

# South West Neuromuscular Network

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## Background — Jennie Shine

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Welcome to the first issue of the South West Neuromuscular Network Newsletter. The South West Neuromuscular Network came into existence following work by the [Muscular Dystrophy Campaign](#). This work led to their report entitled [“Building on the Foundations: The Need for a Specialist Neuromuscular Service Across England”](#) which was produced in December 2007 and highlighted inequalities in the services available to people with neuromuscular conditions. Their report investigated neuromuscular services and care throughout England and identified that life expectancy of a male with Duchenne Muscular Dystrophy varied across the country with the South West looking comparatively poor. This prompted an All Party Parliamentary Group for Muscular Dystrophy to investigate this further which resulted in the production of [The Walton Report](#) in August 2009.

The [South West Strategic Health Authority](#) and the [South West Specialised Commissioning Group](#) were the first NHS organisations to take on the challenge to improve the services and care, and in turn life expectancy, for people with neuromuscular conditions. In January 2009 all fourteen Primary Care Trusts in the South West

signed up and contributed funds to ensure improved provision and delivery of services provided through the Neuromuscular Network and also to provide the backing of key personnel (please see page 4 for their contact details) who will be able to help deliver and meet the aims of the network.

My role as Network Manager has two distinct parts:

- To manage five Neuromuscular Advisors who cover the South West providing support and advice to anyone within the region with a neuromuscular condition. However, please note that the network does not provide support to people with Parkinson's (<http://www.parkinsons.org.uk/>), Motor Neurone Disease (<http://www.mndassociation.org/>) or Multiple Sclerosis (<http://www.mssociety.org.uk/>), as it was felt good support networks were already in place for these conditions.
- To develop and manage the Clinical Network. The plan for the network is to have two main hubs (Bristol and Plymouth) from which the services will radiate like wheel spokes to provide outreach clinics;



## Background (*continued*)

to raise awareness and educate those professionals in contact with people with neuromuscular conditions. In order to provide a service to this group of people, the first step was to recruit Consultant Neurologists who are specialists in muscle disease. The first of these, an adult Neuromuscular Consultant, started at North Bristol NHS Trust in March 2010. A further two posts are on the way; one in Plymouth for adults and one in Bristol for children. There are other posts to be filled, such as physiotherapists and a psychologist, and I am working hard to ensure we get this provision right. As the network is growing it needs to be set up on a formal

footing with a multidisciplinary committee to drive it forward. My role also includes ensuring that the network is strong, resilient, innovative and that the services available to people with neuromuscular conditions in the South West are of a world class standard. The Network will foster collaborative working across the boundaries of professions and geography within the resources available.

There will be further opportunities for you to get involved, but I welcome any comments at anytime.

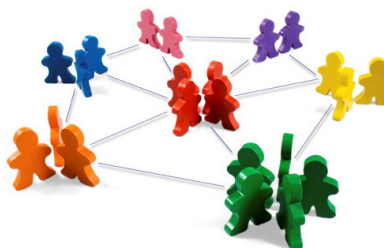
*Jennie Shine*  
South West Neuromuscular Network Manager

## Network Achievements — So Far

Since starting as the Network Manager on 1 October 2009 the following developments have happened:

- There are three new Neuromuscular Advisors in post to cover patients in South Bristol, Wiltshire, Somerset, Devon and Dorset. At present they are building up resources and contacts to enable them to support clinical services;
- We are negotiating the transfer of existing Advisors over to the Specialised Commissioning Group to complete the team of five Advisors;
- We have set up a web page on the Specialised Commissioning Group's website for professionals to share information and knowledge;
- A Neuromuscular Adult Consultant is now in post at North Bristol NHS Trust;
- A Neuromuscular Paediatric Consultant has been appointed and will be in post in Summer 2010 at North Bristol NHS Trust;
- A Neuromuscular Adult Consultant has been appointed and will be in post in Summer 2010 at Plymouth Hospitals NHS Trust;

- The Network Administrator started in Bristol on 1 March 2010;



- Engagement and meeting with clinicians who have shown an interest in neuromuscular conditions around the South West is ongoing;
- A formal meeting of neuromuscular professionals will be held on 18 March 2010—partly for education and partly for planning the structure and working methods of the network;
- The sending out of contact forms to known people with neuromuscular conditions has started with the aim of understanding the numbers and distribution of patients in the South West;
- Development of ideas and plans for filling the specialist physiotherapist posts;
- Assisting in the review of hydrotherapy services in the South West—a directory of services is due out in early March 2010;

- Visits to centres of excellence in Oxford, Newcastle and Cheshire have taken place to review best practice to inform the development of our Network standards;
- The first team meeting for all Neuromuscular Advisors has been held and each Advisor given their own locality to cover;
- A first briefing of our progress has gone back to the House of Lords;
- Negotiations are commencing to construct a South West Neuromuscular Network Steering Group.

## Neuromuscular Advisors

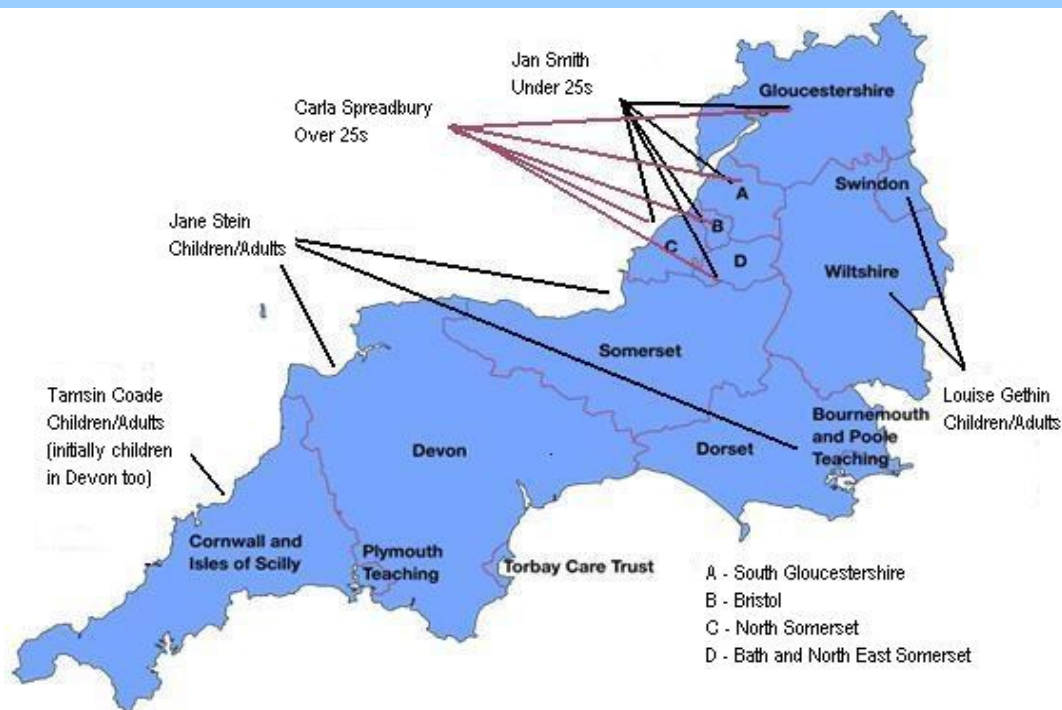
One of the improvements that the Network will institute is the installation of five Neuromuscular Advisors distributed around the region with a set geographical area of responsibility — see Diagram 1 for your Advisor.

The aim of the Neuromuscular Advisors is to help people achieve the best quality of life they can by ensuring they access relevant professionals and services that are available to them. The Advisors will be available in hospital clinics run by the specialist Consultants and they will also do home visits. They will cover people of all ages and so will be available to assist with advice on daily living ranging from school to workplace issues. Therefore, the

Advisors' main roles will be:

- To sit in on the neuromuscular clinic consultations with our new specialised Consultants in their 'patch';
- To offer advice and support about daily living needs and concerns;
- To follow-up clinic appointments in order to arrange home visits, accompaniment on other appointments or referral to other agencies;
- Overall, to help clients of all ages, and at every stage of their condition, to make the most of their lives with neuromuscular disease.

If you have a neuromuscular condition and live within the South West region you are welcome to contact the relevant Advisor direct.



## Network — The Future

### Our Aims

- To improve life expectancy of those people with neuromuscular conditions;
- To listen to people with neuromuscular conditions and to establish equity of care throughout the South West;
- To offer support and information to people with neuromuscular conditions;
- To unite professionals in a common field providing a resource for specialist information.

### Our Plans for achieving the above

- Three new Neuromuscular Advisors now in post and working with clients;
- Development of a Client Satisfaction Questionnaire;
- Build an accurate picture of the region to assist in planning of services so that these are located near patients;
- Development of a Multidisciplinary Neuromuscular Network Steering Group to enable further decision making regarding future service provision;

- Recruitment of Specialist Physiotherapists to support service delivery;
- Build and simplify service provision for new clinics whilst taking into account patient care pathways and standards of best practice;
- Development of services in Wiltshire and Dorset, and potentially Southampton;
- Develop a network of professional and voluntary sector contacts with a specific interest in neuromuscular conditions across the South West;
- Develop a website that professionals and people with Neuromuscular conditions can talk to each other and the network;
- Provide a resource for professional education and training;
- Facilitate the professional development of staff involved with the network in the form of a South West Neuromuscular Conference.

## Network Contacts

### Network Management and Administration

#### Jennie Shine

Neuromuscular Network Manager

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### Neuromuscular Advisors

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### Neuromuscular Consultants

#### Andria Merrison

Consultant Neurologist (Adult)

Bristol, Gloucestershire and Taunton

If you would like an appointment with any of the new Neuromuscular Consultants, please do this via your General Practitioner.