a neurological condition and is open until 30<sup>th</sup> September. A report will follow, with recommendations about how care can be improved, building the strongest case about how services need to change. To take part visit <http://bit.ly/28L3jGU>

## NHS Thames Valley neuro standards

Thames Valley Strategic Clinical Network has launched guidance to local NHS Commissioners, calling for a shift towards more community provision. The guidance reads well from the patient perspective. Commissioners in Berkshire West have been working towards these guidelines for some time.

## WBNA succession planning

The Alliance is having another strong year, with a major conference successfully delivered, four focus groups to be delivered and seats on four NHS decision-making bodies where we represent our sector to good effect. We continue to provide support to West Berkshire Therapy Centre and have provided 40 carer's grants to needy carers. We are financially sound and have a proactive Board of Trustees with a broad skill mix.

To maintain and build on this we must strengthen the Trustee team, to keep up the impact of The Alliance in the years ahead. We are seeking further capable Trustees who will be active in researching and representing the needs of the local neurological sector. Please let us know of anyone who is of the right calibre to join and strengthen our team. Thank you for your ongoing support to the Alliance.

## Dates for your diary

### Open meeting Thursday 14<sup>th</sup> July:

St Joseph's Church Hall, Newbury.

1.45 for 2 pm. Everyone welcome!

**Subjects:** *Continuing Healthcare and Developments in Local Neuro Services*

### AGM Thursday 29<sup>th</sup> September

7 for 7.30 pm: Holiday Inn Padworth

**Speaker** Dr Bal Bahia GP Lead

## West Berkshire Neurological Alliance

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