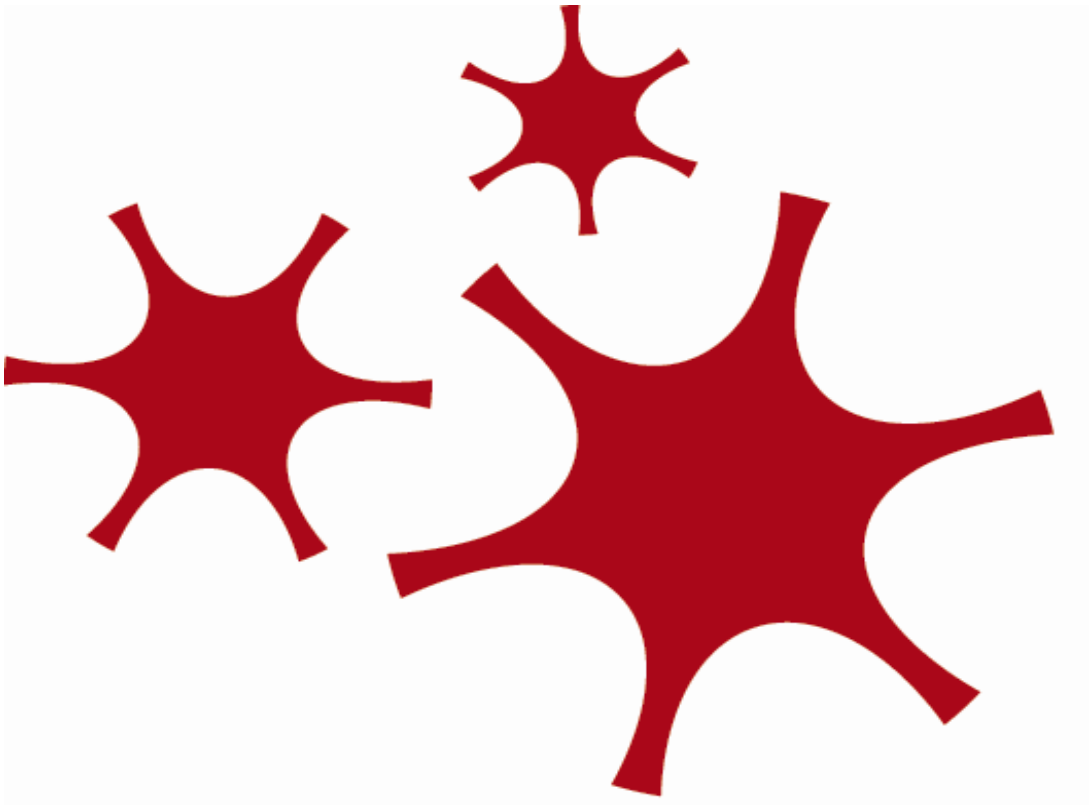
Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Adroddiad Blynyddol

2009

Annual Report



Aelodau Cynghrair Niwrolegol Cymru – *The Wales Neurological Alliance Membership*

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

Pwyllgor Gwaith / *Executive Committee*

Cadair/ *Chair :*	Judi Rhys (MSSoc) - Tach/ *Nov* 2009
Cadair/ *Chair* :	Kevin Thomas (MNDAssoc) - Tach/ *Nov* 2009 -
Ddirprwy gadair/ *Vice chair:*	Kevin Thomas (MNDAssoc) - Tach/ *Nov* 2009
Ddirprwy gadair/ *Vice chair:*	Joseph Carter – Tach/ *Nov* 2009
Trysorydd mygedol / *Honorary Treasurer:*	Don Read (CMT UK)
Ysgrifennydd mygedol / *Honorary Secretary:*	Buddug Williams (GIG)
Aelodau'r pwyllgor / *Committee Members:*	Margaret Read MBE (CMT UK)
	Carol Smith (PDS)
	Kevin Thomas (MNDAssoc) - Ebrill/ *April* 2009
	Elin Ifan (ASBAH) - Medi/ *Sept* 2009
	Kate Thomas (ASBAH) - Medi/ *Sept* 2009
	Carol Thomas-Wyllie (MNDAssoc)
	Gill Gleeson (Cerebra) Medi/ *Sept* 2009 -
	Joseph Carter (MSSoc) - Tach/ *Nov* 2009

Cyd-lynydd Rhan Amser / *Part-time Co-ordinator*
Dave Maggs

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SAESNEG / ENGLISH* tudalen / *page 7

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Rhagair gan James Steers, Cadeirydd Adolygiad Arbenigol Niwrowyddorau Cymru

Roedd 2008 a 2009 yn flynyddoedd o bwys i'r niwrowyddorau yng Nghymru. Yn ystod yr amser hwn bu Adolygiad Annibynnol Arbenigol Niwrowyddorau Cymru wrthi'n casglu ei dystiolaeth a chynhyrchodd ei adroddiad ar gyfer y Gweinidog. Roedd yr adolygiad yn cynnwys yr "holl" niwrowyddorau o sefyllfaoedd brys llym claf yn dychwelyd i'w gymuned leol a gwasanaethau adsefydlu ond gan ganolbwyntio'n benodol ar gyflenwi niwro-lawfeddygaeth. Cyfrannodd Cynghrair Niwrolegol Cymru, boed fel aelodau unigol, mewn grwpiau neu fel un corff, yn helaeth i ddealltwriaeth y grŵp adolygu.

Mae 2010 yn sicr o fod yn flwyddyn bwysig wrth i argymhellion yr adroddiad ddechrau cael eu rhoi ar waith gan gynnig cyfleoedd newydd i gleifion niwrolegol. Wrth i'r argymhellion hyn gael eu cyflawni bydd yn bosib troi at dasg ofal y grŵp adolygu, sef cynllunio'r broses ar gyfer datblygu llwybrau gofal yng Nghymru i bobl yng Nghymru â Chyflyrau Niwrolegol Hirdymor. Mae Cynghrair Niwrolegol Cymru yn parhau i helpu'r grŵp adolygu, gyda'r gwaith hwn.

Bydd problemau yn ystod 2010 yn ddios wrth i gyfleoedd ar gyfer ariannu prosiectau newydd brinhau. Gwerthfawrogir cefnogaeth y Cynghrair Niwrolegol bob amser fel corff ac unigolion a bydd hynny'n wir yn gynyddol dros yr ychydig flynyddoedd nesaf. Mae cydweithio effeithiol rhwng y Gwasanaeth Iechyd a'r Sector Gwirfoddol yn bwysicach nag erioed. Gydag amynedd a gwaith meddwl cadarnhaol wedi'i gyfarwyddo'n dda, gellir dod i hyd i well atebion i sefyllfaoedd anodd.

Mae'r New Oxford English Dictionary yn diffinio Cynghrair fel "undeb o gysylltiadau a ffurfir er lles y naill a'r llall, yn arbennig rhwng gwledydd neu gyrff" . Mae gair yn deillio o ddau wreiddyn sef *alle* (Ffrangeg am fynd neu ffordd) a'r olddodiad *–ance* (Lladin am gyflwr neu ansawdd). Gyda'r wybodaeth am gryfder y gair drwy ei darddiadau gall Cynghrair Niwrolegol Cymru wynebu'r dyfodol yn llawn hyder.

….
Chwefror 2010

Adroddiad y Cadeirydd - Kevin Thomas

Mae Cynghrair Niwrolegol Cymru (y Gynghrair) wedi cael blwyddyn brysurach a mwy cynhyrchiol byth yn 2009. Parhaodd ein haelodaeth i dyfu a'n rhwydweithiau i ehangu wrth i ni gryfhau ein partneriaethau gyda chynghreiriau lleol o gwmpas Cymru, a lluniwyd perthnasau cryf gyda nifer o grwpiau a sefydliadau proffesiynol.

Yn ystod y deuddeg mis diwethaf mae'r Gynghrair:

- Wedi cyfrannu at y trafodaethau ar ddyfodol cynllunio a chyflenwi gwasanaethau iechyd niwrowyddoniaeth yn dilyn cyhoeddi Adolygiad Steers.
- Wedi cynnal arolwg ar ffurf holiadur o unigolion sy'n byw gyda chyflyrau niwrolegol yng Nghanolbarth a De Cymru.
- Wedi cryfhau ein cysylltiadau a'r cydweithio gyda'r Grŵp Niwrowyddorau Trawsbleidiol yng Nghynulliad Cenedlaethol Cymru.
- Wedi cyflwyno ymatebion i sawl ymgynghoriad ac ymholiad gan Lywodraeth Cynulliad Cymru a Chynulliad Cenedlaethol Cymru.
- Gwell rhwydweithio a chyfathrebu gydag aelodau trwy gynhyrchu taflen newyddion reolaidd yn rhoi gwybod i'r Aelodau am waith y Gynghrair.

Mae'r Pwyllgor Gweithredol yn dal i gyfarfod pob chwech i wyth wythnos – sy'n adlewyrchiad o'r gwaith rydym yn ei wneud, ond hefyd o ymrwymiad yr aelodau i gydweithio. Bydd yr holl aelodau'n cyfarfod ddwywaith y flwyddyn.

Hoffem ddiolch i bawb am eu cefnogaeth dros y flwyddyn ddiwethaf. Mae'n amhosibl enwi pawb, ond heb gymorth ariannol, oriau o waith gwirfoddol, arbenigedd a chyngor, ni fyddem wedi cyflawni cymaint. Mae'r heriau ar gyfer 2010 yn golygu fod gennym lawer i'w gyflawni, ond edrychwn ymlaen at eu taclo gyda'n gilydd.

….
Chwefror 2010

Symud Ymlaen

Yn ystod hydref 2009 ymadawodd Cadeirydd y Gynghrair Judi Rhys, yn ogystal ag Elin Ifan, cyn Gyd Is-Gadeirydd a Sue Lloyd, y cyn ysgrifennydd, pob un ohonynt wedi llwyr haeddu eu hymddeoliad! Pob dymuniadau da iddynt i gyd.

CYFLWYNIAD

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.

Aelodau'r Gynghrair Don a Margaret Read yn trafod materion niwrolegol gyda Dr Dai Lloyd AC yn y Cynulliad Cenedlaethol.

Parhaodd y Gynghrair sydd bellach yn ei hwythfed flwyddyn nawr yn 2009 i leisio anghenion y 100,000 a mwy o bobl a'u teuluoedd sy'n byw yng Nghymru a effeithir gan gyflyrau niwrolegol. Ymhlith yr aelodaeth y mae 26 o sefydliadau gwirfoddol a grwpiau gweithwyr proffesiynol iechyd ac mae ganddi bartneriaethau cryf gyda sawl cynghrair leol o gwmpas Cymru. Mae angen rhagor o fuddsoddi a datblygu gwasanaethau iechyd niwrolegol o hyd ac mae'r Gynghrair yn bwrw ymlaen â'r nod hwn trwy ei gwaith.

CYRHAEDDIADAU 2009

Adolygiad Niwrowyddorau Cymru

Ym mis Medi 2008, cyhoeddwyd argymhellion Adolygiad Niwrowyddoniaeth Steers mewn tri adroddiad – Gogledd Cymru, De a Chanolbarth Cymru a Chymru Gyfan. Cyflwynodd y Gynghrair ei hun wybodaeth i'r broses yr Adolygiad yn 2007.

Cafwyd cynrychiolaeth o'r Gynghrair ar Fwrdd Gweithredu Niwrowyddoniaeth Gogledd Cymru (NWNIB) o'r cychwyn cyntaf, ac ar nifer o weithgorau hefyd. Lluniodd y Gynghrair adroddiad ar anghenion pobl a effeithir gan gyflyrau niwrolegol yng Ngogledd Cymru a'i gyflwyno i NWNIB.

Cyfarfu Bwrdd Gweithredu Canolbarth a De Cymru (M&SWIB) am y tro cyntaf yn Ebrill 2009. Bydd yr aelodau'n cofio Cadeirydd y Bwrdd, Dr Alan Axford, yn siarad yng Nghyfarfod Blynyddol Cynghrair Niwrolegol Cymru 2009, gydag Andrew RT Davies AC yn croesawu, ac yn ymrwymo'n gadarn i gynnwys y Gynghrair yng ngwaith y Bwrdd a'i amryfal ffrydiau gwaith. Bu Dr Axford cystal â'i air a chymerodd nifer o aelodau o'r Pwyllgor Gweithredol ran ym mhroses adolygu Bwrdd Gweithredu Canolbarth a De Cymru yn ystod misoedd y gwanwyn a'r haf.

Cyhoeddodd y ddau Fwrdd eu hadroddiadau ym mis Medi. Roedd yn dda gan y Gynghrair weld bod yr argymhellion yn rhoi cyfle am well canlyniadau i gleifion, gofal o well ansawdd a gwelliant sylweddol mewn gwasanaethau a gwell cyfleoedd ymchwil a hyfforddiant i'r dyfodol. Mae'r adroddiadau'n pwysleisio pwysigrwydd mynediad at dimau amlddisgyblaethol gyda gwell mynediad yn lleol i gleifion sy'n cael cefnogaeth gan ganolfannau arbenigol rhagorol. Os caiff yr argymhellion eu cyflenwi, byddant yn darparu gwasanaethau o safon uchel, mwy teg a chynaliadwy i bobl sydd angen ymyrraeth a gofal gan wasanaethau niwrowyddoniaeth.

Rhoddwyd yr adroddiadau i'r Byrddau Iechyd Lleol i'w cyflenwi. Mae hyn yn golygu fod gwaith ar argymhellion pellach, gyda mwy o fanylion am wasanaethau niwrowyddoniaeth, er enghraifft costiadau a chynllunio gweithlu, yn mynd yn ei flaen. Caiff y gwaith hwn ei arwain gan Fwrdd Iechyd Prifysgol Betsi Cadwaladr yng Ngogledd Cymru a Byrddau Iechyd Lleol Prifysgol Caerdydd a'r Fro ac Abertawe Bro Morgannwg yng Nghanolbarth a De Cymru. Bydd y Gynghrair yn parhau i fod yn rhan o'r rhaglen Weithredu ac yn cyfrannu at y manylion.

Mesur Arfaethedig Taliadau Gofal Cymdeithasol (Cymru)

Cyflwynodd y Gynghrair ymateb manwl i ymgynghoriad y Cynulliad Cenedlaethol ar y Mesur arfaethedig hwn ac, yn sgil hyn, derbyniodd wahoddiad i gyflwyno tystiolaeth lafar i Bwyllgor Gorchymyn Cymhwysedd Deddfwriaethol y Cynulliad ym mis Medi. Ers hynny mae'r Pwyllgor wedi cyhoeddi ei adroddiad ac wedi ystyried rhai o argymhellion Cynghrair Niwrolegol Cymru. Am fanylion llawn ewch i: http//www.assemblywales.org/bus-home/buslegislation/bus-leg-measures/business-legislation-measures-scc-2.htm.

Blaenoriaethau Cleifion i Ddatblygu Gwasanaeth Niwrowyddoniaeth yng Nghanolbarth a De Cymru

Cynhaliodd y Gynghrair arolwg ar ffurf holiadur o unigolion sy'n byw gyda chyflyrau niwrolegol yng Nghanolbarth a De Cymru yng ngwanwyn 2009. Dosbarthwyd yr holiaduron gan aelodau'r Gynghrair a derbyniwyd 430 o ymatebion. Roedd yr adroddiad, a gyhoeddwyd yn 2009, wedi'i seilio ar ddadansoddiad o'r ymatebion yn adnabod 9 prif fater gan restru cyfres o argymhellion ar gyfer pob un. Roedd hefyd yn tynnu 5 cynnig blaenoriaeth o'r argymhellion gan fynd i'r afael â materion cysylltiedig â:

Nyrsys arbenigol

- Adsefydlu
- Hyfforddiant
- Gwybodaeth
- Cymhorthion/addasiadau

Anfonwyd yr adroddiad ymlaen i Dr Axford fel Cadeirydd Bwrdd Gweithredu Canolbarth a De Cymru a chyfrannodd at syniadaeth y Bwrdd.

Cynghreiriau Niwrolegol Lleol

Mae Cynghreiriau Niwrolegol Lleol bellach wedi hen ennill eu plwyf mewn sawl ardal ar draws Cymru. Mae'r grwpiau hyn yn dod â gwybodaeth ac arbenigedd ynghyd yn eu cymunedau ac mae'r Gynghrair yn falch o gydweithio gyda phob un ohonynt i sicrhau y ceir llais cydgysylltiedig ar anghenion cleifion dros wella gwasanaethau iechyd ar draws Cymru. Yn 2009 sefydlwyd Cynghrair Niwrolegol De Orllewin Cymru yn cynnwys Pen-y-bont ar Ogwr, Port Talbot Castell-nedd ac Abertawe. Er gwaetha'r ffaith bod Cynghrair Niwrolegol Conwy a Sir Ddinbych (CADNA) wedi penderfynu peidio â chynnal rhagor o gyfarfodydd grŵp, parhaodd Cynghreiriau Gogledd Cymru i gyfarfod o bryd i'w gilydd yn ystod y flwyddyn.

Grŵp Trawsbleidiol Niwrowyddorau

Cynhaliwyd cyfarfod cychwynnol y Grŵp Trawsbleidiol Niwrowyddorau yn Ebrill. Y siaradwr gwadd yno oedd y bencampwraig para-saethwyr Pippa Britton. Cynhaliwyd cyfarfodydd dilynol ym mis Hydref a mis Tachwedd a threfnwyd dyddiadau ar gyfer 4 cyfarfod yn 2010. O dan gadeiryddiaeth Mark Isherwood, AC Gogledd Cymru, mae'r Group wedi bod yn werthfawr eisoes wrth helpu'r Gynghrair i ddatblygu cysylltiadau cryfach gyda'r Cynulliad. Nid yw'n syndod bod Arolwg Niwrowyddoniaeth Cymru wedi bod yn cael llawer iawn o sylw eleni. Yng nghyfarfod mis Tachwedd cafwyd diweddariad ar ddatblygiadau diweddar a chyflwyniad diddorol a llawn gwybodaeth gan Emma Saysell, Cadeirydd Hosbisau Annibynnol Cymru ar y testun 'Gofal Hosbis a Gofal Lliniarol ar gyfer Cyflyrau Niwrolegol'.

Pencampwraig y byd a paralympaidd mewn saethyddiaeth, Pippa Britton oedd y siaradwr gwadd cyntaf ar gyfer cyfarfod Grŵp Trawsbleidiol Niwrowyddorau y Cynulliad Cenedlaethol. Yma gyda aelodau o'r Gynghrair.

Gwefan

Ddiwedd 2009, dyfarnwyd grant i'r Gynghrair o raglen Gwobrau i Bawb Cronfa'r Loteri Fawr i adeiladu a datblygu ei gwefan hygyrch, ddwyieithog a chynhwysfawr ei hun, fydd yn darparu gwybodaeth ddefnyddiol i'r grwpiau sy'n perthyn iddi, cynghreiriau ac unigolion lleol, teuluoedd a gofalwyr ar draws Cymru. Bydd y cyfleuster hwn, sy'n cael i ystyried gan lawer fel eu 'hwyneb i'r byd', o gymorth i'r Gynghrair godi ei phroffil ymhellach, ond bydd hefyd yn 'borthladd galw' cyntaf gwerthfawr i lawer o unigolion, teuluoedd, cyrff a gweithwyr proffesiynol sydd am rwydweithio a dysgu mwy am faterion niwrolegol yng Nghymru.

EDRYCH YMLAEN I 2010

Mae'n edrych yn debyg fod 2010 yn mynd i fod yn brysurach na 2009 hyd yn oed wrth i ni gymryd rhan yn y trefniadau Gweithredu Niwrowyddoniaeth yng Ngogledd a Chanolbarth a De Cymru, gan weithio'n agos gyda'r Byrddau Iechyd Lleol, Llywodraeth Cynulliad Cymru ac Aelodau Cynulliad. Bwriadwn adeiladau ar sail y sylfeini cadarn a osodwyd gan y Grŵp Niwrowyddorau Trawsbleidiol a threfnwyd amserlen o ddyddiadau cyfarfodydd trwy gydol 2010.

Byddwn yn adeiladu, yn llenwi ac yn lansio ein gwefan ddwyieithog arbennig gyntaf er mwyn gwella ein gwasanaeth i aelodau a rhanddeiliaid eraill.

Byddwn yn parhau i gyfrannu i ymgynghoriadau Cynulliad sy'n berthnasol i bobl sy'n byw gyda chyflwr niwrolegol yng Nghymru ac yn trefnu rhaglen o 'Ddyddiau Rheoli Symptomau' gan adeiladu ar sail llwyddiant y diwrnod peilot 'Rheoli Poen mewn Cyflyrau Niwrolegol'.

Yn ôl pob golwg bydd y flwyddyn sydd o'n blaenau mor heriol ag erioed ac mae'r Gynghrair yn edrych ymlaen at wynebu'r heriau hyn.

Mae'r holl destun dan hawlfraint Cynghrair Niwrolegol Cymru 2010 ©

Foreword
By Mr James Steers, Chair of the Wales Neuroscience Review

2008 and 2009 were important years for the neurosciences in Wales. During this time the Expert Independent Review of Welsh Neurosciences gathered its evidence and produced its report for the Minister. The review encompassed the "whole" of neurosciences from acute emergency situations to the return of the patient to their local community and rehabilitation services but had a particular focus on the delivery of neurosurgery. The Wales Neurological Alliance as individual members, or in groups or as a whole made a significant contribution to the understanding of the review group.

2010 promises to be as an important a year as the recommendations of the report begin to be implemented and offer new opportunities for neurological patients. As these recommendations are achieved this will enable the last task of the review group, that of designing the process for the development of care pathways for people in Wales with Long-Term neurological Conditions. The Wales Neurological Alliance continues to assist the review group with this work.

There is no doubt that 2010 will have its difficulties as opportunities for the funding of new projects will become more difficult. The support of the neurological Alliance as a whole and as individual members has always been valued and will be increasingly so over the next few years. Effective working between the Health Service and the Voluntary Sector has never been more important. Out of difficult situations with patience and well directed positive thinking can emerge better solutions.

The New Oxford English Dictionary defines an Alliance as "a union of associations formed for mutual benefit, especially between countries or organizations" the word being derived from two roots alle (French to go or way) and the suffix –ance (Latin state or quality). With the knowledge of the strength of the word through its origins the Wales Neurological Alliance can face the future in confidence.
....
February 2010

Report from the Chair - Kevin Thomas

The Wales Neurological Alliance (the Alliance) has had an even busier and more productive year in 2009. 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 the past twelve months, the Alliance:
- *Contributed to the deliberations on the future of neuroscience health services planning and delivery following publication of the Steers Review.*
- *Undertook a questionnaire survey of individuals living with neurological conditions in Mid & South Wales.*
- *Strengthened our links and networking with the Cross Party Group of Neurosciences in the National Assembly for Wales.*
- *Submitted responses to several Welsh Assembly Government and National Assembly for Wales consultations and inquiries.*
- *Improved communications and networking with members by producing a regular news sheet keeping members informed about the Alliance's work.*

The Executive Committee continues to meet every six to eight weeks – a reflection of the amount of work we undertake, but also of the membership's commitment to work together. The full membership again met twice a year.

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 2010 means we have much to achieve, but we look forward to tackling them together.

….
February 2010

Moving On

Autumn 2009 saw the departure of Alliance Chair Judi Rhys, as well as Elin Ifan, former Co Vice Chair and Sue Lloyd, former secretary to well earned retirements! We wish them all well.

INTRODUCTION

The Alliance in its eighth year, 2009, continued to voice the needs of the 100,000 plus people and their families affected with neurological conditions living in Wales. Its membership includes 26 voluntary organisations and health professional groups and it has strong partnerships with several local alliances around Wales. The need for further investment and development of neurological health services continues and the Alliance pursues this goal through its work.

The aims of the 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.*

Alliance members Don and Margaret Read discuss neurological matters with Dr Dai Lloyd AM at the National Assembly.

ACHIEVEMENTS IN 2009

Wales Neurosciences Review

In September 2008, the Steers Neuroscience Review's 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 was represented on the North Wales Neuroscience Implementation Board (NWNIB) from the outset, and also on several working groups. A report was compiled by the Alliance on the needs of people affected by neurological conditions in North Wales and submitted to the NWNIB.

The Mid & South Wales Implementation Board (M&SWIB) first met in April 2009. Members will recall the Chair of the Board, Dr Alan Axford, speaking at the WNA's 2009 AGM, hosted by Andrew RT Davies AM, and giving a firm commitment to including the Alliance in the work of the Board and its various workstreams. Dr Axford was as good as his word and several members of the Executive Committee participated in the M&SWIB review process during the spring and summer months.

Both Boards published their reports in September. The Alliance was pleased to see that the recommendations provide an opportunity for better outcomes for patients, better quality of care with significant service improvement and better training and research opportunities for the future. The reports stress the importance of access to multi-disciplinary teams with improved local access for patients which are supported by excellent specialist centres. If the recommendations are delivered, they will provide high quality, more equitable and sustainable services for people who require intervention and care from neuroscience services.

The reports have been given to the Local Health Boards to deliver. This means that work on further recommendations, with more detail of neuroscience services, for example costings and workforce planning, is on-going. This work will be led by the Betsi Cadwaladr University Health Board in North Wales and Cardiff and Vale University and Abertawe Bro Morgannwg Local Health Boards in Mid and South Wales. The Alliance will continue to be a part of the Implementation programme and contribute to the details.

Proposed Social Care Charges (Wales) Measure

The Alliance submitted a detailed response to the National Assembly's consultation on this proposed Measure and, as a consequence, was invited to present oral evidence to the Assembly's LCO Committee in September. The Committee has since published its report and has taken account of some of the WNA's recommendations. For full details: http//www.assemblywales.org/bus-home/buslegislation/bus-leg-measures/business-legislation-measures-scc-2.htm.

Patient Priorities for Neuroscience Service Development in Mid & South Wales

The Alliance undertook a questionnaire survey of individuals living with neurological conditions in Mid & South Wales in spring 2009. Questionnaires were distributed by Alliance members and 430 responses were received. Published in August 2009, the report, drawn from the analysis of the responses identified 9 key issues listing a series of recommendations for each one. It also extracted 5 priority proposals from within the recommendations addressing issues concerned with:

- *Specialist nurses*
- *Rehabilitation*
- *Training*
- *Information*
- *Aids/adaptations*

The report was forwarded to Dr Axford as Chair of the M&SWIB and contributed to the thinking of the Board.

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 Alliance is proud to work in partnership with them all to ensure a coordinated voice on patient needs for improving health services across Wales. 2009 saw the establishment of the South West Wales Neurological Alliance covering Bridgend, Neath Port Talbot and Swansea. Despite the fact that the Conwy &

Denbighshire Neurological Alliance (CADNA) decided to discontinue further meetings of the group, the North Wales Alliances have continued to meet periodically during the year.

Cross Party Group of Neurosciences

The inaugural meeting of the Cross Party Group of Neurosciences was held in April where the para-archer champion Pippa Britton was the guest speaker. Follow up meetings were held in October and November and dates set for 4 meetings in 2010. Chaired by Mark Isherwood, AM for North Wales, the Group has already proved valuable in helping the Alliance develop stronger links with the Assembly.

Not surprisingly a key focus this year has been the Wales Neuroscience Review with the November meeting receiving an update on recent developments and a very informative and engaging presentation from Emma Saysell, Chair of Independent Hospices Cymru on 'Palliative and Hospice Care for Neurological Conditions'.

World champion and paralympic archer Pippa Britton spoke at the first National Assembly Cross Party Group for Neurosciences meeting. Pictured with Alliance members.

Website

In late 2009, the Alliance was awarded a grant from the Big Lottery Fund's Awards for All programme to build and develop its own comprehensive, bilingual, accessible website, providing useful information to its member groups, local alliances and individuals, families and carers across Wales. This facility, seen by many organisations as their 'face to the world', will help the Alliance further raise its profile, but will also be a valuable first-port-of-call for many individuals, families, organisations and professionals wanting to network and find out more about all things neurological in Wales.

LOOKING AHEAD TO 2010

2010 looks set to be even busier than 2009 as we participate in the Neuroscience Implementation arrangements in North and Mid & South Wales, working closely with the Local Health Boards, the Welsh Assembly Government and with Assembly Members.
We intend building on the firm foundations laid for the Cross Party Group of Neurosciences and have agreed a schedule of meeting dates throughout 2010.

We will be building, populating and launching our first discrete bilingual website to improve our service to members and other stakeholders.

We will continue to contribute to Assembly consultations relevant to people living with a neurological condition in Wales and set in train a programme of 'Symptom Management Days' building on the success of the pilot day on 'Pain Management in Neurological Conditions'.

The year ahead looks to be as challenging as ever and the Alliance looks forward to rising to these challenges.

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