



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

## **Annual Report 2014 and Financial Statement Cross-Party Group for Neurological Conditions**

### **Aims and Objectives**

#### **Aim**

To improve services for people affected by neurological conditions

#### **Objectives**

1. To engage and work in partnership with people affected by neurological conditions
2. To raise awareness of neurological conditions and their impact on individuals and their communities
3. To inform and influence the Welsh Government about the needs of people affected by neurological conditions
4. To support and promote appropriate research

### **Membership and Meetings of the group:**

The group will consist of Assembly Members drawn from all of the political parties represented in the National Assembly for Wales and representatives from the Wales Neurological Alliance Executive Committee. Meetings are open to the public, but specific invitations are sent to the 32 member organisations of the Wales Neurological Alliance or others with an interest in neurological conditions, who the chair and secretary choose to specifically invite.

The current members are:

Mark Isherwood AM (Chair)

Rebecca Evans AM (until July 2014)

Elin Jones AM

Kirsty Williams AM

Maggie Hayes - Wales Neurological Alliance (Secretary until February 2014)

Urtha Felda – Wales Neurological Alliance (Acting Secretary)

Ana Palazon - Stroke Association (Chair of the Wales Neurological Alliance)

Joseph Carter - MS Society Cymru

Barbara Locke – Parkinson's UK

Dave Maggs - Headway

David Murray - Cure Parkinson's Trust

Carol Ross - Fibromyalgia UK

Ann Sivapatham - Epilepsy Action

Carol Smith - Motor Neurone Disease Association

Kate Steele - Shine Cymru

Alan Thomas - Ataxia UK

Kevin Thomas - Motor Neurone Disease Association

## **Professional lobbyists, voluntary organisations and charities with whom the Group has met during the preceding year**

The group did not meet with any professional lobbyists. Details of voluntary and charitable organisations attending meetings can be found in the 'Membership and Meetings of the group' section of the report.

### **Meetings**

The Cross-Party Group met three times during 2013/14, in October 2013, November 2013 and February 2014. The group was scheduled to meet in June 2014, but the meeting had to be cancelled due to third and fourth reading of the Housing Bill.

#### **October 2013**

This meeting was devoted to showcasing research in Wales. Earlier in the year the Welsh Government had launched the Sêr Cymru project, investing £21.3 million to develop world-class research in Wales. Professor Yves Barde has been awarded £4 million for research into Neurobiology in the School of Biosciences at Cardiff University (September 2013 – October 2018) as part of this project and he joined Professor Bob Woods from Neurodem at the meeting.

The Cross-Party Group showed that the Welsh Government had expanded its investment in research and that due to the Health Information Research Unit at Swansea University, Neurodem, Involving People and the willingness of neurologists and other health professionals to engage in research, Welsh research was in a positive position. However the long term funding of higher education in Wales, the scope of the AWMSG and cross-border services were cited as challenges.

#### **November 2013**

This meeting saw the Cross-Party Group meet in Carmarthen for a meeting focussing on neuropsychology. The meeting was chaired by Rebecca Evans AM and was the third time the CPG had met outside of the National Assembly (the first time in West Wales). The meeting allowed service users to question professionals and politicians on local services, and allowed the West Wales Neurological Alliance to present their report into neuropsychology services. Approximately 50 people attended from the local area including Health Board managers, professionals and service users. There were presentations from Dr Tanya Edmonds, Lead Consultant Clinical Neuropsychologist, AMBU; Dr Claire Willson - Clinical Lead for Neuropsychology in Cardiff & Vale; and Audrey Rogers, Assistant Director Therapies and Health Science, Hywel Dda Health Board.

Rebecca Evans took forward a variety of issues from the meeting and raised them with the Minister for Health and Social Services and with colleagues on the Health and Social Care Committee.

#### **February 2014**

Between October 2013 and January 2014 the Welsh Government were consulting on the draft Neurological Conditions Delivery Plan and a decision was taken to focus the February meeting on the draft plan.

Shortly after becoming Minister for Health and Social Services, Mark Drakeford AM, promised a plan that would take forward outstanding issues from the neurosciences

review as well as respond to the CPG inquiries into understanding of neurological conditions (2011) and access to neurophysiotherapy (2013). The draft Delivery Plan set out the Welsh Government's expectations of the NHS in Wales to plan, secure and deliver high quality person-centred care for anyone affected by a neurological condition.

The document focused on meeting population need, tackling variation in access to services and reducing inequalities in health outcomes across 6 themes

- Raising awareness of neurological conditions
- Timely diagnosis of neurological conditions
- Fast and effective care
- Living with a neurological condition
- Improving Information
- Targeting research.

Chris Jones (Deputy Chief Medical Officer) and Caroline Lewis were invited to present the Delivery Plan to the Cross-Party Group and take questions on the draft document and implementation plan. The Wales Neurological Alliance welcomed the principle of a Delivery Plan and the broad themes, but outlined concerns including the lack of details and inadequate performance measures.

The Welsh Government gave a commitment to engage with the Wales Neurological Alliance in the months following the meeting and throughout the implementation process. On 08 May 2014 the finalised Neurological Conditions Delivery Plan was published. The performance measurements had been improved, there was now a 7<sup>th</sup> theme (children and young people) and 3 representatives from the Wales Neurological Alliance were invited to sit on the All Wales Implementation Group.

The terms of reference of the Cross-Party Group for Neurological Conditions offers a provision for individual organisations to present on a specific issue or concern:

“A 10 minute slot should be made available at every meeting for an individual organisation to raise an issue or campaign. Members of the Wales Neurological Alliance will be invited to bring forward an issue, and if more than one organisation comes forward, the Chair and Secretary will decide which organisation has the right to speak.”

This meeting was the first time since 2011 that an organisation sought to use this provision, so Paul King, Chief Executive of the Dystonia Society (supported by Christine Chapman AM) gave a presentation on the issues affecting people living with Dystonia.

### **Financial Statement**

All costs are paid for by the Wales Neurological Alliance.

	<b>Accommodation and catering</b>	<b>Expenses</b>
October 2013	£51	£26.50
November 2013	£98	£0
February 2014	£64.62	£0
<b>Totals</b>	<b>£213.62</b>	<b>£26.50</b>
<b>Grand Total</b>	<b>£241.22</b>	