



Editorial

Welcome to the Fourth edition of the Neurological Alliance of Scotland's E-Bulletin.

This edition brings an update on the Neurological Voices programme which the Alliance is taking forward to ensure the involvement of people affected in neurological conditions in influencing the NHS. We are currently developing training resources and will work with member organisations and NHS to identify patients and carers who wish to participate in the Neurological Voices training.

We also give an update to the ongoing implementation of the NHS QIS Clinical Standards. NHS Boards have completed self evaluations for both the generic and condition specific standards and a series of events are taking place over the next couple of months. These condition specific events have been planned in partnership with a number of Alliance member organisations.

Finally, we offer a warm welcome to our newest member organisations, Brain Tumour UK and the Scottish Epilepsy Centre. We look forward to working with you.

Launch of the Alliance Manifesto

In partnership with a sub group of Alliance member organisations we have recently published and disseminated the Alliance manifesto. The manifesto sets out a series of 'key requests' which the Alliance wants the Scottish Government to address in order to improve the lives of people affected by neurological conditions in Scotland.

We have sent our manifesto to candidates of all political parties and asking for their support in:

- * Recognising the Impact of neurological conditions on individuals and their families and on Scotland.
- * Ensuring the voices of people affected by neurological conditions are heard.
- * Delivering care services that people affected by neurological conditions need.
- * Increasing knowledge relating to neurological conditions.

Members should have already received a copy of the manifesto. If you'd like any additional copies please [contact Margaret](#) The manifesto is also available as a PDF document on the Alliance website.



A Manifesto for People Affected by Neurological Conditions in Scotland



The Neurological Alliance of Scotland Members are:

25% ME Group	Headway: The Brain Association	Scottish Huntington's Association
Action for ME	Headway Glasgow	Scottish Spina Bifida Association
Alzheimer Scotland	ME Association	Scottish Stem Cell Network
Brain Tumour Action	MND Scotland	Spinal Injuries Scotland
Brain IAC	Momentum Scotland	Sue Ryder Care
Brain Tumour UK	MS Society Scotland	The Dystonia Society
Chest, Heart & Stroke Scotland	Muscular Dystrophy Campaign	The Haven
Child Brain Injury Trust	Pain Concern	The Stroke Association
Edinburgh ME Self Help Support gp.	Parkinson's UK	Tourette Scotland
Epilepsy Connections	PSP Association	The Towpath Trust
Epilepsy Scotland	Revive MS Support	Transverse Myelitis Scotland Support gp.
Epilepsy Support gp. Shetland	Scottish Epilepsy Centre	
	Scottish Head Injuries Forum	



Alliance News

Neurological Voices

The Neurological Voices programme has now commenced with Jan Anderson, Training and Support Coordinator, starting in post with the Alliance at the end of February.

The first phase of the programme will involve shadowing some of the Chest, Heart and Stroke Scotland, Voices training and Jan and Candice have recently attended a 'Chest Voices' training event in Fife. Jan is also beginning to develop specific resources for Neurological Voices training which will be accessible and suitable to all those affected by neurological conditions. The training will take a person centered approach, ensuring that participants are given the space to discuss their experiences, learn about the key structures of the NHS, identify and prioritise specific areas of improvement and develop a 'case for change' which can then be presented to their local improvement group. An advisory group will also be established to advise the initiation and delivery of the Neurological Voices programme and will be particularly useful in guiding with recruitment to the training and deployment of those trained thereafter.

Health Improvement Leads have been identified in all NHS Board areas and all have been contacted in regard to the Neurological Voices programme. The Alliance is seeking to establish what patient representation is already in place at local levels and what future opportunities and mechanisms will be in place for participants of Neurological Voices training. Initial responses have identified some NHS Boards as particularly keen to work with the Alliance regarding delivery of the Voices programme and to support patients and carers to input locally to the improvement of neurological services. Boards are currently in the process of developing three year local improvement plans for neurology and it will be important to provide opportunities for input from people affected by neurological conditions.

All member organisations will be kept up to date with the development of the Neurological Voices programme and it is hoped that many will engage with the programme, providing information and opportunities to get involved to their members. For further information about the programme and to register interest in participating please [contact Jan](#).

Healthcare Improvement Scotland

Healthcare Improvement Scotland (HIS) came into existence on the 1 April 2011 and will build on work previously done by NHS Quality Improvement Scotland and the Care Commission. HIS aims to deliver excellence in improving the quality of the care and experience of every person in Scotland every time they access healthcare by supporting healthcare providers to deliver high quality care; and scrutinise those services to provide public assurance about the quality and safety of that care.

The Clinical Standards for Neurological Health Services are being implemented using HIS improvement methodology. All NHS Boards have now completed their self evaluations of both generic and condition specific services and are being supported by HIS to take forward priorities. A series of teleconference are being held by HIS focusing upon specific areas of improvement in addition to meetings of the advisory group and Health Improvement Leads.

There are a number of condition specific events being held for all staff involved in the delivery of neurological services and people living with conditions. The events aim to share the challenges and opportunities relating to improving neurological services and assist service providers to gain a greater understanding of what is important to people affected by conditions.

To find out more and register for forthcoming events visit the [HIS website](#).



Alliance News

New Staff

The Alliance has now expanded to a team of three staff members! Margaret Kane took over as Alliance Administrator in the autumn of last year and Jan Anderson has very recently begun in post as Training and Support Coordinator and will take forward the delivery of the Neurological Voices programme. Both Margaret and Jan bring a great deal of experience to the Alliance and are sure to be great assets. A very warm welcome to them both.

Brain Awareness Week 2011

The Alliance held an evening reception in the Scottish Parliament on Tuesday 15th March to mark Brain Awareness Week 2011. The event was sponsored by Malcolm Chisholm MSP, and brought together people affected by neurological conditions, voluntary sector organisations, Health professionals and MSPs. This year's event presented the Alliance manifesto and discussed its key asks, hearing examples of what is done well and what still needs to be improved.

The event began with an interview by Catriona MacGregor from Headway UK with Colin who is a member of Edinburgh Headway group. Colin spoke about the impact of living with Acquired Brain Injury and what has helped him to improve his quality of life. Colin's honesty gave a real insight to some of the difficulties of living with what is often a 'hidden' disability.

Karen Thomson presented about the effectiveness of Speech and Language Therapy with people with progressive neurological conditions and the audience were shown a video example of the benefits of SALT with a man living with Parkinson's Disease. The event also heard from Roy Hunter about Chest, Heart and Stroke Scotland's 'Stroke Voices' programme accessible to those with communication difficulties and the value of this approach in involving people affected by Stroke in the NHS.

Feedback about the event has been very good with people particularly enjoying the range of presentations.

Consultation and Policy

The Alliance recently submitted a response to the consultation for the proposed Disability Living Allowance reforms. The views of various member organisations were gathered to inform the Alliance response. Thanks to all those who provided information. [Click here](#) to read the Alliance consultation response on our website.

We intend to conduct a survey with all member organisations in the near future to identify member organisations policy priorities and key issues. We will use the gathered information to identify areas of common concern which can inform future Alliance campaign activity. The survey will be available online making it easy for members to complete in a non time consuming way.

Website

The new and improved Alliance website has been given some excellent feedback by users since its launch in September last year. We want to ensure that the site provides all member organisations with the opportunity to share news and articles of interest and to highlight events. If you have any information you would like to include on the Alliance site please [contact Margaret](#) and she will be happy to add it to the appropriate section.