

REGIONAL NEURO NEWS

Issue 1 January 2010

Welcome to the first issue of a newsletter designed specifically for Regional Neurological Alliances. Its aim is to update everyone about news from the NAs Regional Development Project, to share information about what other RNAs are up to and generally keep you in touch with what is happening nationally. Sections in this issue include

- ✦ New RNAs
- ✦ Events
- ✦ RNA Development Project News
- ✦ Update from RNAs around the country and
- ✦ National News

If you have any news, want to celebrate, need to commiserate or just want to share some information with other RNAs I'd be really pleased to include it in the next issue. In the meantime, I hope you find this useful. Happy reading!

New Regional Neurological Alliances

A huge welcome to five newly affiliated RNAs! Here's a list of them with some brief background information.

London RNA

This group has existed for 3-4 years as the London Neurological Conditions Group and was set up initially as a resource for regional staff. Its chaired by Annie Clacey from Headway and has members from MS Society, Parkinson's Disease Society, Stroke Association, Huntingdon's Disease Association and the MND Association. It covers all of Greater London and has already hosted an event for commissioners and produced a Service Directory that provides standard-format information about the services of its member organisations. Future plans include developing a website and raising awareness amongst GPs. Annie is the main contact and can be reached at London.co-ordinator@headway.org.uk

Oxfordshire RNA

This group formed in 2008, led by a hugely committed volunteer; June Stephen. Its launch event this year was attended by well over 100 delegates from neuro organisations, commissioning bodies and by lots of people with or caring for someone with, a neuro condition. Fred Davison whom many of you will know as our Regional Trustee on the NA Board and Secretary of the thriving West Berkshire RNA put in lots of time to support ONA in its early days, as has Dennis Morgan from the MS Society, who has recently been elected Chair. ONA is now progressing well in providing information and educational events. It has

full support from the local PCT and County Council, sits on the Local Implementation Group and is contributing work to a needs assessment. There are two main contacts; Dennis dmorgan@mssociety.org.uk and Sheila Bailey-Watts sm.bw@virgin.net

Sussex RNA

This group formed recently and is led by Rikki Gandolf from Headway who has been tireless in working towards establishing a strong RNA for Sussex. Aims include campaigning for positive change, providing information, including service users and carers and working in partnership with health and social care. It covers 3 PCTs; East Sussex, West Sussex and Brighton and Hove. Membership currently includes regional staff from PDS, MS Society, MND, HAD, Epilepsy Action and Sussex ASBAH. The extended membership includes a local PCT, the LTC Team Lead for the South east Coast SHA region and the local Fibromyalgia Group lead. Sussex RNA (SRNA) is already represented on some of the key local boards and forums and is quickly becoming established amongst local commissioners as their first port-of-call for the neurological third sector and service user input to service design. SRNA is developing publicity materials to expand membership and is planning a launch conference to be held in the spring. Rikki is the main contact at se.regional.co-ordinator@headway.org.uk

Buckinghamshire RNA (BANO)

The Buckinghamshire Alliance of Neurological Organisations (BANO) formed in Spring and affiliated to us as an RNA IN September 09. It covers Buckinghamshire PCT (excluding Milton Keynes). It is led by Fiona Turner from MND and includes regional staff from Headway, Parkinsons UK, PSP, MS Society, Stroke Association, ASBAH, Sue Ryder Care, HAD, Alzheimers, PSP, Epilepsy Society, Bucks Disability Services. West Berkshire RNA (WBNA) has provided welcome support along the way and still attends meetings. The RNA aims to represent the voice of service users and the 3rd sector at strategic and service development level locally and facilitate user/carers involvement in the commissioning process. It aims to speak for the neurological community with an authoritative and united voice. BANO is already represented on the Bucks Partnership Board and LIT and are consulted regularly by local NSF Leads and Commissioners. Fiona is the main contact and can be contacted at fiona.turner@mndassociation.org.uk

Yorkshire and the Humber RNA (YHANO)

Originally formed as a VOWNnet in 2007, this group affiliated to the NA and re-launched as an RNA in November 09. It covers the entire SHA area (13 PCTs) and aims to establish direct lines of communication between neurological service decision makers and people living with LTNCs. The RNA is already supporting a review of services in NE Lincolnshire and York + N. Yorkshire PCTs and intends to support new/more local RNAs as they establish in the Yorkshire and Humber area. Its membership currently comprises the regional staff of the MS Society, Headway, MND, Parkinsons UK, Huntingdons Disease Association, Epilepsy Action, National Society for Epilepsy, PSP, the Meningitis Trust and Sue Ryder Care. It is chaired by Liz Whilde from the MS Society, who can be contacted at lwhilde@mssociety.org.uk

Events

The RNA Spring Forum isn't far away now. For those who have recently joined us, we hold two fora per year, aiming for one in the north and one in the south of England. Each one is hosted by an individual RNA and receives planning and financial support from the RNA Project. Held over two days the 2010 Spring Forum is being hosted by Greater Manchester Neurological Alliance (GMNA) and is on **21st and 22nd April in Manchester**. 2010 marks the half-way mark for the NSF and this will be the theme for the event, particularly on the second day when we will consider the Department of Health's NSF mid-point review. We will send out more information as we develop the programme, but in the meantime, please do put these dates in your diary! For more info contact GMNAs Co-ordinator, Yvonne Trace at yvonne.trace@gmneuro.org.uk or nicolette123@o2.co.uk

The NSF – halfway there or middle of nowhere? Merseyside and Cheshire RNA is hosting an event to mark the mid-point of the NSF and ask; "Where are we now?" It will be held on the same day and at the same venue that the NSF was originally launched; **10th March at Neurosupport in Liverpool**; – all very synchronistic! Aims of are to

- ✚ Review progress and achievements of the NSF for LTC at its half way point
- ✚ Showcase examples of good practice
- ✚ Provide information on the national and Regional Neurological Alliances
- ✚ Consider the role of the voluntary sector in influencing service developments
- ✚ Encourage active participation and membership of the regional alliance

For further information contact the Chair, Julie McWilliam at jmcwilliam@mssociety.org.uk. To book contact carolyn@neurosupport.org.uk 0151 298 2999

Conference on Epilepsy Services

The Department of Health, UCB Pharma and the Joint Epilepsy Council are hosting "Best Value, Better Care – Commissioning Epilepsy Services" on Tuesday **23 February** 2010 from 9.30am to 4.30pm at the Holiday Inn, London Kensington Forum. This event is a key opportunity for commissioners and clinicians of epilepsy services to come together to find out how commissioning high quality services can make a very real difference to the thousands of children and adults living with epilepsy. For further information, contact Tom Loader 0207 972 3049 tom.loader@ltc-team.org.uk

Managing Long Term Conditions Conference

This year's Harrogate conference is on **15th and 16th April**. As those who have attended in previous years will know, the conference comprises several "streams," each with its own plenaries and workshops. The NA has been invited to organise and chair one of the streams this year and is working hard to ensure that we shape this to reflect current strategic priorities, particularly to health and social care professionals. The opportunity provides us with a great opportunity to influence and engage this key group of people and you are all invited to forward suggestions to help shape the day.

Project News

Brand New Posts; RNA Project Area Leads (RNA PALs)

We are absolutely delighted to announce that the Project will be recruiting to 5 new geographically based posts across England during 2010. Simon Gillespie, the Chief Executive of the MS Society and RNA Steering Group Chair wrote to all Chief Executives of NA member organisations last week inviting applications, so you may already be aware that posts are for 2 days per week on a secondment basis and are open to any regional staff of NA member organisations. These leading roles will work with the Regional Development Manager to establish and strengthen the National RNA Network. They mark an exciting development for the RNA Project and will significantly increase the capacity available to support local RNAs. They are also a great opportunity for successful candidates to take the leading role locally in establishing the National Network. The closing date for the first trench of appointments is 12th February. **If you haven't already received information from your employing organisation and would like to learn more (job description etc or just a chat) Contact Nicolette Williams for more information nicolette123@o2.co.uk or 01905 641 028**

New Project Steering Group

Another exciting development for the project is the establishment of a new senior level steering group. We are delighted to announce that the Group is being chaired by Simon Gillespie, Chief Executive of the MS Society. The RNA-related staff and trustees are hugely grateful to have the sponsorship of such a talented project sponsor and are excited about the future of the project. Other members currently include Steve Ford, CE of the Parkinsons Disease Society, Sue Millman, CE of Ataxia UK, Kirstine Knox CE of MNDA and Fred Davison Secretary of WBNA. News from this important new group will be shared in future issues of this newsletter.

Neural Hub

The Neural Hub is the area of the NAs website that's dedicated to RNAs. Its still in its infancy, but we hope it will become a place to ask questions of colleagues from other RNAs, share news, promote events or even chat using the new chat facility. If you don't have a website or a place to post up documents etc we can set up a restricted area of the Hub that would be accessible only to members of your RNA. London RNA is using this facility now to post up their core documents, news, diary-dates and discussions etc. We're working hard to make the Hub better suit RNA needs and I'll be sending out a brief questionnaire soon to see what facilities and functions you'd like most. I'll use the results of this to work with our web-designer and improve the site. If you're interested in a restricted area of the Hub for your RNA let me know; nicolette123@o2.co.uk

News from RNAs

This is a section for you to share what's going on in your patch, so do let me have items for the next issue. It doesn't have to involve lots of writing; just a couple of bullet points to let each other know what you're focusing on or what your issues are or what you're celebrating, would be great! The deadline for the next issue is 12th March. nicolette123@o2.co.uk or 01905 641 028.

In the meantime, here's some news from around the country to get you started

- ✦ **Northern NA** has secured PCT funding for a Communications and Information Officer post
- ✦ **TVDNY and Northern RNAs** have just appointed a new provider for their shared website, www.na-na.org.uk . As some of you will know na-na also hosts the North East Neurosciences Network website. It is to be refreshed and re-launched and will go live on 1st March
- ✦ **BANO** is working on a Directory of 3rd Sector Neuro Organisations in Bucks and on a BANO promotion / information leaflet
- ✦ **Sussex RNA** is working on a promotional leaflet for Sussex and has advertised locally for a Chair
- ✦ Following their highly successful bi-annual conference Brains, Pains and Gains and internet pain survey, **WBNA** has formulated a number of recommendations on pain services in Berkshire West, particularly in relation to primary care
- ✦ On September 18th ten volunteers from **WBNA** collected £1048 at the gates of Newbury Racecourse at the end of racing
- ✦ **SWANO** wrote to all NA member organisations inviting them to send representatives along and have as a result increased their membership to include 15 separate organisations
- ✦ **Oxfordshire RNA** has secured funding from its local LINKs to produce a promotional leaflet

National News

New Chief Executives for the Alliance

Following the resignation of Lucy Brazg, we are delighted to welcome two new Joint Chief Executives to the Alliance, each of whom will work two days per week. Clare Moonan Health Policy and Campaigns Manager at the Parkinson's Disease Society will lead on policy issues for the Alliance and Katie Smith, Executive Office and Governance Manager at the MS Society will lead on internal issues.

Department of Health Mid-Point Review of the NSF for LTNCs

March 2010 is the mid point of the NSF 10 year strategy for long term neurological conditions. It is therefore a key milestone in the progress towards full implementation.

The DH Long Term Condition Delivery and Support Team has been commissioned by the Department of Health to lead on a Mid Point Review. The team is working closely with representatives of Health, Social Care and the Neurological Alliance to agree a methodology that will enable the review to provide useful and meaningful information to assess progress to date and allow localities to identify areas for further development.

The Review is likely to take place in spring with a report planned for the summer. Further information will be made available once the detail has been agreed. In the meantime, please cascade this information around your organisations and contacts to ensure people are aware of the intended Mid-Point Review as your contribution will be vital to this important piece of work

Care Quality Commission Special Review

Another piece of good news is that indications are positive for the CQC to include neurology on its short-list of topics for a "Special Review." This short-list of topics is due out for public consultation very soon. The results will determine which areas will receive a CQC review over the next two years and it is vital that we get as many people as possible to respond to the consultation with their "vote" for neurology if it is on the short-list as we hope. If it is on the short-list, we will write to you, asking you to get involved and suggesting ways to make your voices heard

NA Policy Group

All member organisations have been invited to join this group which reports formally to the NA Executive. It meets in London and is open to one representative from each of our national member organisations.

These bi-monthly meetings continue to be well attended by staff and volunteers of our member organisations, large and small. It is proving to be a really effective vehicle to allow members more scope to develop Alliance policy and plan our collective work. If you would like to attend but find travelling to London difficult, there is the facility to join via teleconference. If you are interested in attending, contact Clare Moonan

cmoonan@parkinsons.org.uk