



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

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

**Tuesday 9<sup>th</sup> June 2015**

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

**Via VC to Wrexham Maelor Hospital**

**Present**

**Cardiff**

Mark Isherwood AM (Chair)  
Pip Ford, Chartered Society of Physiotherapy  
Lynne Hughes, MS Society Cymru  
Ana Palazon, Stroke Association  
David Murray, Cure Parkinson's Trust  
Rachel Williams, Parkinson's UK  
Megan Evans, WNA Coordinator  
Ann Sivapatham, Epilepsy Action Cymru  
David Maggs, Headway  
Fiona Jenkins, Cardiff & Vale UHB  
Harry Prankard, Parkinson's UK  
Sylvia Prankard, Parkinson's UK  
Jennifer Thomas, Cardiff & Vale UHB  
Kate Skone, Cardiff & Vale UHB  
Kate Steele, SHINE Cymru  
Michelle Herbert, The Brain Tumour Charity  
Miriam Wood, MESIG ME Support  
Jayne Crocker, SHINE Cymru  
Ceri Dunstan, Stroke Association  
Andrea Richards, Cardiff & Vale UHB  
Ian Langfield, WHSSC  
Steve Walford, Ataxia Patients in Wales  
Jean Francis, Ataxia Patients in Wales

**Wrexham link**

Annette Morris, Director of the North Wales Neurosciences Network,  
Betsi Cadwaladr University Health Board  
Urtha Felda, MS Society Cymru

**Apologies** Barbara Locke, Parkinson's UK  
Janet Finch Saunders AM  
Marcus Longley, Cardiff & Vale UHB  
Maria Battle, Cardiff and Vale UHB  
Ruth Crowder, Wales College of Occupation Therapists  
Matthew Makin Betsi Cadwaladr UHB  
Jane Stein, PSP Association  
Carol Smith, MNDA  
Carol McCuddon, Ataxia UK  
Simon Thomas AM  
Kelly Bevan, Child Brain Injury Trust  
Raja Ahmed, Royal College of Psychiatrists  
Linos Wyn Parry, Stroke Association  
Ted Hill, British Polio Society

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

Accuracy – to include Karen Shepherd, Annette and Carol Smith on list of attendees.

Minutes of the meetings held on 24<sup>th</sup> March 2015 recorded as true and accurate account.

Urtha Feldman asked about progress against actions from previous meeting. These are underway.

### **Access to wheelchairs – 2012-2015 – what has changed?**

Kate Steele who sits on the Posture and Mobility Board introduced the item.

### **Service User Perspective**

In Spring 2012 the Health and Social Care Committee held a one day inquiry into wheelchair services. It acknowledged that progress had been made since 2010 – especially from internal management and performance management perspective but this had not necessarily translated into service improvements for current/ future users.

Jayne Crocker, a SHINE Cymru service user gave her perspective of the service she has received and described problems with maintenance of chairs as well as issues with replacement of broken or worn parts.

Harry who is a wheelchair user due to Parkinson's and his wife Sylvia Prankard, described similar problems experienced in North Wales.

### **The Posture and Mobility Partnership Board**

Ian acknowledged the issues experienced by Harry and Sylvia and said that these could be dealt with.

Ian described the structure and purpose of the Posture and Mobility Board is to look at performance and quality of service provision and advise on commissioning strategy. The terms of reference for the Board are approved by all seven Health Boards. The Board struggles to get representation from local authorities and service users.

There is a technical working group and a stakeholder working group for this carefully monitored services to ensure proper use of Welsh Government guidelines. The stakeholder group includes service user voices from across Wales and is chaired by Kate. A plain English waiting times document is being developed with the stakeholder working group.

### **Service Provider Perspective**

Dr Jenny Thomas described the referral process into wheelchair services takes and indicated that there are approximately 200 referrals per week from skilled multidisciplinary teams.

In terms of performance, there has been a 31% increase in the number of powered wheelchairs issued in the last year. 90% of standard wheelchair issues are within 21 days. There have been dips in service provision due to sickness and vacancies although paediatric targets have continued to be met. Rachel Williams asked about succession planning in light of the dips in provision, this is being looked at.

### **Questions and debate**

There was general discussion around the issues highlighted by the presenting service users and a number of key points were raised:

- British Red Cross lending wheelchairs to ALAS cannot provide them – Ian Langfield to look into.
- David Murray – it is important that local authorities engage if joint working is to be effective. Ian Langfield welcomed and work the group could do in this respect.
- Ana Palazon – there is not enough stakeholder representation on the group, suggested deformalizing engagement process so it has a more flexible approach for people to participate and share their views.
- Ana Palazon – queried the use of the complaints process as a means of monitoring good/ bad service pointing out that people will not always complain.
- Pip Ford – detailed a number of issues about the service raised by paediatric physios including concerns over a lack of regular review.

### **Closing remarks**

The Group agreed a number of actions to be taken forward from the meeting as follows:

- Write to the Minister for Health and Social Services to ask:

- (a) How Welsh Government are monitoring progress against recommendations from previous inquiries into wheelchair services in Wales since 2012;
  - (b) What measures are being taken to ensure that local authorities take on board are fully engaged as active partners in posture and mobility services.
- Write to local authority chairs of Health and Social Care Scrutiny Committees to ask what measures are taken locally to ensure social services departments are fully engaged as active partners in posture and mobility services. Copy to Social Services Directors in all local authorities.
  - Consider how the WNA can engage with a wider stakeholder group to feed in service user views to the Posture and Mobility Board Stakeholder sub group.

**Dates of future meetings:**

The dates of the next meeting is 22 September 2015 at 6.30pm in Committee Room 4, Senedd, Cardiff Bay. There will be a VC link to Wrexham Maelor Hospital.