



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Annual Report 2018 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, Parkinson's UK
Dave Maggs, Headway
David Murray, Cure Parkinson's
Kevin Thomas/Emily Wooster, MND Association

Ann Sivapatham, Epilepsy Action
Carol McCudden, Ataxia UK
John Meredith, Dystonia Society
Kate Steele, Shine

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:

- ☐ Brain Injury Rehabilitation Trust
- ☐ British Polio Fellowship
- ☐ 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
- ☐ Motor Neurone Disease Association
- ☐ Multiple Sclerosis Society Cymru
- ☐ Muscular Dystrophy UK
- ☐ Neuro Therapy Centre
- ☐ Parkinson's UK
- ☐ 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

March 2018

A meeting was planned for 20th March 2018 to discuss working in partnership with Pharmaceutical Industry in improving neurological services in Wales, unfortunately the speakers had to pull out of the meeting with little notice so the meeting was cancelled.

July 2018

This was a special meeting of the Cross Party Group which invited people living with neurological conditions across Wales to discuss their experiences.

The Welsh Government's Neurological Delivery Plan says that all staff involved in managing care for people with neurological conditions should have an appropriate understanding of the condition and its impact on the individual and their family.

These basic principles are needed to make sure that people with neurological conditions have confidence their condition is understood by which ever health or social care service they access.

Participants were asked to consider the following key questions.

Q1. Share your experiences where your neurological condition was well/ poorly understood and the difference that made to your care?

Q2. Which professionals do you think need to be our priority?

Q3 What are the key things that they need to understand about your neurological condition/ or neurological conditions generally?

Q4. What do you think are the best methods for raising awareness?

A summary of the responses was be produced and will be used to inform the next stages of the Wales Neurological Alliance Raising Awareness project.

The meeting also heard from the Cabinet Secretary for Health and Social Services about the Welsh Government's commitment to raising awareness of neurological conditions.

December 2018

The Cross Party Group received the Annual report 2017 which had been delayed in coming to a meeting due to the cancelled meeting in March and the special meeting in July. The report was accepted unanimously.

Mark Isherwood AM was elected as Chair for a further term, and Diane Gleeson, in her role as WNA Co-ordinator was nominated as Secretary. Both accepted for a further term.

The meeting then received a report on the Social Services and Wellbeing Wales Act and the experiences of people living with a neurological condition survey

In summary a total of 415 people living with a neurological condition responded: MS – 25.74%, Parkinson's – 23.28%, Dystonia – 16.19%, Epilepsy – 5.39%, MND – 3.68%, Acquired brain injury – 2.94%, Ataxia – 2.94%, Other – 19.85%.

22% of respondents had been diagnosed for more than five years and 49% for more than ten years.

56% of respondents were aged 36-64, 30% were aged 65 or older, 9% 18-35 and 4% 0-17.

73% of respondents had not been offered or requested a formal assessment indicating that people's rights to a formal assessment are not being promoted, or that people are not aware of their rights.

80% of respondents did not receive any services from a local council as a result of a care plan, indicating that a care plan does not necessarily lead to social care support.

64% of respondents did not see any information that would help them with a social care or support need and only 37% were given advice from a professional that would help with a social care need.

46% of respondents have paid out of their own money for additional support which is completely unacceptable when they should receive this from statutory services.

An open discussion followed with various other examples given of people living with neurological conditions having very little knowledge of the Act. A general consensus from the meeting was that people living with a neurological condition in Wales are being failed by the Act and are missing out on vital support and services.

Professor Anne Rosser gave the WNA Member Presentation on the South Wales Huntington's Disease Service and asked the CPG for help taking the recommendations forward.

Financial Statement

All costs are paid for by the Wales Neurological Alliance.

| | Accommodation and Catering Expenses |
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| Catering 2018 | £59.40 |
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| Total | £59.40 |