



Cynghrair Niwrolegol Cymru Wales Neurological Alliance

Minutes of the Cross-Party Group of Neurological Conditions

Tuesday 22nd October 2013

Committee Room 4, Tŷ Hywel, National Assembly for Wales

Present

Cardiff

Mark Isherwood AM (Chair)

Aled Roberts AM

Andrew R T Davies AM

Rob Thomas, UCB Pharma

Ann Sivapatham, Wales Neurological Alliance and Epilepsy Action Cymru

Dave Maggs, Wales Neurological Alliance and Headway UK

Pip Ford, Chartered Society of Physiotherapy

Michelle Price, Powys Teaching Health Board

Lisa Morgan, Cardiff and Vale University Health Board

Steve Walford, Ataxia UK

Alan Thomas, Wales Neurological Alliance and Ataxia South Wales

Monica Busse, Cardiff University

Professor Bob Woods, NEURODEM and Academic Lead for the North Wales Neurosciences Network

Bangor University

Professor Yves Barde, Cardiff University

Dr Jenny Thomas, Cardiff and Vale University Health Board

Dr Swaroop Shanbhag, Cardiff and Vale University Health Board

Joseph Carter, Wales Neurological Alliance and MS Society Cymru

Kate Steele, Wales Neurological Alliance and Shine Cymru

Maggie Hayes, Wales Neurological Alliance

Wrexham link

Karen Shepherd – Patient Representative, Neuroscience Network Board

Kevin Thomas, Wales Neurological Alliance and Motor Neurone Disease Association

Urtha Felda, Wales Neurological Alliance and MS Society Cymru

Annette Morris, Director of the North Wales Neurosciences Network
Betsi Cadwaladr University Health Board

Bangor link

Catriona Fearn, Occupational Therapist, Betsi Cadwaladr University Health Board

Nia Campbell, Physiotherapist, Betsi Cadwaladr University Health Board

Walton Centre Link

Dr Rhys Davies, Consultant Neurologist, Walton Centre NHS Foundation Trust

Apologies

David Melding AM

Simon Thomas AM

Darren Millar AM

Christine Chapman AM

Bethan Jenkins AM

Nia Came, Lead Speech & Language Therapist, Cardiff and Vale

Karen Bonham, Lead Speech & Language Therapist, Rookwood

Mr. Sreedhar Kolli, Consultant, Rookwood

Andrea Tales, Swansea University

David Murray, Wales Neurological Alliance and Cure Parkinsons

Carol Ross, Wales Neurological Alliance and Fibromyalgia Wales

Mark Isherwood AM thanked the IT technicians for making it possible for colleagues in Walton Centre (Liverpool), Wrexham and Bangor to take part in the meeting.

Minutes of the last meeting

Accuracy – Maggie Hayes apologies was not recorded. Neither was Nia Campbell or another person from Bangor.

Duplication of Carol Ross apologies in Minutes.

CPG

Mark Isherwood stated that there are new rules and recommendations for CPGs:

1. CPGs needs to re-register
2. Each CPG has to have an AGM
3. Minutes of CPG meetings must be collected and made publicly available
4. Each CPG needs to produce annual accounts (showing, for example, the cost of coffees and refreshment provided).
5. Each CPG has to elect a secretary.

Action: It was proposed, seconded, agreed and accepted that Maggie Hayes is the secretary of the WNA CPG.

Paper of research

Joseph Carter presented his paper on research stating that it is timely with the commencement of the SER project.



Research in Wales -
briefing for CPG - 22.

Presentation from Professor Barde

Professor Barde is a Neuro-Biologist. The SER project aims to increase investment in research. Professor Barde stated that research will be disseminated and the speed with which things are unfolding is remarkable. See his presentation



Professor Barde -
Wales Neurological AI

Questions asked of Professor Barde

1. Joseph Carter asked if Professor Barde has looked outside the university to the NHS and surrounding hospitals. Are there good links between Cardiff University and other hospitals? Professor Barde responded by saying that he must establish the laboratory and credibility first. He will be in Cardiff for some time. As a medic he has made contact with the University Hospital of Wales, Cardiff. He will see how this project unfolds. He does not like over promising. He wants to establish a credible base and he has all the contacts he needs.

Talk from Professor Bob Woods

Professor Bob Woods leads Neurodem. His talk focused on the dementias. The Welsh Government has a vision for dementia and supports research into the cause and cure of dementia. £4 million is coming to Wales for a dementia project. Dementia research is strong in Wales. However, it is still the poor relation of medical and health research. The cost of dementia in Wales is £1.35 billion per year. The UK is hosting the first G8 dementia summit. There is lots of collaboration facilitated by Neurodem in universities in Wales. Professor Bob Wood is looking at how we can transfer cognitive rehabilitation to other conditions not just dementia. Presentation to follow.



NEURODEM - Prof
Bob Woods.ppt

Update on the North Wales Neurosciences Network from Annette Morris

The North Wales Neurosciences Network have reviewed service options for the future delivery of neurophysiology services in North Wales, and are potentially looking to centralise the neurophysiology service in Llandudno Hospital. A board has been set up for neuro-rehabilitation services and they are developing a service model for level 2 in North Wales. The preferred option is an incremental development of existing facility.

The Neurosciences Network is working with public health to carry out a needs assessment in North Wales. The Network has recently established an Academic, Education and Information Subgroup, chaired by Professor Bob Woods, Director of NEURODEM at Bangor University. The remit is research (promoting links between academic research and health and social care practice for neurological conditions), education (promoting joined up training between health and social care for neurological conditions) and information (developing improved information for people living with a neurological condition at a time and in an appropriate form that meets their needs).

DSAGS (disease specific advisory groups) have been set up for MND, MS and now epilepsy.

- MND chair is Dr Liz Williams, Associate Specialist in Palliative Care Medicine, BCUHB
- MS chair is Dr Rhys Davies, Consultant Neurologist, Walton Centre NHS Foundation Trust
- Epilepsy chair is Dr Dave Smith, Consultant Neurologist, Walton Centre NHS Foundation Trust

Work is also being done to establish a North Wales Neuroscience Service User Forum. Two new sets of referral guidelines have been approved. These include guidelines for

- EEG
- EMG NCS

Talk from Dr Monica Busse

Dr Busse talked about Huntington's Disease research in Wales. Please see her presentation. Gwent has its own team which is an additional resource but it is a small team and there isn't a physiotherapist in post.



Dr Monica Busse
Presentation - CPG 2:

Questions for the Minister for Health and Social Services

We want research to be included in the Neurological Delivery Plan.

AOB

Mark Isherwood AM has been approached by Chris Chapman of the Dystonia Society to talk at a future CPG meeting. It was agreed that CGP meetings should have a short presentation from a neurological charity.

Mark Isherwood AM thanks contributors and attendees.

Future meeting date

- Carmarthen 22nd November chaired by Rebecca Evans AM.

- 11th February 2014 – Please note this meeting has now been moved to the 18th February 2014.
- 25th June 2014
- 21st October 2014.