Number 52

# West Berkshire Neurological Alliance Neuro Newsletter

#### Speech, swallowing and communications

Important recommendations from our most recent focus group, 'living with speech, language, swallowing or communication impairment', include:

- A need to clarify the care pathway
- Easier access and less rationing of services
- More resources for those with communication needs
- Better links to sister services
- Better links with the voluntary sector

Dr Daphne Banat, Head of Scheduled Care at Berkshire NHS Healthcare Trust, was our guest at our January meeting and welcomed our report. An array of ideas is under consideration. Our thanks for that and to everyone who took part in the project.

#### living with incontinence

An analysis of the responses has commenced of our survey 'Living with Incontinence'. This work was financed by West Berkshire LINk and supported by many of our members. It is clear that there are some major discrepancies in the help and support that people receive, anything from 'excellent' to 'none'. The impact of incontinence on people's lives is often devastating and the right information, support and products can make a huge difference. We will publish our report as soon as possible and raise the issues in all the right places. Our thanks to everyone who took part.

#### Living with several long-term conditions?

If you have a neuro condition and also another long term conditions you may wish to attend our focus group on the afternoon of 25th March, on co-morbidity. This is an opportunity to talk about your experiences with others who may be in a similar situation. The findings will help to inform service providers about the needs of those living with two or more long-term conditions, and how services might be improved. To attend, contact John on 01635 33582 or johnmholtbsc@aol.com

Further ahead we are considering a focus group on 'Coping when health and social care systems falter'. If any reader has any other suggestions for local research that will 'make a difference' we would be pleased to hear from you.

### Hydrotherapy and specialist rebab sym

We are delighted to report that the project Board has an excellent plot under consideration and, as soon as written agreement is made, our sub-committee, 'Friends of West Berkshire Therapy Centre', led by Christine Eeley, is ready to raise the outstanding money needed to build the facilities. All offers of help to make this project happen will be most welcome!

### Neurology on the CCG agenda!

Elizabeth Johnson, Lead GP for South Reading Clinical Commissioning Group, was our guest at our November open meeting. Constructive exchanges covered a range of opportunities for the CCGs in Berkshire West, both to improve the outcomes and quality of services needed by neuro patients and to spend NHS money more effectively.

This led to an invitation to explain our vision, to the Berkshire West Long Term Conditions Board, as to how neurological and allied services should be better designed and delivered.

Already the CCGs have recognised the need for an epilepsy nurse specialist and for a service for those with ME/Chronic Fatigue Syndrome. A review is under way that will lead to improved information for both clinicians and neuro patients. It is great to see the CCGs initiating so much so fast.

The existing Neuro Implementation
Team will report to the Long Term
Conditions Board and the Alliance will
continue to play its active role. We
continue to press for a co-ordinated
vision for neurology and that the muchoverdue Neuro Needs Assessment
should be completed and issued for
comments urgently. NHS spending on
neurology must become transparent,
to help redirect NHS money to where it
will be most effective. There is much to
do and we look forward to working with
the CCGs wherever possible.

#### High level NHS focus on neurology

The NHS Commissioning Board has recruited a National Clinical Director for chronic disability and neurological conditions. A national champion at last!

Each new NHS Local Area will have a neuro network from April. Over the years we have accumulated much evidence to feed into such a Network! Less happily, the Strategic Health
Authority's project for minimum
standards for neuro rehab has hit more
delays. Undeterred, we continue to
press that an acceptable standard for
the region is agreed soon.

#### Healthwatch

On 1<sup>st</sup> April, Local Healthwatch will replace the three existing local health watchdogs, the LINks. We congratulate the LINks for their achievements and now look forward to working with all three incoming Healthwatch groups in Berkshire West, to get neurological and allied services matters onto their agendas and onto the agendas of the new statutory Health and Well-being Boards.

#### Mick Amor

It is with much sadness we report that stalwart WBNA volunteer, 'Mick' Amor, passed away on 16<sup>th</sup> January following a short illness. Her cheeriness, resolve, inner strength, insights and dedication to our work will be very much missed.

## Dates for your diary

Open meeting dates for 2013: All 1.45 for 2 pm, St Joseph's, Newbury

March 14<sup>th</sup> Speaker tba

May 9<sup>th</sup> Speaker tba

July 11<sup>th</sup> Dr Marko Bogdanovic

Nov 14<sup>th</sup> Speaker tba

September AGM (evening tba)

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