



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

## **Minutes of Cross-Party Group Neurological Conditions meeting on**

**Wednesday 22<sup>nd</sup> July 2020 (via ZOOM)**

### **Present**

Mark Isherwood, MS (Chair)  
Dai Lloyd MS  
Vikki Howells MS  
Ana Palazon, Parkinson's UK Cymru & Chair of WNA  
Dave Maggs, Headway  
Ann Sivapatham, Epilepsy Action Cymru  
Carol McCudden, Ataxia UK  
Melanie Andrews, MND  
John Meredith, Dystonia Association  
Rebecca Brown, WNA Awareness Raising Officer  
Diane Gleeson, WNA Co-ordinator  
Fiona McDonald, MS Society Cymru  
Matthew O'Grady, Stroke Association  
Dawn McGuinness, Parkinson's UK  
Robert Wilson Thomas, FND Hope UK  
Lesley Morris, Epilepsy Wales  
Miriam Wood, MESiG  
Alan Thomas, Ataxia and Me  
Rebecca Hoskin BAVO  
Annette Morris, Director of Neurosciences CUHB  
Natalie Phillips, Assistant Psychologist Morriston Hospital  
Phil Smith, Consultant Neurologist UHW  
Tanya Edmonds, Swansea Bay UHB Neuropsychology  
Karen Shepherd  
Una Jones  
Fiona Kettell  
Councilor Rylan  
Ally  
B3-A30  
Sian Dorward  
Nailia RCSLT  
Margaret Ware  
Kham Steventon  
Rebecca Hoskin  
Lynda Kenway, Stroke and Neurological Conditions Implementation Groups  
Coordinator NHS Wales Health Collaborative  
Jacq Ogden  
Martin McCudden

(Names have been recorded from the name displayed on the screen at the time of the meeting. If no name was displayed, attendance has not been recorded. No formal introductions took place due to the high volume of attendees). Please email the CPG Secretariat on [wnacoordinator@gmail.com](mailto:wnacoordinator@gmail.com) to add or rectify your name accordingly so the record is accurate. Thank you.

## **Apologies**

Lynne Hughes, MS Society Cymru, (WNA Vice Chair)  
Kate Steele, Shine  
Catriona Fearn, BCUHB  
Helen Owen, Swansea Bay UHB  
Chris Bennett, MNDA  
Cynthia Shepherd, MS Society  
Dawn Golder, FND Hope UK  
Llyr Gruffydd, MS  
Mike Hedges, MS

## **Introduction**

Mark Isherwood, Chair, introduced the meeting & welcomed everyone. Due to the high number of online participants, individual introductions did not take place.

## **Minutes of the last meeting and matters arising**

Minutes of the last meeting were recorded as a true and accurate account. Proposed by Ana Palazon, seconded by John Meredith.

There were no matters arising.

## **Annual Reports 2018 and 2019 and election of Chair and Secretary**

Due to the nature of the last three meetings being part of the CPG Inquiry on the Neurological Conditions Delivery Plan (NCDP) It was not possible to table the 2018 Annual Report and Financial Statement or hold the AGM in December 2019. Both annual Reports were tabled at this meeting.

Ana Palazon summarised both reports. There were no questions.

Ana Palazon asked for nominations for Chair. Mark Isherwood was proposed by Dai Lloyd and seconded by John Meredith.

Mark Isherwood asked for nominations for Secretary. Diane Gleeson was proposed by Ana Palazon and seconded by John Meredith.

## **The Cross Party Group on Neurological Conditions Inquiry Report**

Mark introduced the presentation reminding the group that the three meetings in 2019 had centred around this subject, taking oral evidence from people living with neurological conditions, their carers, clinicians and professionals. The Inquiry Report was due to be launched in March 2020 however, due to the pandemic, that meeting and launch were cancelled until this meeting in July. Immediately prior to this meeting a copy of the report was circulated to everyone on the mailing list. It was also published on the WNA website and Cross Party Group website and a press release was issued.

Ana then delivered a presentation to the group summarising the Inquiry Report findings. (copy attached)

The meeting was then opened up to questions and comments:

Annette Morris, Director of Neurosciences BCUHB queried the comment regarding BCUHB on page 18. She thought it was inaccurate and the report did not provide a balanced view of the health board.

Matt O'Grady, Stroke Association commented that the Inquiry Report had many similarities with the report issued following the Inquiry into the Stroke Delivery Plan. He questioned why this report did not make the case for condition specific delivery plans going forward.

John Meredith, Dystonia Society, concerned that the Inquiry Report will not be given the focus it deserves between now and the forthcoming Wales elections.

Phil Smith, Consultant Neurologist UHW, suggested it would be a good idea for people to be more involved in their own care by getting copies of all letters from the specialists.

Jacq Ogden, who lives with chronic migraines, wants to raise awareness of this condition. She believes it should be recognised as a neurological condition and included in the NCDP.

Lynda Kenway, Stroke and Neurological Conditions Implementation Groups Coordinator NHS Wales Health Collaborative welcomed the report and will ensure formal response is issued in due course.

Several attendees congratulated the CPG on the report.

### **WNA response to Health and Social Care Committee's Inquiry into COVID-19**

Rebecca Brown, WNA Awareness Raising Officer, delivered a brief presentation to the group on the findings that WNA gathered and presented to the COVID-19 Inquiry. The meeting was again opened up to questions:

John Meredith, Dystonia Society, concerned that since lockdown many people will have had issues with rehabilitation and routine self-care as a result of pool & park closures. This will be compounded further if a second spike occurs.

Ana Palazon expressed concern about the impact of COVID-19 on rehabilitation services for people with neurological conditions. Lynda Kenway informed the group that Michelle Price, Clinical Lead for Neurological Conditions is working with Welsh Government to put in place a post COVID-19 rehab framework for Wales.

### **Next Steps**

Mark thanked everyone who contributed to the Inquiry. He asked for any further comments/questions and ideas for next steps.

Tanya Edmonds suggested that she attends a future meeting to explain how she allocated the community neurorehab funding in South West Wales.

Mark suggested that he uses his debate session in September to present the Inquiry Report to Welsh Government.

### **Actions:**

- A copy of the Inquiry Report PowerPoint presentation to be circulated to the group
- Tanya Edmonds to be invited to a CPG meeting to present on the neuropsychology rehabilitation work done during the current NCDP period – DG to send her 2020 dates
- Jacq Ogden to be invited to a CPG meeting to discuss the issues she raised further on how to raise awareness of chronic migraine – DG to send 2020 dates
- Robert Wilson Thomas, FND Hope UK to be invited to a CPG meeting to raise awareness of his charity and how they can raise awareness- DG to send 2020 dates
- A copy of this Inquiry Report to be submitted to Welsh Government – AP
- Mark to use his debate time in September to present the Inquiry Report to Welsh Government - MI
- ANA & Mark to meet in the next month to plan how future CPGs can be used to continue the focus on the report recommendations – DG to arrange

### **AOB**

Ana asked for feedback on the success of the ZOOM meeting. One comment was that possibly Teams may be a better option as some organisations did not allow their employees to use ZOOM at work. It was agreed that this would be considered for the next meeting of this type.

### **Close**

Mark closed the meeting at 3.10pm thanking everyone for joining.