

## **Foreword**

By Kevin Thomas (MND Association), Chair, Wales Neurological Alliance

I have been very proud and excited to Chair an organisation which has grown from humble beginnings to being recognised locally and nationally as a leading influence in representing the views of people living with a neurological condition in Wales. With the help and support of my fellow Executive Committee members we have continued to increase our influence and profile. However, our increasing influence continues to present us with organisational challenges as we struggle with limited resources.

2010 has been another busy year for the Alliance. We continue to build on our authority and credibility in our role as secretariat for the Cross Party Group on Neurosciences. This has ensured that we have kept the recommendations of the Neuroscience Review firmly on the political agenda. We continue to be active within the Implementation Boards and Project Teams in North, Mid and South Wales and have made representations at senior political and civil servant levels when momentum has slipped.

The Cross Party Group (CPG) on Neurosciences has not only been a vehicle for informing and debating with politicians. But, this year we have been unique amongst CPG's in bringing the group out to the people. A CPG was held in Wrexham and was attended by over a hundred people including people living with a neurological condition, carers, health and social care professionals.

We are extremely proud to be launching our website at this year's AGM and are grateful to the Big Lottery Fund for financing this initiative. We hope that the website will be informative by updating members on our work, events of significance, and providing links to key resources. We also hope that the website will be an important resource for people with a neurological condition in finding support and advice by signposting to condition specific member organisations.

During the year we have strengthened the Executive Committee through a review of our structure and processes. This has been supported by new committee members who bring additional skills and expertise. However, we have also lost a valuable founder member who contributed so much to the work of the Alliance. Margaret Read MBE, sadly died in December. Margaret's tenacity and her spirited response to issues concerning people with a neurological condition were beyond compare. Her contribution as a representative of Charcot-Marie-Tooth embodied that of the Alliance in which the smallest member has equity of voice with the largest member. She will be sadly missed by the Alliance as an organisation and by me personally for her support and advice.

As I reflect on my 18 months as Chair I am particularly pleased to have seen the influence and profile of the Alliance grow. Looking forward to the challenges and opportunities of 2011 I am confident that the Alliance is well placed to ensure that the voice of people living with a neurological condition is heard at all levels. I wish my successor well.

February 2011

## **Margaret E Read, MBE**

**Founding and Executive Committee member of the Wales Neurological Alliance 2002-2010**



In December 2010, Margaret Read passed away unexpectedly. Margaret, along with her husband Don, have been active members of the Alliance since its first days. Most recently Margaret was the Alliance's minutes secretary, editor of the regular news sheet distributed to all members and co-ordinated the Symptom Management Study Day.

Margaret worked tirelessly for many voluntary groups and was awarded an MBE for services to the community. She was also very active within CMT-UK (Charcot-Marie-Tooth disease), a condition with which she was affected, and was always supportive and enthusiastic to contribute to areas of the Alliance's work. Margaret will be greatly missed by all her friends within the Alliance.

## **INTRODUCTION**

### **About us**

The Wales Neurological Alliance is a focused and purposeful forum representing many thousands of people affected by neurological conditions in Wales.

The Alliance was launched in 2002 to ensure that neurological services are given priority at all levels of health and social care planning. The Alliance enables neurological organisations/groups to campaign together and speak with an influential voice.

### **Our Mission Statement**

We support people with neurological conditions in Wales in living the best life possible through influencing policy, raising awareness and developing services.

### **Our Vision**

People living with neurological conditions will have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.

### **Aims**

We aim 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.

We do this by:

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

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## **ACHIEVEMENTS IN 2010**

### **Wales Neurosciences Review**

#### ***North Wales***

The North Wales Neurosciences Plan submitted to the Minister in October 2009 detailed a 5 year plan for the development of neurological services in North Wales in response to the James Steers Review. Within this plan immediate, medium and long term priorities were identified. To implement the recommendations within the Betsi Cadwaladr University Health Board will require major revenue investment in the order of £10 - £15m plus capital implications of equal or far greater amounts. Clearly within the current financial environment we need to reflect on our ability to deliver our original plan within the identified timescales. This is a key piece of work that is now being progressed by each of the work streams.

Progress has continued within each of the five Project teams that have been established around the following key areas:

- Head Injury, Acute Neurological Emergency and Neurocritical Care
- Stroke and Medical Neurology
- Diagnostics (to include Neurophysiology and Imaging)
- Rehabilitation, Continuing and Palliative Care
- Specialist Spinal Injury and Surgery (Task and Finish Group)

The Programme Board has been leading on a piece of work with each of the Project Teams to identify immediate action plans (including key early work, and relationships with the Welsh Health Specialised Services Committee (WHSSC), 5 year action plans and detailed annual plans of action. It is acknowledged that fully implementing the recommendations will require significant change and investment over time. The project is taking into account the known and anticipated wider service developments in North Wales as the programme of work is interrelated to other work such as the future configuration of acute services and is dependent upon the planned development of Llandudno General Hospital.

The project is currently focussing on tasks that require additional investment through the implementation of best practice or redistribution of resources in the system to include the necessary effective clinical demand management. We are also working with WHSSC and the Walton Centre to ensure to ensure best value from our contract.

#### ***Mid and South Wales***

The first phase of implementing the neurosurgery-related recommendations from the Axford report was completed by the summer. Although some aspects remain to be finalised, the single-site neurosurgery service in Cardiff is in place. Work around neurorehabilitation services for patients recovering from neurosurgery is also underway, with changing the configuration of the service in the West (Swansea) and also in the East (Cardiff).

The remaining recommendations of the report - which include those areas for neurology, neurophysiology and supportive care and management for conditions - are now to be undertaken in a second phase, which sees the project team responsible for delivering these recommendations under a new chair and with more active participation from the six Health Boards in Mid & South Wales. Meetings will be monthly and will be outlining the pace of the programme and the stages of implementing the recommendations.

The Alliance has a place on the project team and will be monitoring the progress and detail of the work to implement the recommendations as well as providing constructive comments and views from the perspective of our membership and of patients.

## 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.

The local alliances established to date are: Montgomery Alliance of Neurological Groups and Organisations (MANGO), Neurological Alliance Wrexham (NAW), South Gwynedd Long Term and Chronic Conditions Alliance, the Ynys Môn and North Gwynedd Long Term and Chronic Conditions Alliance, RCT & Merthyr Chronic Conditions Management Focus Group, West Wales Neurological Alliance (Hywel Dda HB area), and the South West Wales Neurological Alliance (ABM HB area).

## Cross Party Group for Neurosciences

2010 was a busy year for the Cross-Party Group for Neurosciences – the group that brings together Assembly Members, professionals and the Alliance to raise common concerns of people living with neurological conditions. In addition to updating politicians on the neurosciences review, the group (chaired by Mark Isherwood AM) began 2010 by investigating what palliative care was available for individuals affected by conditions other than cancer. Baroness Ilora Finlay of Llandaff, Chair of the Palliative Care Implementation Group gave a presentation to the group explaining what the Welsh Government was seeking to achieve with its recent review and investment in this area, whilst Emma Saysell, Chair of Independent Hospices Wales sought to involve the Alliance in predicting what the demand would be for palliative care support.

In September we hosted the first Cross-Party Group for Neurosciences meeting in North Wales. The meeting focused mainly on the Neurosciences Review in North Wales and was attended by over 100 people including senior directors from the Walton Centre and the Betsi Cadwaladr University Board. Those who attended found it interesting and there was demand to hold something similar in future.



Cross-Party Group for Neurosciences Meeting,  
North Wales, Sept 2010

In the Autumn, the Cross-Party Group initiated an inquiry into the lack of understanding of neurological conditions within Emergency and Admissions Units in Wales. People living with neurological conditions were asked to give examples of both negative and positive experiences they had received when admitted to Emergency Units, and the result was a series of distressing case studies. The Cross-Party Group will be publishing its report in March 2011 and it is hoped that the Health, Wellbeing and Local Government Committee will take the issue forward and launch its own inquiry.

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## **Carers Strategies**

### ***Assisting law-making in Wales***

In late 2009 and throughout 2010 the Alliance helped contribute to laws affecting carers and people receiving home care and support services. The Alliance was invited to give evidence to the National Assembly for Wales committee, which scrutinised both of the laws (or “Measures”). On the Social Care Charges (Wales) Measure 2011 the Alliance expressed concerns about how the proposed cap of £50 a week for home care would work in practice and how the plans would affect people using direct payments. On the Carers Strategies (Wales) Measure 2011 the Alliance was keen to see minimum standards on what information would be provided and to ensure that examples of good practice by local councils providing support for carers would not be lost by Health Boards taking over this work.

Both Measures were passed and are now law. In both cases the Alliance ensured that the concerns of people living with neurological conditions were understood by Assembly Members of all parties, and that our concerns were reflected in amendments to the Welsh Government’s proposed Measures.

## **Map of Medicine**

In early 2010, Alliance members were representatives on the Welsh Neuroscience expert group, which agreed the development of care pathways for neurological conditions and considered the breadth of areas that needed to be included, such as early recognition, prompt diagnosis and treatment; acute care; community rehabilitation; specialist equipment; accommodation and support for family and carers. The outcome from the expert group was the Map of Medicine which is an online clinical knowledge resource, designed and developed by healthcare professionals to provide specialist-level information to the right person at the right time.

Map of Medicine provides 24/7 access to evidence-based clinical pathways, grouped into broad areas of clinical practice, via an intuitive web-based interface.

The Map of Medicine has been selected as the clinical pathways tool to help healthcare professionals plan the best possible treatment programmes for Welsh patients.

The Map, which offers over 400 patient-care pathways, was selected following a competitive national procurement and is now available across NHS Wales.

### ***Features and Benefits***

Map of Medicine provides:

- Access to specialist level knowledge, available every day, all day, through an easy to use, intuitive graphical interface
- Clinical effectiveness, by facilitating local implementation of clinical guidelines and care pathways
- Current evidence-based knowledge, assured through quarterly updates
- Information tracking made easy, by means of fully printable pathways, local administration information, personal notes and standardised referral templates
- Teaching, learning, and ongoing professional development for health care professionals at every level
- Integrity of content and quality of application functionality that is assured by robust clinical review and critique at every level, as well as via easy-to-use feedback links found on every page

Informing Healthcare has evaluated the usefulness of a clinical pathways tool. Map of Medicine is the product that was chosen for the evaluation and has now been licensed for use for 3 years.

Map of Medicine has provided immediate benefits during the pilot period and helped to identify whether Wales could continue with a clinical pathways tool in the future. Members of the Alliance are participating in the neuroscience related pathways contributing an essential third sector perspective.

### **Wheelchair Services Review / Posture and Mobility Review** ***Improving wheelchair services in Wales.***

Throughout 2010 the Alliance has been working with the NHS managers, the Welsh Government and opposition parties in the National Assembly for Wales to improve access to wheelchairs in Wales.

In May 2008 the Minister for Health and Social Care announced a review of wheelchair provision in Wales to look in detail at long and short-term loans, adult and paediatric wheelchair services. The review was slow progress and the Alliance was concerned by the number of people who had to wait over 18 months for an electric wheelchair.

The Alliance gave evidence to the Health, Wellbeing and Local Government Committee when they launched an inquiry into wheelchair waiting lists. This resulted in a report in May 2010 that reflected the Alliance's concerns and was very critical of the Artificial Limbs and Appliances Service (ALAS).

Following this report the Welsh Government launched Phase 2 of their own review, its aim being to make recommendations for improvements to the service by looking in closer detail at the eligibility criteria, quality indicators and key performance indicators together with a range of actions to ensure provision of an efficient and effective service to both established and new users.

The Alliance was represented on the Posture and Mobility Steering group, and members from across Wales provided case studies and testimonies to inform and influence phase 2 recommendations and the final report.

We are monitoring the implementation of this service improvement programme and will continue to do so, to ensure that wheelchair services are improved to meet the needs of our members across Wales.

### **Symptom Management Study Day**

In February the Alliance, in association with Swansea University, piloted a study day for health professionals on the theme of "Pain Management in Neurological Conditions".



Baroness Ilora Finlay, Alan Thomas, Ataxia, Wales, and John Dare, CMT United Kingdom (Charcot-Marie-Tooth disease)

Opened by Baroness Ilora Finlay the day's programme included three other speakers. Their subjects were "Chronic Pain Management", "the Pharmaceutical Approach" and "the Biopsychosocial Approach". There were also three separate workshop subjects, "Fatigue and Pain", "Mobility and Exercise" and "Electrotherapy".

The general view from delegates, and those Alliance members present, was that the day had been a success. There were clear lessons to be learnt both in areas that were done well and others which could be improved. The Alliance considers that more study days on a similar basis should be arranged, as and when resources allow.

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## **Website**

The Alliance received a Big Lottery Fund 'Awards for All' grant in early 2010 to develop an accessible, bilingual website. Work progressed during the year with the developer Lightsauce, and a pilot site was uploaded in October for Executive Committee members to peruse and comment on. In the last 3 months, some new and amended content has been added, some design features have been altered, and a translator has been commissioned to produce a Welsh language version of the site. The website will be unveiled at the Alliance's Annual General meeting on 23<sup>rd</sup> March 2011.

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