



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Monday 5th December 2017

**Committee Room 5, Tŷ Hywel, National Assembly for Wales
Via VC to Wrexham Maelor Hospital**

Present Ty Hywel

Mark Isherwood AM (Chair)
Caroline Jones, AM
Lynne Hughes, MS Society Cymru
Carol Smith, MNDA
Ana Palazon, Parkinson's UK & Chair of WNA
Diane Gleeson, WNA Coordinator
Rachel Williams, Parkinson's UK
Astrid Burrell, Brain Involve
Hilary Mott, CWM Taf UHB
Jonathon Canty, The Brian Tumour Charity
Richard Pawsey, The Chartered Society of Physiotherapy
Lesley Williams, Epilepsy Cymru
Margaret Ware, MDUK & Myalonic Dystrophy Sub Group
Judith Rice
Peter Roberts
Irena Erchova
Miriam Wood
Jenny Thomas, Cardiff & Vale UHB
Robin Moulster, BASW Cymru

Presenters

Helen Howson, Director of Bevan commission
Ruth Glew, ABM ULHB
Kevin Thomas, MNDA
Michelle Price, Powys Teaching Health Board
Louise Ebenezer, Parkinson's Disease Nurse Specialist
Malisa Pierri, Cardiff & Vale UHB
Mark Morgan, MESIG

Wrexham Maelor VC link

Annette Morris, Director of Neurosciences
Jackie Hughes, Neuro Therapy Centre
Karen Shepherd
Tracy Stockin, Parkinson's UK

Jan Paterson, Epilepsy UK
Jane Johnston-Cree, Neuro Therapy Centre
Sylvia Prankard

Apologies Simon Thomas, AM
Llyr Huws Gruffydd, AM
Ann Sivapatham, Epilepsy Action Cymru
Andy Burgen, North Wales Community Health Council
Eirwen Malin
Gareth Llewelyn, ABUHB
Martin McCudden
Bryn Waldron
Moiria Gleed
Jean Francis
Gareth Llewelyn, ABUHB
Helen Owen, ABM ULHB
Jon Barnes, Epilepsy Action
Rhodri Davies, Stroke Association
Dave Maggs, Headway
Pip Ford, The Chartered Society of Physiotherapy
Carol McCudden, Ataxia UK

Introduction

Mark Isherwood, Chair introduced the meeting and attendees in Ty Hywel and in North Wales introduced themselves. Ana Palazon read out the apologies.

Minutes of the last meeting and matters arising

The minutes of the last meeting were recorded as a true and accurate record, proposed by Lynne Hughes and seconded by Leslie Williams.

Prudent Healthcare

Helen Howson, Director of the Bevan Commission presented on this topic, outlining the background, challenges, principles of Prudent Healthcare and progress to date.

The principles are:

Any service or individual providing a service should:

- achieve health and wellbeing with the public, patients and professionals as equal partners through co-production
- care for those with the greatest health need first, making the most effective use of all skills and resources

- do only what is needed, no more, no less; and do no harm
- reduce inappropriate variation using evidence based practices consistently and transparently.

Bevan Academy

- The Bevan Academy for Leadership and Innovation strives to develop Prudent Healthcare and promote better health and healthcare in Wales.
- The Bevan Commission identified the need for an Academy to strengthen leadership and innovation in health across Wales and beyond, sharing their excellence and expertise further afield.
- The Academy provides a dynamic learning and development environment to support inspirational leadership, innovative ideas and new ways of working. It promotes open innovation, encouraging people, professionals and organisations to collaborate in a non-competitive environment.
- The Academy builds upon core foundations of research, innovation and skills development to help inspire and create a sustainable, prudent and vibrant NHS in Wales. The Bevan Innovators and the Bevan Innovation Hubs play an important part in achieving these objectives.

The Bevan Academy Innovation Hubs

- The Central Bevan Innovation Hub is hosted within Swansea University at the School of Management has strong links with the Colleges of Medicine and Human and Health Sciences.
- It provides a responsive and flexible infrastructure, bringing together diverse ideas to address the challenging issues we face in healthcare today.
- It will draw together existing resources from across various areas of expertise, including: clinical care; patient experience; prevention; health economics or data and information.
- The central Bevan Innovation Hub supports local Bevan Innovation Hubs, providing the opportunity for people to come together to solve problems, discuss issues of concern or develop thinking to address key challenges.
- Each local Bevan Innovation Hub will have a central base within the main hub, but will take the lead on its designated innovation area, testing innovative elements informed by wider expertise.
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Helen concluded by saying that more change must be stimulated to allow people to do things differently, creating a real hub where we can all work together to find the solutions that we need.

Mark thanked Helen for her presentation and the floor was opened for questions & discussion.

Innovation in Practice - Motor Neurone Disease

Kevin Thomas, Regional Care Development Adviser MND Association for North Wales and the Isle of Man, Ruth Glew, Lead Care Co-ordinator South Wales and Michelle Price, Consultant Therapist for Stroke and Neurorehabilitation Powys Teaching Health Board presented separately to the meeting outlining the different models of care in MND across Wales.

Mark thanked them all for their presentations opened the floor to questions and discussion.

if you would like further information about the models of care in MND please contact Kevin Thomas kevin.thomas@mndassociation.org

If you would like a copy of any of the presentations, please contact wnacoordinator@gmail.com

Innovation in Practice – Specialist Nursing

Louise Ebenezer, Parkinson's Specialist Nurse ABMU and Malisa Pierri, Epilepsy Specialist Nurse presented separately to the meeting on the innovative approach they have adopted.

Mark thanked them all for their presentations opened the floor to questions and discussion.

If you would like a copy of either of the presentations, please contact wnacoordinator@gmail.com

WNA Member Presentation – Lyme Disease

Mark Morgan, MESiG presented to the meeting his experiences of Lyme Disease and the challenges currently being faced in Wales including the lack of understanding of the disease. More research is needed into the causes & more recognition and support is needed. Mark asked for the Chair's help in this matter.

Agreed Actions:

1. Bevan Commission agreed to keep links with WNA to consider opportunities for highlighting innovations in care
2. WNA to draft a letter to the Cabinet Secretary for Health and social Services regarding the insufficient number of specialised nurses & suggesting innovative solutions
3. WNA to write to the Cabinet Secretary for Health and social Services regarding Lyme's Disease asking him to note and respond to the call at the meeting for regulation on blood contamination
4. WNA and MESiG to provide the Chair with a briefing and suggested motion if they would like him to seek an opportunity for an Assembly Debate on Lyme Disease

Mark Isherwood AM thanked everyone for their input and closed the meeting at 8:15pm.

Date of next meeting – to be confirmed.