

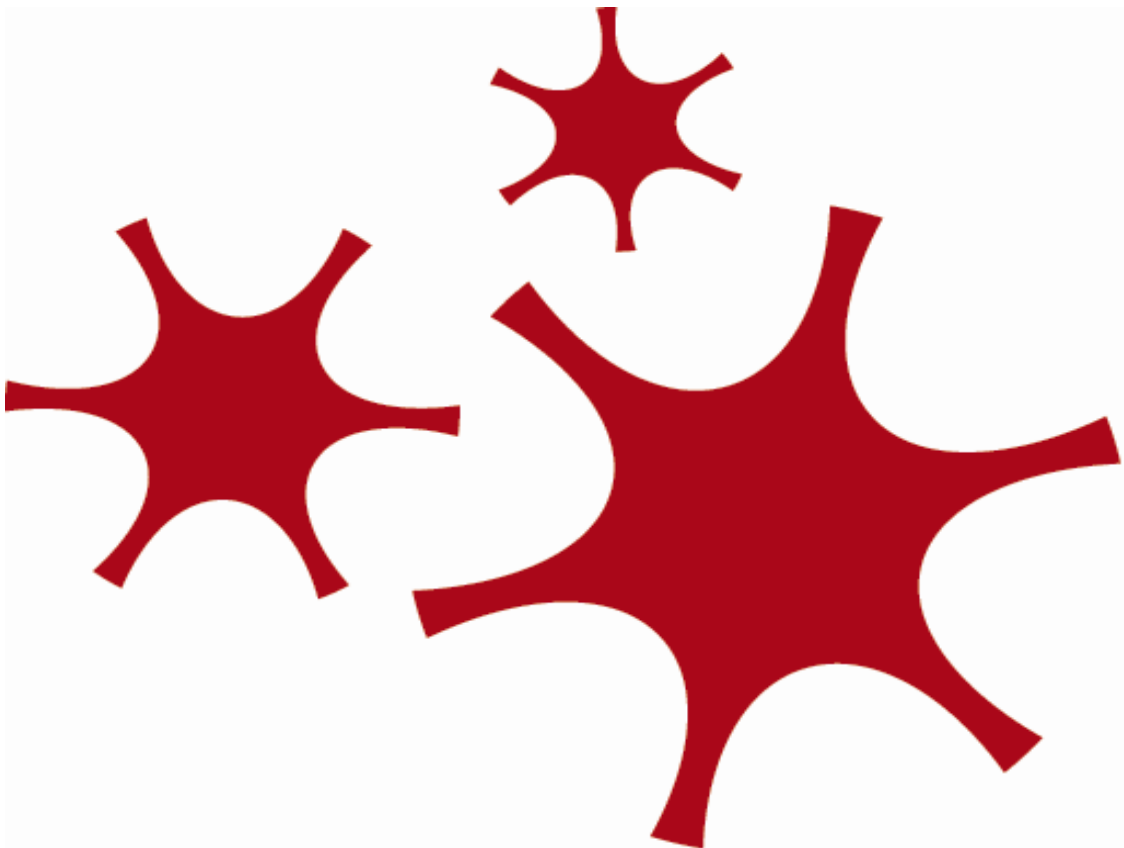


Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

# **Adroddiad Blynyddol**

**2008**

**Annual Report**



## Cynghrair Niwrolegol Cymru – The Wales Neurological Alliance - 2008

### Aelodau / Members

Alzheimer's Society  
Association of Spina Bifida and Hydrocephalus (ASBAH)  
Cerebra  
Charcot-Marie-Tooth United Kingdom (CMT UK)  
Chartered Society of Physiotherapy  
Child Brain Injury Trust UK  
College of Occupational Therapists  
Dystonia Society  
Epilepsy Action  
Epilepsy Wales  
Genetic Interest Group (GIG)  
Guillain-Barré Syndrome Support Group  
Headway  
Huntington's Disease Association  
Motor Neurone Disease Association (MNDAssoc)  
Muscular Dystrophy Campaign  
Myasthenia Gravis Association  
Myotonic Dystrophy Support Group  
Multiple Sclerosis Society Cymru (MSSoc)  
Parkinson's Disease Society (PDS)  
Progressive Supranuclear Palsy Society  
Stroke Association  
Tourette's Syndrome Association  
Tuberous Sclerosis Association  
Welsh Association of ME & CFS Support



### Pwyllgor Gwaith / Executive Committee

Cyd-ddirprwy gadair / Co-Vice chair:  
Cyd-ddirprwy gadair / Co-Vice chair:  
Trysorydd mygedol / Honorary Treasurer:  
Ysgrifennydd mygedol / Honorary Secretary:  
Alodau'r pwyllgor / Committee Members:

Elin Ifan (ASBAH)  
Carol Thomas-Wyllie (MNDAssoc)  
Don Read (CMT UK)  
Buddug Williams (GIG)  
Simon Hatch (PDS)  
Margaret Read MBE (CMT UK)  
Judi Rhys (MSSoc)  
Carol Smith (PDS)  
Kevin Thomas (MNDAssoc)

### Cyd-lynydd Rhan Amser / Part-time Co-ordinator

Phil Davies

### Manylion Cyswllt / Contact Details

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### Rhagair

gan yr Athro Y Barwnes Ilori Finlay o Landaf

Dylai'r flwyddyn nesaf ddod a gwelliannau pwysig i gleifion â chyflyrau niwrolegol. Mae strategaeth gofal llinariol i Gymru eisoes yn cael ei weithredu drwy Fwrdd Gweithredol sy'n atebol i'r Gweinidog Iechyd a Gwasanaethau Cymdeithasol. Bydd llawer o'r pynciau allweddol o fudd i gleifion sydd â chyflyrau niwrolegol datblygiedig. Mae'n flaenoriaeth i'r Bwrdd fod dosbarthiad têt o ofal llinariol arbenigol ar gael ar hyd a lled Cymru, ynghlwm a'r cydnabyddiaeth fod yn rhaid i gleifion allu derbyn arbenigedd pryd bynnag maent yn wael, ac, o'r herwydd, rhaid i wasanaethau fod ar gael 7 diwrnod yr wythnos.

Dylai'r gwasanaethau rhain helpu i osgoi mynediad di-angen i'r ysbyty. Mae cleifion angen derbyn offer ac addasiadau tai sydd yn amserol, ac o'r herwydd, mae'r Gweinidog wedi cynyddu gwasanaethau physiotherapi a therapi galwedigaethol gofal llinariol. Dros y flwyddyn a ddaw bydd angen i nyrsus arbenigol niwroleg, a nyrsus arebenigol gofal llinariol, gydweithio yn agos, ynghyd a thimau meddygol, i sicrhau y rhannir arbenigedd.

Mae'r Bwrdd Gweithredol wedi buddsoddi mewn rhaglen o addysg i sicrhau fod gan weithiwy'r cymunedol, a'r rhai mewn ysbytai, gyda'r sgiliau addas i ddarparu gofal diwedd-bywyd da i rai â afiechyd datblygiedig. Mae hefyd yn hanfodol bwysig i'r rhai sydd yn yr amser cynnar o'i afiechyd wybod y bydd gofal ar gael pan fo'r angen, ac y bydd wedi ei ddarparu mewn ffordd sydd yn galluogi, yn cynnal urddas, a hyrwyddo annibyniaeth y claf.

Fel y dywedodd Cicely Saunders, sylfaenydd y Symudaid Hosbis: "Rydych o bwys oherwydd eich bod yn chi". Dyna beth ddylai danseilio athroniaeth pawb sydd yn cynnig gofal, fel bod y dyfodol heb ei orbwyso gan ofn, a fod bob claf yn hyderus ei clywir, a chânt ei trin â pharch a charedigrwydd, ac y bydd staff yn mynd y filltir ychwanegol er mwyn cyfarfod eu anghenion.

### Chwefror 2009

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## Adroddad y Pwyllgor Gweithredol

Bu 2008 yn flwyddyn brysur a chynyrchiol iawn i Gynghrair Niwrolegol Cymru. Parhaodd nifer yr aelodaeth i dyfu, ac ymledwyd ein rhwydweithiau drwy gynyddiad yn ein partneriaethau â chynghreiriau lleol o gwmpas Cymru, a thrwy ffurfio perthynasau cryf gyda amryw o rwpiâu a chyrrff proffesiynol.

Yn y deuddeng mis diwethaf, cyfranodd y Gynghrair i amryw o ardaloedd polisi yn ymwneud â chyflyrau niwrolegol, ac i wasanaethau niwrowyddonol. Parhawyd i weithio'n galed i sicrhau fod safbwynt y clâf a'r teulu yn ganolbwynt ein gwaith - drwy wrando, a chysylltu â'n aelodau a chynghreiriau lleol, i sicrhau ein bod yn rhoi llais i bryderon a barn y rhai rydym yn gweithio i gynorthwyo.

Mae'r Pwyllgor Gweithredol yn awr yn cwrdd yn rheolaidd bob chwech i wyth wythnos – adlewyrchiad o maint y gwaith yr ymgwymerwyd â, a hefyd ymrwymiad yr aelodau i gydweithio yn agos. Eleni, rydym wedi datblygu systemau i sicrhau ein bod yn parhau i gyfathrebu gyda'n aelodau – cyhoeddir newyddlen yn rheolaidd sy'n disgrifio datblygiadau diweddaraf ein gwaith, ac, erbyn hyn, rydym â phresenoldeb ar y rhwydwaith byd eang!

Sefydlwyd y Cynghrair i ddilyn a gwella safonau gofal i blant ac oedolion â chyflyrau niwrolegol. Drwy ein aelodaeth galluogir ni, gyda'n cryfder unedig, i symud ymlaen gyda'n gilydd. Hoffem ddiolch i bawb am eu cefnogaeth dros y flwyddyn a fu. Nid yw'n bosibl enwi neb, ond heb eich cymorth ariannol, oriau o wirfoddoli, doethineb a chynghor, ni fuasem wedi medru cyflawni cymaint. Mae digon o sialensau o'n blaen yn 2009, ac mae llawer i'w gyflawni, ond edrychwn ymlaen i gydio ati gyda'n gilydd.

## Chwefror 2009

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**Phil Davies, Aelod cychwynnol a Chadeirydd cyntaf y Gynghrair 2002 – 2006, Cyd-drefnydd rhan-amser 2007 – 2008**

Collodd y Gynghrair gyfaill annwyl a gwerthfawr drwy farwolaeth sydyn Phil Davies ym mis Tachwedd. Roedd Phil yn ran allweddol o ffurfio'r Gynghrair, ac ef oedd y Cadeirydd cyntaf. Drwy ei waith caled, yn cyd-weithio gydag eraill, sefydlwyd y Gynghrair i fod yn lais credadwy ar faterion yn ymwneud a gwasanaethau iechyd niwrolegol.

Yn dilyn ei ymddeoliad o Gymdeithas Alzheimer's, bu Phil yn Gyd-drefnydd rhan amser i'r Gynghrair, a, drwy ei brofiad a'i gyngor, galluogodd y Gynghrair i fynegi ei barn a safle, yn ogystal a'i datblygu ymhellach i sefydlu ei unrhywiaeth, ac enw da.

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## CYFLWYNIAD

Parha Cynghrair Niwrolegol Cymru i leisio anghenion rhai â chyflyrau niwrolegol sy'n byw yng Nghymru. Heddiw, cynnwys yr aelodaeth 25 o elusennau gwirfoddol a grwpiau broffesiynol iechyd, ac mae partneriaethau cryf yn bodoli gyda gynghreiriau lleol ledled Cymru. Yn 2008, ei seithfed flywddyn ers ei sefydliad, gwelir y Cynghrair yn parhau i gynnal barn y dros 100,000 o bobl a'u teuluoedd sydd wedi ei effeithio â chyflyrau niwrolegol. Parha yr angen i fuddsoddi a datblygu gwasanaethau niwrolegol iechyd, a dilyna y Cynghrair y nod hwn drwy ei gwaith.

### Amcanion

Amcanion Cynghrair Niwrolegol Cymru yw i:

- Godi ymwybyddiaeth o gyflyrau niwrolegol a'u heffaith ar unigolion a chymdeithas.
- Gynorthwyo a dylanwadu ar wneuthurwyr polisi yng Nghymru gogyfer ag anghenion pobl sydd â chyflyrau niwrolegol.
- Sicrhau gwasanaethau a gofal amgenach i bobl sy'n byw yng Nghymru â chyflyrau niwrolegol.
- Hyrwyddo lledaenu gwybodaeth am gyflyrau niwrolegol.
- Gefnogi a hyrwyddo gwaith ymchwil priodol.

### Nodau

Nodau Cynghrair Niwrolegol Cymru yw i:

- Sicrhau fod gan bobl fynediad llawer gwell i wasanaethau diagnostig arbenigol.
- Sicrhau fod yna fynediad o ansawdd da i driniaeth, cefnogaeth, gofal ac adferiad lleol.
- Wella argaeledd gwybodaeth, cyngor a gwasanaethau ar lefel lleol
- Hyrwyddo'r ymarfer o gasglu data clir ar gyffredinolrwydd cyflyrau niwrolegol
- Cefnogi datblygiad archwiliadau a gwaith ymchwil



Wales Neurological Alliance meeting in 2008

### Gwefan

Mae'r Cynghrair nawr ar y We gyda'i enw tiriogaeth ei hunan:

**[www.cynghrairniwrolegolcymru.org.uk](http://www.cynghrairniwrolegolcymru.org.uk)** a **[www.walesneurologicalalliance.org.uk](http://www.walesneurologicalalliance.org.uk)**

Yn bresennol, Cyngor Gweithredu Gwirfoddol Cymru, drwy ei rhaglen 'Codi Pontydd Cadarn' ,sydd yn dal tudalennau'r wefan ar ein rhan. Yno y gwelir ein gwybodaeth allweddol, manylion cyswllt, a chyhoeddiadau. Y nod yw adeiladu a datblygu safle unigryw ein hunain i roi gwybodaeth perthnasol i aelodau, cyngrheiriau lleol ac i unigolion, teuluoedd a gofalwyr ledled Cymru.

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## CYRHAEDDIADAU 2008

### Grwp Adolygiad Niwrowyddonol Cymru

Ym mis Medi 2008, cyhoeddwyd Adolygiad o Wasanaethau Niwrowyddonol (Adolygiad James Steers) mewn tri rhan – un ar Ogledd Cymru, un ar Dde a Chanolbarth Cymru, ac un ar Gymru gyfan. Cyfrannodd y Cynghrair wybodaeth i'r Adolygiad yn ystod 2007.

Mae gan y Gynghrair gynrycholiad ar Grwp Gweithredol Niwrowyddonol Gogledd Cymru, ac hefyd ar amryw o'r grwpiau gwaith perthnasol. Casglwyd barn anghenion bobl yng Ngogledd Cymru mewn adroddiad gan y Cynghrair, a bydd hwn yn allweddol i gyflwyno ein barn fel y gwneir benderfyniadau ar ddatblygiadau gwasaneth niwrowyddonol yng Ngogledd Cymru. Mae'r adroddiad ar gael i'w lawrlwytho o safle we y Gynghrair.

Bydd Grwp Gweithredol y De a'r Canolbarth yn cyfarfod yn 2009, ac mae'r Cynghrair eisoes mewn cyswllt â'r Cadeirydd, ac yn awyddus i sicrhau cynrycholiad drwy ystod y gwaith.

### Adolygiad Commisiwn Iechyd Cymru

Cyhoeddwyd Adolygiad o waith yr uchod eleni hefyd. Rhoddwyd dystiolaeth gan y Cynghrair ac amryw o'u aleodau i'r adolygwyr yn 2007. Dros yr Haf 2008, rhoddodd y Gynghrair ymateb i'r Grwp Gweithredol ar ddulliau apelio. Yn benodol, pwysleisiodd y Gynghrair y pwysigrwydd o eglurder ac atebolrwydd pan mae'r Comisiwn yn gwneud penderfyniadau ar reolaeth a gofal unigolion.

### Cynghreiriau Niwrolegol Lleol

Bodolir amryw o Gyngreiriau Lleol ar draws Cymru erbyn hyn. Maent yn tynnu gwybodaeth arbenigol o'u cymunedau, a ymfalchia y Gynghrair i weithio mewn partneriaeth â hwy oll i sicrhau fod llais cyd-gysylltiedig clir ar anghenion cleifion, er mwyn gwella gwasanaethau iechyd dros Gymru.

Cynghreiriau lleol mewn bodolaeth hyd yma yw: **Cynghrair Sir Drefaldwyn o Rwpiau a Chymdeithasau Niwrolegol**. **Cynghrair Niwrolegol Wrecsam**, **Cynghrair Niwrolegol Conwy a Dinbych**. **Cynghrair Cyflyrau Tymor Hîr a Chyflyrau Cronig De Gwynedd** a **Cynghrair Cyflyrau Tymor Hîr a Chyflyrau Cronig Ynys Môn a Gogledd Gwynedd**.

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**Diwrnodau Trafodaeth a Diwrnod Astudiaeth Broffesiynol  
- mewn partneriaeth â Chanolfan Walton ar gyfer Niwroleg a Niwrollawdriniaeth  
Ymddiriedolaeth GIG, Lerpwl.**

Parhaodd ein perthynas cryf a llesol â Chanolfan y Walton, Lerpwl drwy gydol 2008 drwy gyd-drefnu tri digwyddiad – dau ddiwrnod trafodaeth Niwroleg, ac un diwrnod Astudiaeth Broffesiynol

Targedwyd y Diwrnodau Trafodaeth ar gyfer bobl gyda chyflwr niwrolegol, a'u teuluoedd a gofalwyr, a cynhaliwyd hwy yn Wrecsam yn Ebrill ac ym Mangor mis Hydref. Aneliad y dyddiau oedd i roi gwybodaeth am waith Canolfan y Walton, a'i gysylltiadau â gwasanaethau cymunedol lleol. Daeth dros 140 o bobl i'r diwrnodau. Cafwyd siaradwyr megis unigolion gyda cyflwr niwrolegol, nyrsus arbenigol, ymgynghorwr niwrolegol, un o'r Ganolfan Cynhaliath-Niwro, Lerpwl, ac aelodau o Gynghreiriau lleol.



*Trafodaethau yn Niwrnod Trafodath Niwrolegol Gogledd Cymru*

Daeth dros 140 o bobl wedi'w effeithio gan gyflyrau niwrolegol i'r ddau Ddiwrnod Gwybodaeth Niwrolegol yn Ngogledd Cymru yn 2008

Daeth dros 135 o bobl broffesiynol gofal iechyd i'n diwrnod Astudiaeth yn Ngogledd Cymru.

Cynhaliwyd Diwrnod Addysgol Broffesiynol yng Nghyffordd Llandudno yng Ngorffennaf. Anelwyd y diwrnod hwn at bobl broffesiynol yn myd iechyd a gwasanaethau cymdeithasol â diddoerdebydd mewn dysgu mwy am yr agwedd amlddisgyblaethol o weithio gyda bobl â chyflwr niwrolegol.

Roedd yr adborth o'r dyddiau yn ardderchog, a gofynnwyd i gyfranogwyr am ei barn ar ddatblygiadau i wasanaethau niwrowyddonol yng Ngogledd Cymru. Canlyniadau eraill o'r dyddiau oedd yr awch i sefydlu **Rhwydwaith Broffesiynol Niwrolegol** yng Ngogledd Cymru i hybu datblygiad broffesiynol, a'r angen i'r Cynghrair wneud fwy o waith allanol i gryfhau ei rhwydweithiau lleol drwy Gymru. Oherwydd hyn, bydd y Cynghrair yn cynnal **'Dyddiau Rheolaeth Symptomau'** yn 2009.

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## **Grwp traws-bleidiol Nirowyddonol**

Mae'r Cynghrair yn dechrau paratoi i symud ymlaen i weithio gyda Aelodau'r Cynulliad o bob blaid dros Gymru i greu Grwp traws-bleidiol Nirowyddonol. Pwrpas hwn fydd i ddatblygu ymhellach cysylltiadau cryfion â Aelodau'r Cynulliad i roi gwybodaeth iddynt am bersectif a barn y rhai â chyflyrau niwrolegol. Bydd y gwaith hwn yn allweddol i'n ffocws a'n cyfraniad i'r gweithrediad fydd yn dilyn o'r Adolygiadau Nirowyddonol.

## **Cynghrair Niwrolegol (Lloegr)**

Ein prif siaradwr mewn cyfarfod llawn o'r Cynghrair yn yr Hydref oedd Kirstine Knox, Cadeirydd Cynghrair Niwrolegol yn Lloegr. Rhannwyd gwybodaeth a gwnaed dechreuad ar ddatblygu perthynas agosach ar gyfer y dyfodol. O'r herwydd, gwahoddwyd y cyd-is gadeiryddion i Dderbyniad yn y Ty Cyffredin, San Steffan a roddodd hyn gyfle iddynt godi achosion yn berthnasol i Gymru ger bron Aelodau Seneddol.

## **EDRYCH YMLAEN I 2009**

Mae'r flwyddyn a fu wedi bod yn un ffrwythlon iawn i'r Gynghrair, ac mae 2009 yn debyg o fod yn un fwy brysur byth fel y bydd aelodau yn ymgymeryd gyda gwaith y Grwpiau Gweithredol Nirowyddonol.

Blaenoriaeth cynnar fydd creu Grwp traws-bleidiol Nirowyddonol tu fewn i'r Cynulliad, i sicrhau ymhellach ein bod yn cyfleu perpectif y rhai sydd â chyflyrau niwrolegol yn unionsyth i gynyrchiolwyr aelodedig a hefyd i Lywodraeth y Cynulliad.

Byddwn yn brysur yn sicrhau y bydd barn ein aelodau a'n partneriaid yn gysylltiedig â waith y Grwpiau Gweithredol Nirowyddonol a'r Grwp Gweithrediad yr Adolygiad o Wasanaethau Arbenigol.

Byddwn yn parhau i gryfhau ein partneriaethau, a'n gwaith, gyda gynghreiriau lleol, a bwriadwn gefnogi rhai newydd i sefydlu mewn ardaloedd eraill o Gymru.

Yn olaf, bydd y Cynghrair yn brysur mewn cymunedau dros Gymru drwy gynnal nifer o weithdai ar 'Reolaeth Symptomau'. Bydd yn eu trefnu mewn partneriaeth â gweithiwr gofal iechyd ac academwyr, a Phrifysgol Abertawe. Pwrpas y gweithdai fydd i ddarparu datblygiad broffesiynol parhaol, gyda ffocws ar bynciau sydd yn berthnasol i bobl â chyflyrau niwrolegol.

Edrychwn ymlaen i'r gwaith a'r sialensau sydd o'n blaen yn 2009.

**Mae'r holl destun dan hawlfraint Cynghrair Niwrolegol Cymru 2008**

## **Foreword**

By Professor the Baroness Ilorá Finlay of Llandaff

The coming year should bring important improvements for patients with neurological disease. The palliative care strategy for Wales is now being implemented, through an Implementation Board that is answerable to the Minister for Health and Social Services. Many of the key areas that are being addressed will benefit patients with advanced neurological disease. The fair distribution across Wales of specialist palliative care is priority for the Board, linked to recognition that patients must be able to access expertise whenever they are ill, so services must be available 7 days a week.

Services need avoid unnecessary admissions to hospital. Patients need equipment and home adaptations that are timely, so the Minister has increased palliative care physiotherapy and occupational therapy. Over the coming year neurology specialist nurses and palliative care specialist nurses, as well as the medical teams, need to work closely to make sure that expertise is shared.

The Implementation Board has invested in a programme of education to ensure staff in the community and in hospitals have the skills to provide good general end-of-life care for those with advanced disease. And for those whose disease is much earlier in its time course, it is important to know that care will be available and provided in a way that empowers the patient, maintains dignity and maximises independence.

As Cicely Saunders, founder of the Hospice Movement said, 'You matter because you are you'. That should be the underlying philosophy for all those involved in providing care so that the future is not dominated by fear, and that every patient can feel confident that they will be listened to, will be treated with respect and kindness, and that staff will go the extra mile to meet their needs.

**February 2009**

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## Executive Committee Report

The Wales Neurological Alliance has had a very busy and productive year for 2008. Our membership continued to grow and our networks widened as we strengthened our partnerships with local alliances around Wales and forged strong relationships with several professional groups and organisations.

In these twelve months, the Alliance has contributed to several important policy areas relating to neurological conditions and neuroscience services. We continued to work hard to ensure the patient and family perspective remained central to our work, through listening and communicating with our members and to local alliance members to ensure we gave voice to the concerns and opinions of those whom we work to help.

The Executive Committee now meets regularly every six to eight weeks – a reflection of the amount of work we undertake, but also in the membership's commitment to work together. In this year, we have also developed systems to ensure we keep communicating with all our members – a regular news sheet is available for all to find out about the very latest developments and we have a presence on the world-wide web!

The Alliance was established to pursue and improve standards of care for all those affected by neurological conditions, both adults and children. Through membership of the Alliance our united strength allows us to push forward together. We wish to thank everyone for their support over the last year. It is impossible to name them all, but without financial support, hours of voluntary work, expertise and advice, we would not have achieved so much. The challenges for 2009 means we have much to achieve, but we look forward to tackling them together.

**February 2009**

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**Phil Davies,**  
**Founding member and first Chair of the WNA 2002 - 2006,**  
**Part-time Coordinator 2007 - 2008**

The Alliance lost a valuable and dear friend with the unexpected death of Phil Davies in November. Phil was instrumental in forming the Alliance and was the first Chair. Through his hard work alongside others, the organisation was founded as a credible voice on matters regarding neurological healthcare services.

Following his retirement from the Alzheimer's Society, Phil became the Alliance's part-time coordinator, enabling us to benefit from his experience and knowledge in communicating the Alliance's views and position; further establishing the organisation with its own identity and reputation. He will be greatly missed by all his friends within the Alliance.

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## INTRODUCTION

The Wales Neurological Alliance continues to voice the needs of those affected with neurological conditions living in Wales. Its membership includes 25 voluntary organisations and health professional groups and it has strong partnerships with several local alliances around Wales. In its seventh year, 2008 saw the Alliance continue to represent the views of the 100,000 plus people and their families affected by a neurological condition living in Wales. The need for further investment and development of neurological health services continues and the Alliance pursues this goal through its work.

### Aims

The aims of the Wales Neurological Alliance are to:

- Raise awareness of neurological conditions and their impact on individuals and society.
- Inform and influence policy makers in Wales about the needs of people with neurological conditions.
- Secure improved services and care for people with a neurological condition living in Wales.
- Promote the dissemination of information about neurological conditions.
- Support and promote appropriate research.

### Objectives

The objectives of the Wales Neurological Alliance are to:

- Ensure that people have significantly improved access to expert diagnostic services.
- Ensure good quality access to local treatment, support, care and rehabilitation.
- Improve availability of information, advice and services at a local level.
- Promote a clear data gathering exercise of the prevalence of neurological conditions.
- Support the development of audit and research.



Wales Neurological Alliance meeting in 2008

### Website

The Wales Neurological Alliance is now active on the internet with its own domain name - **[www.walesneurologicalalliance.org.uk](http://www.walesneurologicalalliance.org.uk)** and **[www.cynghrairniwrolegolcymru.org.uk](http://www.cynghrairniwrolegolcymru.org.uk)**. At present, the web page is kindly provided by the Wales Council for Voluntary Action's Building Strong Bridges programme and holds key information, contact details and publications. The aim is for the Alliance to build and develop its own site, providing useful information to its member groups, local alliances and to individuals, families and carers across Wales.

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## ACHIEVEMENTS IN 2008

### Wales Neuroscience Review Group

In September 2008, the Neuroscience Review's (the Steers Review) recommendations were published in three reports – North Wales, South & Mid Wales and All Wales. The Alliance submitted information to the Review process itself in 2007.

The Alliance is represented on the North Wales Neuroscience Implementation Group (NWNIG) since its establishment, and also on the several working groups. A report has been compiled by the Alliance on the needs of people affected by neurological conditions in North Wales and will be central in representing their views as decisions are made about neuroscience in North Wales. This report is available to download on the Alliance's website.

The South & Mid Wales group's work will not be underway until 2009, but the Alliance has already been proactive in approaching the Group's Chair and will pursue representation throughout its work.

### Review of Health Commission Wales

The Specialist Services Commissioning Group's Review was also published this year. In 2007 the Alliance and several of its member groups had submitted evidence to the work. Over the summer of 2008, the Alliance responded to the implementation group's work on appeals procedures. Specifically, the Alliance high-lighted the importance of transparency and accountability about decisions made affecting the management and care of individuals and the Alliance looks forward to continue participating in this work area.

### Local Neurological Alliances

Local Neurological Alliances are now well established in many areas across Wales. These groups are bringing together knowledge and expertise in their communities and the WNA is proud to work in partnership with them all to ensure a coordinated voice on patient needs for improving health services across Wales.

The local alliances established to date are: **Montgomery Alliance of Neurological Groups and Organisations (MANGO)**, **Neurological Alliance Wrexham (NAW)**, **Conwy & Denbighshire Neurological Alliance (CADNA)**, **South Gwynedd Long Term and Chronic Conditions Alliance**, and the **Ynys Môn and North Gwynedd Long Term and Chronic Conditions Alliance**.

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## Discussion Days & Professional Study Day

- in partnership with the Walton Centre for Neurology and Neurosurgery NHS Trust, Liverpool.

The Alliance continued its constructive relationship with the Walton Centre, Liverpool in 2008 by jointly organising a series of three events – two Neurological Discussion Days and a Professionals Study Day.

The Neurological Discussion days were targeted at people with a neurological condition, their families and carers and held in Wrexham and Bangor in April and October, respectively. The days were aimed to provide information about the role of the Walton Centre and the links with community services. Over 140 people attended the events. Speakers included people with a neurological condition, Consultant Neurologists, Specialist Nurses, The Neurosupport Centre, Liverpool and members of the local Alliances.



*Discussions at the North Wales Neurological Discussion Da*

Over **140** people affected by neurological conditions attended our Neurological Discussion days in North Wales in 2008.

Over 135 healthcare professionals attended our Study Day in North Wales

The Professionals Study Day was held at Llandudno Junction in July and attended by over 135 professionals. The event was aimed at health and social care professionals interested in learning more about the multidisciplinary approach to working with people who have a neurological condition.

Feedback from all the events was excellent and attendees were surveyed to give their opinions about the future of neuroscience services in North Wales. Other outcomes from the event included a desire to establish a **Professionals Neurological Network** in North Wales for continued professional development, and also a demand for further outreach initiatives from the Alliance to strengthen its infrastructure in localities around Wales. This has directly fed into the development of the Alliance's plans for 2009 and introducing its '**Symptom Management Days**'.

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## **All Party Neuroscience Group**

Although still in the preparatory stages, the Alliance is moving forward to work with Assembly Members from all parties across Wales to establish an All Party Neuroscience Working Group. The aim of this is to ensure the Alliance can further develop strong links with Assembly Members to ensure more effective discussions to inform them about the perspectives and opinions of those with neurological conditions. This work is seen as a key move around the implementation of the Neuroscience Reviews and the Group will be focussing on this area initially.

## **Neurological Alliance (in England)**

Kirstine Knox the Chief Executive of the English Neurological Alliance addressed a full members meeting of the WNA in October. This allowed for an exchange of information and began a closer working relationship for the future. In recognition both Vice Chairs of the WNA were invited to a reception in the House of Commons providing an opportunity to raise issues relating to Wales with MPs and decision makers.

## **LOOKING AHEAD TO 2009**

This year has been very productive for the Alliance and 2009 looks set to be even busier as we are actively involved in the Neuroscience Implementation Groups' work.

An early priority is establishing an All Party Neuroscience group within the National Assembly, to further ensure we can inform and engage the views of those affected by neurological conditions directly to elected representatives and the Welsh Assembly Government.

We will also be active in ensuring the Neuroscience Review Implementation Groups' work is linked with the views of our members and our partners and also for the Health Commission Wales / Specialist Services Review Implementation.

We will also be continue strengthening our partnerships and work with local Alliances as well as establishing new Alliances in other areas of Wales.

Last, but not least, the Alliance will be active in communities across Wales through a series of workshops on 'Symptom Management Days'. These events will be organised by the Alliance in partnership with healthcare professionals and academics, including Swansea University. Their aim is to provide continuing professional development focussing on a particular subject relevant to people affected by neurological conditions.

The year ahead looks to be as busy as ever and the Alliance looks forward to the work and challenges ahead.