



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

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

**Tuesday 16<sup>th</sup> September 2014**

**Committee Room 4, Tŷ Hywel, National Assembly for Wales**

**Present**

**Cardiff**

Mark Isherwood AM (Chair)  
Keith Davies AM  
David Rees AM  
Joseph Carter, Wales Neurological Alliance (WNA) and MS Society  
Chris Dawson, Welsh Government  
Pip Ford, Chartered Society of Physiotherapy  
Caroline Lewis, Welsh Government  
Barbara Locke, WNA and Parkinson's UK  
Dave Maggs, WNA and Headway UK (Wales)  
John Meredith, Dystonia Society  
Lesley Morris, Epilepsy Wales  
Robin Moulster, BASW Cymru  
Helen Owen, MS Specialist Nurse  
Ana Palazon, WNA and Stroke Association  
Cath Taffurfill, BASW Cymru  
Alan Thomas, WNA and Ataxia South Wales  
Steve Walford, Ataxia South Wales  
Margaret Ware, Myotonic Dystrophy Support Group  
Rachel Williams, Parkinson's UK

**Wrexham link**

Urtha Felda, WNA, MS Society Cymru and  
WNA rep on the North Wales Neurosciences Network  
Annette Morris, Director of the North Wales Neurosciences Network,  
Betsi Cadwaladr University Health Board  
Kevin Thomas, Vice Chair WNA and MNDA.  
Catriona Fearn, MS OT Specialist BCUHB.  
Leigh Campbell Neuro Physio Specialist BCUHB.  
Karen Shepherd Patient NNB Member.  
Carol Davies, BASW.

**Apologies** David Murray Cure Parkinsons Trust, Carol Smith Motor Neurone Disease Association. Mohammed Asghar AM, Janet-Finch Saunders AM, Gayle Pearson NVP, Huw Dylan Owen Carmarthenshire LA, Clive Harffy CMTUK, Vincenzo Straccio CNS.

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

Accuracy – Dave Maggs to be added to list of attendees.  
Correct spelling of Shine Cymru noted.

Minutes recorded as true and accurate account of the meeting.

### **Election of chair and secretary**

At each AGM the Chair and Secretariat of the Cross Party Group is elected.

Current Chair, Mark Isherwood AM, nominated by Rachel Williams, Parkinson's UK. Nomination seconded by Ann Sivapatham.

Current Secretary, Urtha Feldman, nominated by Mark Isherwood AM. Nomination seconded by Alan Thomas.

Ana Palazon confirmed the re-election of Mark Isherwood AM as Chair and Urtha Feldman as Secretary of the Cross Party Group on Neurological Conditions.

### **Presentation of the annual report**

Joseph Carter presented the Cross Party Group on Neurological Conditions Annual Report and Financial Statement. The report contains details of the aims and membership of the group, a brief synopsis of meetings held/ activities undertaken and a statement of the group's finances for 2013/14.

Joseph Carter moved the report and it was seconded by Dave Maggs.

### **Implementing the Delivery Plan**

- Welsh Government:

Caroline Lewis and Chris Dawson of Welsh Government broadly outlined the purpose of the Neurological Conditions Delivery plan, and delivery plans generally, as having a greater focus on actions and aligning plans to performance measures.

Chris remarked that the group could not underestimate the impact it has had in shaping the plan. Transparency in delivering against the plan will be crucial and annual reports will be published at a local health board level. There is also a role for everyone in the scrutiny of the plan.

The comments received via the consultation on the draft plan were taken on board and amendments made where appropriate. For example, a chapter of the plan

specific to children and young people with neurological conditions has now been included.

Following WNA feedback, an 'easy read' summary version of the plan has been circulated for feedback and will be published in due course.

The major conditions area of the Welsh Government website will be developed to include the suite of delivery plans. It is likely that the Neurological Conditions Delivery Plan will be first to be placed on the website and it's possible that the site will include a combination of videos, documents and audios. It was asked if there could be 'quick links' to each of the LHB plans.

The deadline for submission of draft LHB delivery plans is the end of October 2014. At November's meeting of the Neurological Conditions Delivery Plan Implementation Group a peer review of the plans will be undertaken. The deadline for final plans to be submitted to Welsh Government is the end of January 2015.

The Implementation Group is chaired by Professor Matthew Makin, Executive Medical Director at Betsi Cadwaladr University Health Board. There are three WNA representatives on the Implementation Group.

At the first meeting of the Implementation Group four priority areas were agreed for inclusion in each LHB plan as follows:

- Raising awareness with the public and professionals;
- Population needs assessment and prediction;
- Clear information for patients and families;
- Consistent neuro-rehabilitation services.

The Implementation Group will retain oversight of the LHB delivery plans and progress against the four priorities. A task and finish group will be established to look at outcome measures for the first year. The first annual reports on the delivery plans will be due in June 2015.

- **Wales Neurological Alliance:**

Barbara Locke; one of the three WNA representatives on the Implementation Group; gave an outline of the inaugural meeting of the group which took place in August.

Barbara reported it as a positive experience with all Local Health Boards, Welsh Health Specialised Services Committee (WHSSC) and the Welsh Ambulance Service NHS Trust around the table with a common focus on neurology. Barbara described the first meeting as open, honest and bold and was pleased to be able to represent the third sector at the same table as LHBs bringing an added dimension to the discussions.

- **Annette Morris, Betsi Cadwaladr University Health Board:**

Annette presented to the group about the North Wales Neurosciences Network, including its aims and structure, as well as some of the challenges facing the network.

The Network's Board constitutes statutory and non-statutory bodies which, by working collaboratively, are able to commission high quality services, making the best use of resources in North Wales. Annette is Director of the Network and Professor Makin is Chair of the Network.

There are a number of clinical and non-clinical Disease Specific Advisory Groups (DSAGs) which work to prioritise and plan for specific areas and drive up skills and knowledge. The terms of reference of these groups reflect those of the Neurosciences Network Board.

The Academic/ Information Group links clinical practice to research into neurological conditions. It is a multi-stakeholder group and drives key areas of the health agenda such as self-management and the 'dignity and respect' agenda. The group has held successful study days around MS and MND.

A network service user forum is currently being established and is linked to local alliances. A rehabilitation board to look specifically at neuro rehabilitation services has also been established.

Annette reported that the network is integrated across borders, organisations, local authorities and cuts across all of the Health Board's clinical programme structure. The success of the network is attributable to the fact it is clinically led.

Annette mentioned that the challenges of delivering against the Neurological Conditions Delivery Plan should not be underestimated. For instance the initial focus was on adults but now the plan also encompasses services for children and young people where a paediatric clinical lead will be required.

Annette also described the challenge of continuous engagement with service users and carers throughout the life of the plan, particularly as the plan cuts across such a wide range of neurological conditions.

Understanding patient pathways across multi-disciplinary teams is also a challenge but it is important to understand the role and input of all professionals and the resource implications despite the complexities of doing so.

- Dr Jenny Thomas was unable to attend as scheduled so this part of the item did not go ahead.

- Discussion and debate:

Ana Palazon asked if there would be a formal consultation regarding the outcome measures for the delivery plan?

Caroline replied that there would not be a formal consultation but the process would be informal and involving via organisations around the table.

Ana asked about the relationship between the Neurological Conditions Delivery Plan and other plans such as the Stroke Delivery Plan and the Implementation Plan for Rare Diseases.

Chris responded that responsibility for all of the plans sits under the same area and there will be a need for them to link up following the introduction of the 3 year plans under the NHS Finance (Wales) Act 2014.

He agreed that there is commonality across some plans and also links to the Social Services and Well-being (Wales) Act, including population and outcome planning. Local Service Boards will need to look across the broad spectrum of local level planning and ensure join up where necessary.

Keith Davies AM pointed to the reshuffled Cabinet responsibilities and the fact that the Minister for Health is now the Minister for Health and Social Services as a factor in the integration of services.

Keith Davies AM queried the current situation with the 3 year financial plans noting that the Hywel Dda LHB plan had not been accepted. Chris indicated he would find out if required.

It was agreed that the group would write to the Minister for Health and Social Services regarding the situation with the 3 year financial plans.

Keith Davies AM mentioned that, in Hywel Dda, some services are provided for by ABMU LHB and there is a need to plan for this.

Caroline indicated that it has been acknowledged that there is a need for effective planning across borders at the local level and the peer review process for the Neurological Conditions Delivery Plans should check for the inclusion of this.

Alan Thomas queried whether it would be possible to hold an event to track progress against the delivery plan. John Meredith agreed this would be a good idea so that people can share experiences.

Caroline stated that it may be possible to hold such an event in order to gather people's experiences, particularly in the absence of other baseline information, for the work on outcome measures.

Chris indicated that the intention is not just to produce annual reports illustrating progress against the plan every year but for there to be ongoing challenge of progress at all stages.

Pip Ford raised the issue of what is the best way for the Cross Party Group to look at and scrutinise the LHB delivery plans and suggested it may be pertinent to invite LHB representatives involved in delivering the plans to provide updates to future meetings as a part of this scrutiny process.

Mark Isherwood AM suggested the WNA should consider if more meetings are needed in order for patients to share their experiences and asked how Welsh Government can ensure service user input.

Caroline agreed there is a reliance on the input of individual groups such as those around the table and there is recognition of the need to look at other means of engagement.

Mark Isherwood AM asked Annette about progress on engagement with groups in North Wales that he had previously been made aware of.

Annette responded that service users were now a part of the network.

Joseph asked if Welsh Government will be reviewing the engagement processes undertaken in developing the local plans as a part of the peer review.

Caroline indicated that this could be included within the peer review which will be undertaken by the lead for each LHB in conjunction with a small number of others e.g. from local alliances/ stakeholders. The WNA representatives will also have an input into the reviews.

### **Closing remarks**

Mark Isherwood AM thanked everyone for their attendance and input and also thanked Kevin Thomas for his MND Ice Bucket nomination!

### **Dates of future meetings:**

The date of the next meeting is Friday 14 November at 2pm at the Oriel Hotel, Upper Denbigh Rd, St Asaph, Denbighshire, LL17 0LW at 2pm. Refreshments will be served from 1.30pm

Meeting dates for 2015 will be circulated at a later date.