



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Annual Report 2017 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 at least three 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 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 members as of the inaugural meeting of the group in the fifth Assembly are:

Mark Isherwood AM, Welsh Conservatives (Chair)
Dr. Dai Lloyd AM, Plaid Cymru
Vikki Howells AM, Welsh Labour
Lee Walkers AM, Welsh Labour
Huw Irranca-Davies AM, Welsh Labour
Angela Burns AM, Welsh Conservatives
David Rees AM 14, Welsh Labour

Lynne Hughes, MS Society
Ana Palazon, Stroke Association
Dave Maggs, Headway
Barbara Locke, Parkinson's UK
David Murray, Cure Parkinson's
Kevin Thomas, MND Association

Ann Sivapatham, Epilepsy Action
Dafydd Williams, Muscular Dystrophy UK
Carol McCudden, Ataxia UK
Michelle Herbert, The Brain Tumour Charity
Dilwyn Jones, Brain Injury Rehabilitation Trust
Ahmad Butt, British Polio Fellowship

The Neurological Conditions Cross Party Group meetings are open to the public and that invitations are sent to WNA member organisations and others with an interest in neurological conditions.

The current members of the Wales Neurological Alliance are:

- ☐ Ataxia UK
- ☐ Brain Injury Rehabilitation Trust
- ☐ Brain and Spine Foundation
- ☐ British Polio Fellowship
- ☐ Charcot Marie Tooth UK
- ☐ Chartered Society of Physiotherapy
- ☐ Child Brain Injury Trust
- ☐ College of Occupational Therapists
- ☐ Different Strokes
- ☐ Dystonia Society
- ☐ Epilepsy Action Cymru
- ☐ Epilepsy Wales
- ☐ Headway Wales
- ☐ Huntingtons Disease Association
- ☐ Meningitis Now
- ☐ Motor Neurone Disease Association
- ☐ Multiple Sclerosis Society Cymru
- ☐ Muscular Dystrophy UK
- ☐ Myotonic Dystrophy Support Group
- ☐ Neuro Therapy Centre
- ☐ Parkinson's UK
- ☐ Progressive Supra Nuclear Palsy Association
- ☐ Shine Cymru
- ☐ Stroke Association
- ☐ The Brain Tumour Charity
- ☐ The Cure Parkinson's Trust
- ☐ The Neurological Alliance
- ☐ Welsh Association of ME & CFS Support (WAMES)

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

July 2017

The first meeting of the year was held in North Wales at the National Assembly for Wales, North Wales Visitor and Information Centre, with people joining by VC from Cardiff Bay.

The meeting included the Annual Meeting of the Group, whereby the Annual Report was discussed and agreed and Mark Isherwood AM was re-elected as the Chair, and the Wales Neurological Alliance re-elected as the Secretary.

The meeting received a presentation by Claire Nelson, Specialist Planner, Welsh Health Specialised Services Committee on their recent review of neurosciences.

The WNA Member presentation was given by Jane Johnston-Cree on the successful work of the North Wales Neuro Therapy Centre.

September 2017

This meeting included an update on the role of the Wales Neurological Alliance's involvement in the refreshed Neurological Conditions Delivery Plan, which included the facilitation of three stakeholder events with people living with neurological conditions on the draft actions and proposals in the plan. This formed the basis of a report that was submitted to the Neurological Conditions Implementation Group. It was agreed that the Cross Party Group plays an active role in scrutinising how the Welsh Government and Health Boards implement the actions in the plan.

The meeting then focused on revisiting the Neurophysiotherapy Report that the Group had published in 2013. The meeting welcomed Pip Ford MBE, MCSP, Public Affairs and Policy Manager for the Chartered Society of Physiotherapy in Wales

All Health Boards and the Welsh Government have contributed to a review and given information on their progress against the original recommendations. The Chartered Society of Physiotherapists have collated this and produced a full report. 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.

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.
- 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.

The WNA member presentation was received from The Brain Tumour Charity Jonathan Canty, Policy Officer outlined the aims of the Brain Tumour Charity which are to see a world where brain tumours are defeated.

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.

The Dystonia Society also gave an update following correspondence he had received following on from the presentation given by them at the CPG last autumn.

Financial Statement

All costs are paid for by the Wales Neurological Alliance.

	Accommodation and Catering Expenses
Catering	65.10
Total	65.10