



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

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

**Thursday 11<sup>th</sup> March 2021 4pm (via ZOOM)**

### **Present**

Mark Isherwood, AS/ MS (Chair)  
Ana Palazon, Parkinson's UK Cymru & Chair of WNA  
Lynne Hughes, MS Society  
Kate Steele, Shine  
John Meredith, Dystonia Association  
Rebecca Brown, WNA Awareness Raising Officer  
Fiona McDonald, MS Society  
Jane Johnston-Cree, Neurotherapy Centre  
Clinton Mitchell, Neurologist UHW  
Ann Sivapatham, Epilepsy Action Cymru  
Tom Hughes, Neurologist UHW  
Rachel Williams, Parkinson's UK  
Victoria Wareham, Dystonia Association  
Sian Guest, MNDA  
Anna Maclean  
Jacq Ogden  
Sian Dorward, MS Society  
Martin McCudden  
Liz Ken  
Janet Paterson  
Kripen Dhrona British Polio  
Professor Mark Edwards, St George's University Hospital London  
Dawn Golder FND Hope UK  
Ffion Jones  
Dora Szalkay  
Rhys Bowler

(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 amend your name accordingly so the record is accurate. Thank you.

### **Apologies**

Karen Shepherd  
Matt O'Grady Stroke Association

Llyr Gruffydd AS/ MS  
Rhun Ap Iorwerth AS/MS  
Annette Morris, Director of Neurosciences CUHB

### **Introduction**

Mark Isherwood MS, 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 Kate Steele

There were no matters arising.

### **Functional Neurological Disorder**

Dawn Golder CEO, Executive Director of FND Hope UK and Professor Mark Edwards presented on the role of FND Hope UK and the work that has been undertaken in England to develop an optimum care pathway for people with FND (the presentation will be circulated at a later date as the pathway is still draft.)

The session was opened up to questions, with several people commenting on the similarities/ overlap between FND and other chronic neurological conditions, and if we can get the care pathway optimised for one condition then lessons could be learned quickly for other conditions.

It was highlighted that there was a lack of robust data to understand the scale of the condition.

### **Chronic Migraine**

Dr Anna MacLean and Dr Jacq Ogden talked about chronic migraine and its' impact as both clinicians and people who live with the condition.

(for further information: [migrainetrust.org](http://migrainetrust.org), [nationalmigrainecentre.org.uk](http://nationalmigrainecentre.org.uk), [migraineworldsummit.com](http://migraineworldsummit.com), [migraineagain.com](http://migraineagain.com))

### **Welsh Government response to the Cross Party Group on Neurological Conditions Inquiry Report**

A written response from the Minister for Health and Social Services has been received (copy attached). The Chair summarised the response and opened up for comments. It was agreed that whilst it was disappointing that all the recommendations from the report had not been agreed, it was positive that we now have a strong lever to hold the Welsh Government and the Neurological Conditions Implementation Group to account.

### **Legacy Report**

Fiona McDonald outlined the key areas of work that would be included in the legacy report from the work programme of the Cross Party Group in this Senedd's term, including the issues raised today. The report will be distributed to all members of the CPG.

### **Personal Health Budgets**

Rhys Bowler talked about his campaign to see personalised care including Personal Health Budgets (PHBs) rolled out to all people in Wales. He explained that such an approach would enable people to be in control of their own care, allowing them to manage their own funding, how it is spent, and choosing and employing their own staff. Personal health budgets are available in England. There has been a petition to the Welsh Parliament/ Senedd which will be considered by the Petitions Committee in due course. <https://petitions.senedd.wales/petitions/200182>

**Actions:**

- Include FND and the development of a care pathway in Wales in the legacy report
- Include the need to raise awareness of chronic migraine, improve services in Wales and address the variation of care in the legacy report.
- Invite the next Minister for Health and Social Services to a future meeting of the Cross Party Group to discuss progress against the recommendations.
- Mark Isherwood MS to consider convening a roundtable to discuss personalised health budgets if he is re-elected

**AOB**

Ana Palazon thanked the Chair for all his hard work and commitment to the Cross party Group during this term and wished him well in the forthcoming elections.

**Close**

Mark Isherwood MS closed the meeting at 6pm thanking everyone for joining.