



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Annual Report 2016 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

In 2016, the Cross-Party Group met three times, February 2016 in the fourth Assembly term, and June 2016 and October 2016

January 2016

The last meeting of the Cross Party Group in the fourth Assembly term saw Caroline Lewis of the Welsh Government's Major Conditions Policy Team give a presentation on the first Annual Report of the Neurological Conditions Delivery Plan.

In June 2015, the Deputy Minister announced investment in neuro-rehabilitation services investing £1.2 million with three quarters of the funding being provided by the neurological group. The groups also agreed to jointly focus on patient experience to better understand the needs of people investing £40,000 each. The last element of the neurological conditions delivery plan funding, £60,000, was spent on increasing access to specialist neuromuscular care advisors.

In relation to neuro-rehabilitation, nine bids were approved for recurrent funding as follows:

Aneurin Bevan University Health Board for community neuro-rehabilitation service (CNRS) - £206,000

Abertawe Bro Morgannwg University Health Board for Early Supported Neurology Discharge Team (ESD) or a Stratified Community Neurorehabilitation Team (with in-reach) - £152,000

Betsi Cadwaladr University Health Board for support towards establishment of a level 2 neuro-rehabilitation unit in North Wales - £100,000

Cardiff & Vale University Health Board for community neuro-rehabilitation service (CNRS) - £174,000

Cwm Taf University Health Board for a multidisciplinary Community Neurorehab Team - £117,000

Hywel Dda University Health Board for a stratified, integrated community neurostroke rehab - £145,000

Powys teaching Health Board for community rehabilitation - £96,000

Neuro Muscular Network to develop a specialist physiotherapy service for adult patients with neuromuscular (NM) conditions - £60,000

Welsh Health Specialised Services Committee for a paediatric Neuro- Rehabilitation service - £150,000

Health boards indicated they would not be able to use full funding for these services during the 2015/16 financial year. As only part year funding, of £337,000, was issued this year the remaining funding was issued for one-off basis for 2015/16.

Non-recurrent funding has been allocated as follows:

ABMU – equipment to support neuro-rehabilitation - £129,000

ABUHB – IT to support delivery of existing Community Neuro Rehabilitation

Service - £146,000

BCUHB - improve facilities for neuro-rehabilitation and stroke patients at

Llandudno General Hospital - £173,000

CVUHB – Functional Electrical Stimulation equipment to support the management of patients with MS and Stroke - £100,000

CTUHB – support for Multi Disciplinary Community Neuro-rehabilitation Team - £79,000

HDUHB - establishment of an advanced scope, multidisciplinary, peripatetic specialist neurological team - £92,000

PTHB – training and support for existing community rehabilitation and reablement services - £31,000

The Implementation Group has agreed the following priorities for 2016/17:

Developing a co-productive approach to increasing awareness of neurological conditions

Delivering clear consistent patient information

Delivering access to neurology services, for patients of all ages, consistently throughout Wales

Developing consistent and coherent neuro-rehabilitation services, for patients of all ages

Developing and responding to patient experience and outcome measures

All LHB's have produced annual reports which should be available on their individual websites.

The Annual Report had showed some progress including decreased death rate, decreased waiting times, and decreased length of stays in hospital plus research into quality of life indicators for people with neurological conditions. There had been a significant increase in funding for neurological conditions in Wales.

The Welsh Government's delivery plan is to be extended to 2020, from 2017.

June 2016

This was the inaugural meeting of the Cross Party Group in the fifth Assembly term.

A background to the role and function of the Cross Party Group was given to new members and a summary of its achievements during the period that the Fourth Assembly was given; including

- Inquiries into Neurological Conditions (2011) and Access to Neuro-physiotherapy (2013), which contributed to the previous Welsh Government's commitment to produce a Neurological Conditions Delivery Plan.
- Responding to the draft Neurological Conditions Delivery Plan, the WNA now having three representatives on the Neurological Conditions Implementation Group.

The Government had also promised that the Neurological Conditions Delivery Plan will be refreshed in 2017 so the CPG will have a key role to play to ensure that the voice of people affected by neurological conditions is included in this process.

There then followed the election of the Fifth Assembly Neurological Conditions Cross Party Group chair and secretary.

Mark Isherwood AM, was voted in as CPG chair, proposed by Ana Palazon, seconded by David Murray

Megan Evans, WNA Coordinator was voted in as CPG secretary, proposed by Dilwyn Jones and seconded by Lynne Hughes.

The opportunity was then given for Assembly Members to meet with members of the WNA.

October 2016

At the meeting we heard from Alison Shakeshaft, Director of Therapies and Health Science, ABUHB & Interim Chair of the NCIG who presented on the Role of the NCIG, progress to date, successes & challenges and refreshing the Welsh Government's Neurological Conditions Delivery Plan.

The group also discussed its Forward Work Programme or CPG and agreed that we should revisit previous reviews and check on progress against recommendations of previous inquiries, broadening out the review of care within emergency units to care within acute settings.

It was agreed that the Cross Party Group should also carry out a survey (or similar) of people living with neurological conditions about their experiences off the Social Services and Wellbeing (Wales) Act.

Given their central role in supporting people with neurological conditions it was agreed that we should review the neurological workforce particularly Specialist Nursing Provision in Wales.

The group also heard from Nina Bergonzi from the Dystonia Society South Wales Support Group who gave us a very comprehensive presentation on how living with Dystonia has affected her life and that of her family particularly in relation to the lack of specialised services within Wales to treat her condition.

Financial Statement

All costs are paid for by the Wales Neurological Alliance.

	Accommodation and Catering Expenses
February 2016	£66.00
June 2016	£80.58
September 2015	£97.74
Total	£244.32