



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Tuesday 18 October 2016

Committee Room 4, Tŷ Hywel, National Assembly for Wales

Via VC to Wrexham Maelor Hospital

Present

Cardiff

Mark Isherwood AM (Chair)
Barbara Locke, Parkinson's UK & Vice Chair WNA
Lynne Hughes, MS Society Cymru & WNA
David Murray, Cure Parkinson's Trust & WNA
Michelle Herbert, Brain Tumour Charity & WNA
Ann Sivapatham, Epilepsy Action Cymru & WNA
Dilwyn Jones, Brain Injury Rehabilitation Trust BIRT & WNA
David Maggs, Headway & WNA
Kevin Thomas, MND & WNA
Diane Gleeson, Stroke Association & WNA
Alison Shakeshaft, ABUHB & Interim Chair of NCIG
Lee Waters, AM
Sue Mullock, ABMUHB
Peter Evans, ABMUHB
Pip Ford, Chartered Society of Physiotherapy
John Meredith, Dystonia Society
Dr Gareth Payne, Dystonia Society, CAU/Cwm Taf/BCUHB
Catherine Clenaghan, HD Nurse Specialist, Cardiff University
Kay Holmes, Huntington's Disease Association
Carol Smith, MND ?
Manel Tippet, Royal College of Psychiatrists
Miriam Wood, MESIG ME Support
Anne Gibby, HDUHB
Carol Davies, British Association of Social Workers
Emma Hughes, Genetic Alliance
Gareth Llewelyn, ABUHB
Javvad Haider, C&VUHB
Jean Bergonzi, Dystonia Society
Nina Bergonzi, Dystonia Society
Kym Trosas, HDUHB
Jim Wilson
Mhairi Wilson
Rebecca Brown, MNDUK advocate

Peter Roberts, The Brain Group
Rachel Williams, Parkinson's UK
Richard Pawsey, ABMUHB
Tanya Edmonds, ABMUHB Neuropsychology
Fiona McDonald, MS Society
Phil Smith, Associate British Neurologists
Kenneth Dawson, ABUHB
Mark Morgan, Lyme Disease/MESIG

Wrexham link

Annette Morris, BCUHB
Jackie Hughes, Neuro Therapy Centre
Jane Johnston-Cree, Neuro Therapy Centre
Karen Shepherd BCUHB Neurosciences Board patient representative
Moira Gleed & Guest, Dystonia Society

Apologies

Gemma Hamblin, Stroke Association Wales
Margaret Ware, Myotonic Support Group
Kay Holmes, Huntington's Disease Association
Ahmad Butt, British Polio Fellowship & WNA
Ana Palazon, Stroke Association & WNA
Margaret Ware, Myotonic Support Group
Sylvia Prankard, Parkinson's UK
Dafydd Williams, Muscular Dystrophy UK
Paul Roberts, ABMUHB
Helen Owen, ABMUHB
Simon Thomas, Assembly Member
Eluned Plack, Wrexham Neurological Alliance
Andrew Wilson-Mouasher, Marie Curie
Astrid Burrell
Barbara Moore
Carl Cooper, PAVO
Cynthia Cynics
Dr Evan Moore, BCUHB
Jacqueline Brown, PAVO
Jane Stein, PSP
Jon Barnes, Epilepsy
Llinos Wyn Parry, Stroke Association
Louise Bretland-Treharne
Michael Walker
Sue Bennett
Jan Russell, WAMES
Ruth Glew, ABMUHB
Simon Thomas, AM
Angel Burns, AM
Dafydd Elis-Thomas, AM

Mark Isherwood, chair introduced the meeting and attendees and thanked the IT department for their support.

Minutes of the last meeting and matters arising

Minutes of the meetings held on 14th June 2016 were recorded as true and accurate account. Proposed by David Murray, seconded Lynne Hughes.

There were no matters arising.

Alison Shakeshaft, Director of Therapies and Health Science, ABUHB & Interim Chair of the NCIG presented on The Role of the NCIG, progress to date, successes & challenges and refreshing the Welsh Government's Neurological Conditions Delivery Plan.

AS confirmed that the role of the NCIG (Neurological Conditions Implementation Group) consists of overseeing local development plans, developing forums to share good ideas, gives the opportunity for setting joint priorities with SIG (Stroke Implementation Group), helps to develop national priorities and looks after the £1m of investment and decides how it is spent.

AS went on to explain that the group meets four times a year and also meets jointly with SIG twice a year. The membership is widespread and is made up of representatives from the health service both clinical and management, WNA (Wales Neurological Alliance), WHSSC (Welsh Health Specialised Services Committee), the ambulance service and public health Wales.

Priorities 2016/17 & progress so far

The group has asked for updates this week on the progress each organisation has made with this project so far as they have to show they are making a difference, some examples of this are;

Developing consistent and coherent neuro-rehabilitation services, for patients of all ages

This was agreed as the top priority & the majority of the funding went into this area. £4m of bids were received against funding available of £1.2m (extra £.2m came from the Stroke Association), this funding was distributed to all health boards.

- Aneurin Bevan University Health Board have used the funding to expand community neuro-rehabilitation service (CNRS)
- Betsi Cadwaladr University Health Board have used funding for support towards establishment of a level 2 neuro-rehabilitation unit in North Wales
- Cardiff & Vale University Health Board, Cwm Taf University Health Board & Powys teaching Health Board have used funding for community neuro-rehabilitation service (CNRS)

Updates are outstanding from Welsh Neuro Muscular Network and WHSSC.

Developing and responding to patient experience and outcome measures

The group is currently working with The Stroke Association to test outcomes. It is due to test 800 stroke patients, 200 face to face, 200 by telephone, 200 by paper questionnaire and 200 by electronic means.

Developing a co-productive approach to increasing awareness of neurological conditions

WNA (Wales Neurological Alliance) were not successful with their original bid however since they have been awarded £40k to employ a project manager hosted by the MS Society which will look at patients and carers needs and how to raise awareness of the challenges they face.

Delivering clear consistent patient information

Very little progress so far, will roll over to next year

Delivering access to neurology services, for patients of all ages, consistently throughout Wales

Very little progress so far, will roll over to next year

Successes so far

AS is very sure that in the future the group will be able to demonstrate the real differences from the investment it has had.

Challenges

AS explained that working across two groups sometimes makes it difficult to keep both together with communication. Now both groups sit on same day to overcome this issue. Need peer review of plans going forward and need better reporting/monitoring of what money is spent on. It has been agreed that a sub group will look at a refresh plan next Summer/Autumn.

AS then took questions from the floor.

Forward Work Programme for CPG

Lynne Hughes reminded members of the previous work that had been undertaken by the Cross Party Group in previous terms of the National Assembly for Wales (Legacy paper attached)

The Group agreed that we should revisit previous reviews and check on progress against recommendations. It was suggested that the Chair write to Director of Therapies and Health Science in each Health Board to ask for an update against the recommendations of the review into neurophysiotherapy.

In terms of the Understanding of Neurological Conditions within Emergency Units report, it was suggested that a further review needs to be carried out but with a broader remit including admission to acute wards. It was also agreed that awareness of neurological conditions amongst primary care staff was mixed and that the group should invite the Royal College of GPs to a future meeting.

It was agreed that the Cross Party Group should also carry out a survey (or similar) of people living with neurological conditions about their experiences off the Social Services and Wellbeing (Wales) Act.

Given their central role in supporting people with neurological conditions it was agreed that we should review the neurological workforce particularly Specialist Nursing Provision in Wales.

Nina Bergonzi Dystonia Society South Wales Support Group

Nina gave us a very comprehensive presentation on how living with Dystonia has affected her life and that of her family particularly in relation to the lack of specialised services within Wales to treat her condition. She currently has to travel to Bristol to see a specialist. She also along with John Meredith from the Dystonia Society explained that at the moment many Dystonia patients are not being given Botox at the recommended frequency which increases the pain and symptoms of the condition.

MI suggested a letter to the Cabinet Secretary on how this can be progressed.

A representative from the ME support group also asked that MI write to the cabinet Secretary to ask about the poor service for people with ME in Wales.

Closing remarks and dates of future meetings

MI asked that John Meredith's request for a day time meeting at least once a year is agreed to enable people who cannot easily travel into Cardiff for evening meetings to attend. It was agreed that this would be scheduled. It was also agreed that the next CPG will be held in North Wales with a date to be agreed.