

Neuro News

ALLIANCE NEWS

NEUROLOGICAL ALLIANCE MOVING TO A NEW OFFICE SPACE

The Alliance has been offered excellent rent-free accommodation in the Dana Building of the Science Museum, 165 Queens Gate, London SW7 5HE (www.danacentre.org.uk). The American philanthropic organisation the Dana Foundation, which contributed to the construction of this inspiring building, has a strong interest in brain research and leads Brain Awareness Week. The Alliance will have access to spacious meeting rooms and two hot desk spaces for visiting member organisation staff or Trustees. We hope that the Dana Centre, which includes public spaces for science learning events, will become a hub for the neurological community. We intend to move at the end of July and will send out full new contact details then.

Moving means leaving the Stroke Association, who have been generous and supportive hosts of the Alliance for 3 years. On behalf of the Alliance staff and Trustees we would like to extend sincere thanks to Alliance Trustee and Chief Executive of the Stroke Association Jon Barrick, and all his team who have made the Alliance so welcome - we will miss being based in the same offices but plan to go on working with them closely.

NEUROLOGICAL ALLIANCE MANIFESTO

The Neurological Alliance has developed a set of core asks that make up our Manifesto (attached). Many of our member organisations have played an active role in developing the manifesto, for which the Trustees and staff of the Alliance are very grateful. The official launch of the Manifesto will take place this autumn, at which point your organisation will be receiving:

- • a longer version, containing supporting evidence,
- • ideas on how to use the Manifesto locally and nationally, and
- • lots of hard copies of the short version for staff and contacts.

We are sharing the asks with you now because we will be discussing them in a number of meetings with government stakeholders over the next few weeks. These are the things which we collectively believe would move us from a vision of excellent services to a reality of high-quality joined-up care throughout England. Please take any opportunity to talk about the Manifesto asks: together we can make a really strong case for action.

If you want to support our work or receive hard copies of the Manifesto 'postcard', please email manifesto@neural.org.uk

Write to your local MP. For guidance and links on how to campaign in Westminster, please visit

<http://www.neural.org.uk/campaigning/campaigning-in-westminster>

NEUROLOGICAL ALLIANCE ESTABLISHES FORMAL POLICY GROUP

The Trustees of the Alliance have agreed that our member organisations should have more scope to debate and discuss Alliance policy and to plan our collective work. They have therefore decided to replace our old informal Parliamentary Affairs Network with a more formal Policy Group.

We would like to invite members to nominate a staff member to join the new Neurological Alliance Policy Group. This group will nominate its own Chair, who will be invited to attend all meetings of the Executive Committee.

The Policy Group will meet every two months in London and is open to one representative from each of our national member organisations. The first meeting will take place on **Monday 13 July** from **10am to 12pm** at the **Parkinson's Disease Society**, PDS National Office, 215 Vauxhall Bridge Road, London, SW1V 1EJ. Please email **Tahani Saridar** at tahani.saridar@neural.org.uk or call 020 7566 1540 if you would like to join the Group, or require any further information. The Terms of Reference for the Policy Group is attached.

ENGAGING WITH NHS CHOICES: IMPROVING THE QUALITY OF NEUROLOGICAL INFORMATION

As you will be aware, the Neurological Alliance is working with NHS Choices to improve the quality of neurological information and advice available on-line. Many of you attended the event held on 12 May at the Imperial War Museum, London, hosted by NHS Choices, at which it was agreed that the immediate focus for collaborative working would be the review of the website's Health A-Z.

Yesterday saw the launch of the review, which will be carried out over a 12 month period, with neurological conditions being reviewed in four batches. If you would like to improve the information relating to the condition your organisation represents, and provide case studies and links to specific pages on your website, please contact **Tahani Saridar** at tahani.saridar@neural.org.uk or call 020 7566 1540. The Health A-Z content submission form, containing further information, is attached.

MEMBER ORGANISATION AND RELATED NEWS

NUMBERS OF PEOPLE WITH MS HIGHER THAN PREVIOUSLY ESTIMATED

The MS Society has funded a study of GP records, which provides an accurate estimate of the number of people living with a diagnosis of MS in the UK. The results show that there is likely to be around 100,000 people with MS in the UK - a 20 per cent increase on previous estimates of 85,000 people. The revised figure has major implications for health and social services and the study is a precursor to a pilot MS Register, which will provide much more information on exactly how MS affects individuals.

Knowing how many people have MS is important so that health and social

services can provide the right types of care and support. In many areas of the country people do not currently have access to all the nursing care, drugs and treatment regime that they so desperately need.

(Source – MS Society website

www.mssociety.org.uk/news_events/news/press_releases/numbers_pwms.html)

Read the full Strength in Numbers briefing document at

http://www.mssociety.org.uk/downloads/MS_prevalence_study_briefing_June_2009.da86e70b.pdf

Download the Strength in Numbers campaign leaflet at

http://www.mssociety.org.uk/downloads/Strength_in_Numbers2NEW.42fc66de.pdf

NHS EVIDENCE AND THE LESSONS LEARNED REVIEW

As you will already be aware, the National Library for Health (NLH) and its specialist libraries became part of NHS Evidence on 1 April 2009. The NHS Evidence portal and search engine became available on 30 April 2009 at www.evidence.nhs.uk

As part of ongoing developments, the specialist libraries have changed their names and are, as a group, now called specialist collections. This individual collection is now NHS Evidence – neurological conditions.

Following the move from the National Library for Health to NHS Evidence, the Specialist Collections (formerly the NLH Specialist Libraries) are undergoing a Lessons Learned Review over the summer, looking at what works well and what we should be focusing on in the future. As part of the review, NHS Evidence have put together a survey open to all members of the specialist collection advisory, stakeholder and external reference groups. If you would like to feed into this review, the survey can be found at

http://www.surveymonkey.com/s.aspx?sm=VTHTV5XNK7UiKT81zV03EQ_3d_3d – the closing date is Friday 10th July.

(Source – Neuro Specialist Collection newsletter)

NEURO SPECIALIST COLLECTION EMAIL UPDATE

The Neuro Specialist Collection produce an email update on their activities, which many of you may find useful. If you would like to sign up, please visit www.library.nhs.uk/neurological/Page.aspx?pagename=NEWSLETTER

HEALTH NEEDS ASSESSMENT FOR LONG TERM NEUROLOGICAL CONDITIONS IN NORTH EAST ENGLAND

A health needs assessment (HNA) for Long Term Neurological Conditions (LTNC) has been carried out by the North East Public Health Observatory (NEPHO) on behalf

of the Regional Neuroscience Commissioning Network. The HNA has been developed in parallel with the North East Strategic Commissioning Plan for Neurosciences. The key policy document underpinning this HNA is the National Service Framework (NSF) for Long-term Conditions. The purpose of this HNA is to provide an overview of the demand for neurological services across the network, although it also describes the data that are available and the problems and limitations associated with them.

(Source: NEPHO, 5 June 2009)

DEPARTMENT FOR WORK AND PENSIONS LAUNCH RIGHT TO CONTROL SCHEME

On 11 June, the Department for Work and Pensions launched a national consultation that could dramatically change the way every disabled person lives their life. Right to Control is a shake up of the way disabled people can use the funding they receive from the state. The policy forms part of the Government's radical welfare reforms and will for the first time enshrine in legislation the principle that disabled people are the experts in their own lives and have the right to choice and control over their support.

Under the new scheme, disabled people will be able to choose who delivers their services and how they receive them. Disabled people and their organisations are being asked to help shape this initiative – by taking part in the consultation they can influence how the Right to Control works.

(Source – News Distribution Service for Government and the Public Sector)

Individuals and organisations can take part in the consultation by visiting www.odi.gov.uk/right-to-control or calling 020 7449 5093.

For the full article, please visit <http://www.neural.org.uk/updates/69-DWP-launch-Right-to-Control-scheme>

CARERS STRATEGY ONE YEAR ON: NEW HOTLINE FOR CARERS LAUNCHED

A one-stop information and advice service for carers was officially launched on 10 June by Care Services Minister Phil Hope. The Carers Direct (www.nhs.uk/carersdirect) hotline aims to make England's 5 million carers' lives easier and reduce the time and stress of searching out essential advice. The launch comes on the one-year anniversary of the publication of the Government's Carers Strategy. Later this year, they carers will also receive more support to get or return to work.

Carers Direct is complemented by Caring with Confidence (www.caringwithconfidence.net) a training course available to carers face-to-face, online and by distance learning. Caring with Confidence inform carers of their rights, the services available to them and networks which might support

them. The Department of Health is investing around £4.6 million a year into Caring with Confidence.

(Source – News Distribution Service for Government and the Public Sector)

For the full article, please visit <http://www.neural.org.uk/updates/68-Carers-Strategy-One-Year-On:-New-hotline-for-carers-launched>

UK RATIFIES HUMAN RIGHTS TREATY FOR DISABLED PEOPLE

On 8 June, the Minister for Disabled People, Jonathan Shaw, announced UK ratification of an international treaty that enshrines the human rights of disabled people.

The United Nations Convention on the Rights of Persons with Disabilities is a powerful and explicit statement, which states that disabled people must be able to enjoy, on an equal basis, the same human rights as others.

(Source – News Distribution Service for Government and the Public Sector)

For the full article, please visit <http://www.neural.org.uk/updates/67-UK-ratifies-human-rights-treaty-for-disabled-people>

FORTHCOMING EVENTS

SAVE THE DATE! NEUROLOGICAL ALLIANCE AGM SET FOR TUESDAY 24 NOVEMBER

The Alliance is holding its 2009 Annual General Meeting and a mini-conference on Access to Services on Tuesday 24 November. To be held at the Dana Centre, this day will also give you the opportunity to see the Alliance's new office space. Please save this date: more information will follow shortly.

WEST BERKSHIRE NEUROLOGICAL ALLIANCE CONFERENCE

Brains, Pains and Gains

Date: 9 July 2009

Time: 9am to 5pm.

Venue: Arlington Arts, Mary Hare School, Newbury, RG14 3BQ

West Berkshire Neurological Alliance (WBNA) is hosting a one-day conference on managing pain. Speakers include pain consultant Dr Stephen Allen, Neuro-Rehab consultant Professor Christine Collin and Neuro-physio Penny Lilley.

Further information is available on the WBNA website: www.wbna.org.uk.

For any enquiries, please contact WBNA on 01635 202605 or email conference@wbna.org.uk.

Persons living or working in Berkshire West (Newbury, Reading, Wokingham and surroundings), are invited to contribute to the **Berkshire West Pain**

Survey on pain and pain management. Please visit www.wbna.org.uk to access the survey.

ASSOCIATION OF BRITISH NEUROLOGISTS (ABN) ORGANISE A FUN RUN TO RAISE AWARENESS OF NEUROLOGICAL CONDITIONS

The Association of British Neurologists is hosting their 2009 Annual Meeting at The Arena and Convention Centre (ACC), Liverpool this week. Optimising on the opportunity provided by having a large number of neurologists gathered in one location, neurologist Dr. Peter Moore has organised a 5k waterfront run/race for neurologists. Taking place today, this 'fun run' aims to raise awareness of neurological conditions and the charities that represent them. Members of the Alliance have shown overwhelming support for this event. Thanks go to the many organisations who donated branded t-shirts for neurologists to run in, and in particular to Gillian Carberry from the Parkinson's Disease Society and Chris Lynch and Alun Owen of the MND Association, for volunteering to act as stewards at the run. Thank you also to Tony Murphy, PALS Manager at The Walton Centre, for facilitating this event and to Neurosupport for kindly manning a stall on the Alliance's behalf at the ABN Conference.

For the full stories reported here, please visit the Neurological Alliance website www.neural.org.uk or sign up to our Neural Hub <http://neuralhub.ning.com> where you can discuss these news items directly with other Neurological Alliance members.