



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

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

**Tuesday 19<sup>th</sup> September 2017**

**Committee Room 4, Tŷ Hywel, National Assembly for Wales  
Via VC to Wrexham Maelor Hospital**

**Present Ty Hywel**

Mark Isherwood AM (Chair)  
Lynne Hughes, MS Society Cymru  
Carol Smith, MNDA  
Mark Morgan, MESIG  
John Meredith, Dystonia Society  
Dean Carey, Dystonia Society  
Jonathon Canty, The Brian Tumour Charity  
Dave Maggs, Headway  
Pip Ford, The Chartered Society of Physiotherapy  
Debbie Davies, The Chartered Society of Physiotherapy  
Richard Pawsey, The Chartered Society of Physiotherapy  
Ruth Crowder, College of Occupational Therapists  
Lesley Williams, Epilepsy Cymru  
Fiona Macdonald, MS Society Cymru

**Wrexham Maelor VC link**

Annette Morris, Director of Neurosciences  
Moira Gleed, Dystonia Support Group Coordinators, Shropshire,  
Borders and North Wales  
Mike Gleed, Dystonia Support Group Coordinators, Shropshire,  
Borders and North Wales  
Jackie Hughes, Neuro Therapy Unit, Saltney

**Apologies**

Ana Palazon, Parkinson's UK & Chair of WNA  
Ann Sivapatham, Epilepsy Action Cymru  
Kevin Thomas, MNDA  
Diane Gleeson, WNA Coordinator  
Rhodri Davies, Stroke Association  
Jane Jonhstone-Cree, Neuro Therapy Centre  
Phil Smith, Consultant Neurologist  
Sylvia Prankard

Neil McEvoy, AM  
Kym Troman  
Rachel Williams, Parkinson's UK  
Alison Shakeshaft, Aneurin Bevan UHB – Family and Therapies  
Carol McCudden, Ataxia UK  
Astrid Burrell  
Jon Barnes, Epilepsy Action  
Sioned Larsen  
Rebecca Brown  
David Linden  
Laura Bunting  
Simon Thomas, AM  
Helen Owen, ABMUHB  
Caroline Walters  
Bryn Waldron

## **Introduction**

Mark Isherwood, Chair introduced the meeting and attendees and thanked everyone for their patience whilst IT tried to set up VC link with North Wales. He also gave apologies that we hadn't been able to do this and would have to use phone conferencing instead

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

The minutes of the last meeting were recorded as a true and accurate record, proposed by Carol Smith and seconded by Fiona Macdonald.

Mark Isherwood informed the meeting that he had sent a letter to Betsi Cadwaladr University Health Board regarding how they had used funding towards the establishment of a level 2 neuro- rehabilitation unit. He had received a response which will be circulated for information with the minutes (Appendix 1)

## **Update on WNA involvement in the refreshed Neurological Conditions Delivery Plan**

Lynne Hughes updated the meeting on how the WNA had held three stakeholder events with people with neurological conditions of the draft actions and proposals in the refreshing of the Welsh Government's Neurological Conditions Delivery Plan. A copy of the report submitted to the Neurological Conditions Implementation group will be circulated with the minutes (Appendix 2).

It is key that the Cross Party Group now scrutinises how the Government and Local Health Boards implement the key actions in the plan. Mark Isherwood informed the group that the Welsh Government is due to give a statement on the Neurological Delivery Plan 2017 – 2020 at Plenary on 26th September.

John Meredith explained how services for people with Dystonia in Wales were not adequate now and not fit for the future given the marked increase in the numbers of people diagnosed with Dystonia in Wales.

### **Neurophysiotherapy Review – progress since 2013.**

Mark Isherwood AM welcomed Pip Ford MBE, MCSP, Public Affairs and Policy Manager for the Chartered Society of Physiotherapy in Wales.

Pip Ford gave some background to the agenda item, reminding us of that the original report was written by the Cross Party Group in 2013 and reviewed for the first time in 2014. All Health Boards and the Welsh Government have contributed to this review and given information on their progress against the original recommendations. The Chartered Society of Physiotherapists have collated this and produced a full report of the findings will be circulated with the minutes (Appendix 3).

Pip Ford concluded that the review certainly helped to put neurophysiotherapy services on the radar and, rehabilitation services more widely. So often, it is the acute services that get the investment and rehabilitation can be an afterthought and fails to receive adequate investment.

She also felt that the neuro and stroke delivery plans making rehabilitation a priority has certainly helped with regard to some targeted investment in neurophysiotherapy services. We discussed whether this investment was enough and thought that this was probably not the case but hoped that service users are seeing some improvements.

Two important targeted pieces of work – on equipment and hydrotherapy have also meant the service has had to spend time reviewing these in more detail and that has been good to take a 'Wales-wide' approach.

Debbie Davies from the CSP thanked the Cross Party Group for undertaking the original Inquiry as it had helped Neurophysiotherapy managers to ensure services are maintained, for example the report was used as evidence for maintaining the hydrotherapy pool at Prince Charles Hospital. Debbie thought it was vitally important that service users were involved in defining the outcome measures for Neurophysiotherapy services and was keen to see a shift in services out of hospitals and into community and leisure centres.

Richard Pawsey CSP informed the group of the role of ACPIN who support clinicians who support people with neurological conditions. They have a particular role in supporting Local Health Boards to achieve recommendation 4 and 5 in the report. The group are keen to work further with the CPG and the WNA.

There was a discussion on the benefits and some of the challenges of self-referral into physiotherapy services, particularly in relation to some of the delays that people with Dystonia had faced in North Wales.

The review made the following recommendations:

- The CPG may like to undertake a questionnaire of patients/service users to see what their experience of neurophysiotherapy services is like now – do they see a difference? Are there issues of importance to them, which are not being picked up by the physiotherapy service? – They might like to widen the review, perhaps to look at rehabilitation services more generally.
- The CPG may like to follow up with the neurophysiotherapy services again in due course, not necessarily across the detail of all the recommendations but just to ask them how they feel their services have progressed.
- The CPG may wish to follow up with physiotherapy and other therapy services to track the progress of the investment in rehabilitation services from the neurological and stroke national delivery plans.

It was agreed that the Wales Neurological Alliance would discuss these recommendations and propose further action to be taken forward. Mark Isherwood thanked the Chartered Society of Physiotherapy for their contribution to the meeting and for their work in preparing for today.

### **WNA member presentation: The Brain Tumour Charity**

Mark Isherwood AM introduced Jonathan Canty, Policy Officer.

Jonathon outlines the aims of the Brain Tumour Charity which are to see a world where brain tumours are defeated. In Wales, the latest figures show that 728 people were diagnosed with a primary brain tumour in 2014 and 271 people died from a brain tumour. The charity has three main strands to their work:

- They fund research to find new treatments, improve understanding, increase survival rates and bring us closer to a cure.
- They raise awareness of the signs and symptoms of brain tumours, to reduce diagnosis time.
- They provide support and information for anyone affected to improve the quality of life.

In Wales more than a third of people were diagnosed with a brain tumour by an emergency admission to hospital which is far higher than any other cancer type which highlights the importance of raising awareness of signs and symptoms to drive earlier diagnosis and treatment.

The most recent Wales Cancer Patient Experience Survey highlighted that only 56% of people with a brain/ CNS tumour found it easy to contact their key worker and less than half had received the information by staff in relation to financial help.

The Brain Tumour Charity is engaging with the NeuroCentre at UHW through their Healthcare Professional Engagement Team. They are also promoting their Patient Guide to Brain Tumour Treatment and Services.

The Charity is also trying to promote greater access to effective treatments including 5-ALA.

### **The Dystonia Society**

John Meredith also gave an update following correspondence he had received following on from the presentation given by them at the CPG last autumn. The Dystonia Society is keen to meet with the Chair of the Neurological Conditions Implementation Group. Mark Isherwood AM will write to request this.

It was agreed that Mark Morgan will present on Lyme Disease at this slot in the December meeting.

Mark Isherwood AM thanked everyone for their input and closed the meeting at 1:30pm.

Date of next meeting 5th December 2017 6pm – 7:30 pm