



Network Update

Issue 1 | August 2014

In the world of neuromuscular medicine, I'm pleased to report that our own south west wide network has made a major comeback. Despite the huge changes in the NHS, the transfer of specialised commissioning to NHS England, the centralisation of specialist paediatric services from Frenchay Hospital to the Bristol Royal Children's Hospital and adult neurology services to Southmead Hospital, the network has survived and come out the other side as an Operational Delivery Network (ODN).



Thank you for confirming your continued interest in the SW Neuromuscular ODN. We are delighted to deliver this bumper **SWiM Bulletin** to you — our first newsletter since becoming the SW Neuromuscular ODN. We keep getting asked, "What is an ODN?" Well, it's a clinically driven network of neuromuscular specialists and our aim is to work with all stakeholders (doctors, allied health professionals, trust management, primary care, commissioners, third sector organisations and, most importantly, patients and their families) to develop equitable, high standard services in the south west for patients with a neuromuscular condition.

There have been a number of changes to the network including new staff, hosting arrangements and governance structure. The SW Neuromuscular ODN is now hosted by North Bristol NHS Trust but, as you can see from the Who's Who list on page 3, ODN staff are hosted in a number of NHS organisations across the south west. Many of the staff are part time, so their over-arching role will be to attend specialist neuromuscular clinics, provide a specialist resource for colleagues throughout the region and offer training via local events and the SWiM Conference. Our aim is to ensure teams are confident in working with patients with rare neuromuscular conditions closer to where their patients live. We are in the process of updating the Board membership to comply with new governance arrangements and will keep you informed of developments via our new ODN website once this goes live.

Now that the dust has settled, I think the SW Neuromuscular ODN is going to be one of the most exciting places to be in the NHS right now. With your input we are in a position to improve and mould NHS services in the south west, and nationally, to greatly improve the treatment and quality of life of our patients and their families. This SWiM Bulletin will be one of the ways we keep you informed as an affiliate member of the network. It should also be used by you to inform your colleagues around the region of developments you have taken forward locally and share your knowledge and best practice. Our next Bulletin in January 2015 will focus on the exciting new genetic breakthroughs emerging right here in the south west. So, if you would like to contribute, please get in touch with myself or the Network Co-ordinators. Finally I hope you will be able to attend the next SWiM Conference on 20 November 2014; further details can be found on page 2.

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Get Involved

As the SW Neuromuscular ODN develops its governance structure and sets out its priorities, we would value input from our colleagues across the south west.



We will be developing patient care pathways for neuromuscular patients which involve multiple specialist input. There is an urgent requirement for pathways involving the following specialties:

- ◆ Respiratory
- ◆ Cardiac
- ◆ Gastroenterology
- ◆ Transition

If you have a particular interest in this field of medicine, and see patients with a neuromuscular condition, we would really appreciate you getting involved with the network. We will be developing specific patient pathway working groups, and if you would like to contribute to these and help shape and improve services across the south west, and possibly nationally, please contact the Network to register your interest.

We've lost touch

Unfortunately, due to changes with the Network and the overall NHS restructuring, many health and social care professionals have moved organisation and the Network has lost touch with them.

If you have a colleague who may benefit from being an affiliate member of the SW Neuromuscular ODN we would be very grateful if you could forward our Network Leaflet accompanying this Bulletin to them.

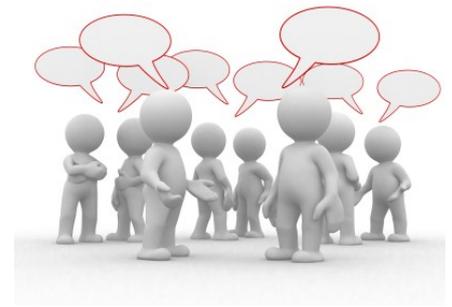


Any health or social care professional who has an interest in, or is delivering services for, people with neuromuscular conditions should be encouraged to become an affiliate member of the Network to ensure they are kept updated and have access to our specialist resources.

Winter South West Interest in Muscles (SWiM) Conference Thursday 20 November 2014 @ Taunton Racecourse

We are pleased to announce the date of the Winter SWiM Conference to be held on 20 November 2014 in Taunton.

The final programme will be published in August along with registration details. However, here is a summary of the programme, which we hope will convince you to attend! Based on past feedback for this FREE conference, it is not only a great opportunity to improve your knowledge about rare neuromuscular conditions, it also provides a great opportunity to network with your colleagues from a variety of specialist teams across the south west.



The morning session will focus on psychosocial aspects of living with muscle disease, including specific talks on quality of life from Dr Michael Rose (Consultant Neurologist, King's College London) and Mr David Abbot (Reader in Social Policy, Norah Fry Research Centre, University of Bristol) on research looking at the experiences of young men with Duchenne Muscular Dystrophy. There will also be an interactive workshop looking at how we can support young people to be ready for the transition to adult health services.

The afternoon session will focus on genetics and genetic treatments that are about to come on line and potentially revolutionise our care. Dr Andrew Norman (Consultant Geneticist, Bristol Royal Children's Hospital) will be talking about genetic treatments and Dr Antoniadi will be talking about new genetic technology. We will end the day with a panel discussion with the speakers about the impact of genetic discoveries and new technologies on neuromuscular patients followed by an open question and answer session.

Please keep your eyes open for the Programme and Registration Form in August and let your colleagues know to register their e-mail address with the Network if you think they would be interested in attending.

Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign (MDC) was awarded half a million pounds from the Department of Health in July 2013 for their ["Bridging the Gap"](#) Project. We are pleased to report that the SW Neuromuscular ODN will be collaborating with the MDC to deliver their national programme in the South West. We have agreed to have a SW Bridging the Gap Working Group that will link into the SW Neuromuscular ODN Board. The working group will consist of network clinicians, physiotherapists, GPs, commissioners, patient representatives and a member of the MDC. The MDC has set up a number of Neuromuscular Forums across England and Wales to deliver their national project of:



- * On-line map of neuromuscular services
- * GP e-learning module developed with the Royal College of General Practice
- * Emergency Care Plans to help reduce admissions but also to provide condition specific alert cards to help professionals when patients with rare conditions come in through Casualty.
- * Up-skilling events for healthcare staff around the region
- * Developing Standards of Care and NICE Guidelines.

Who's Who in the SW Neuromuscular ODN?

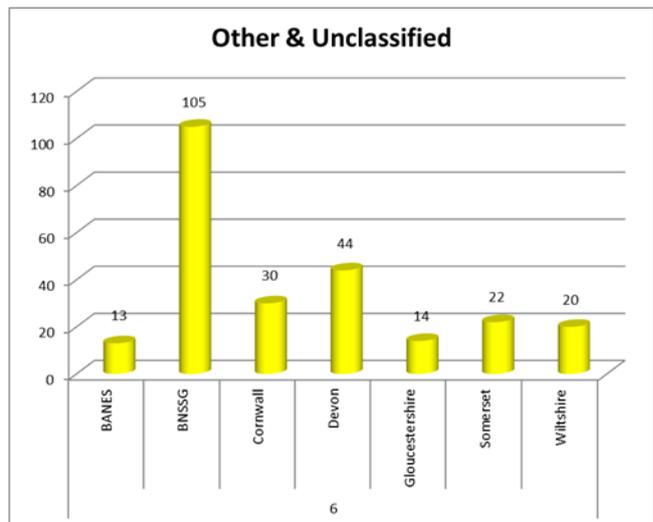
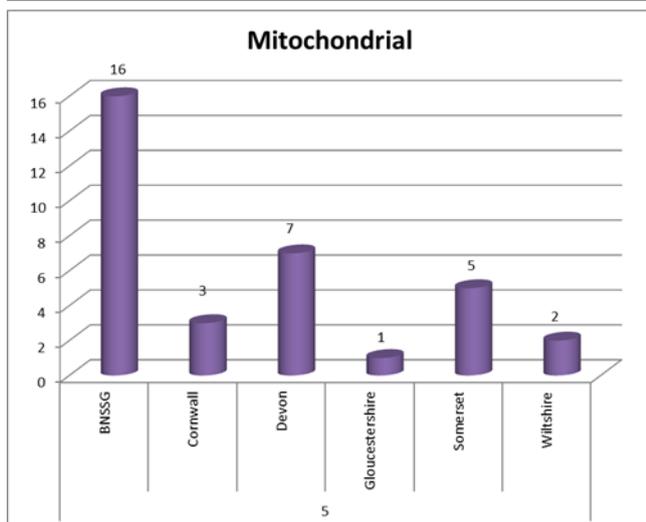
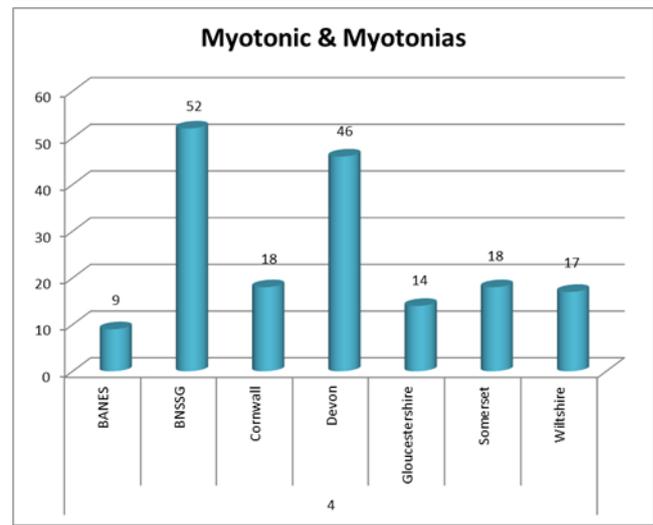
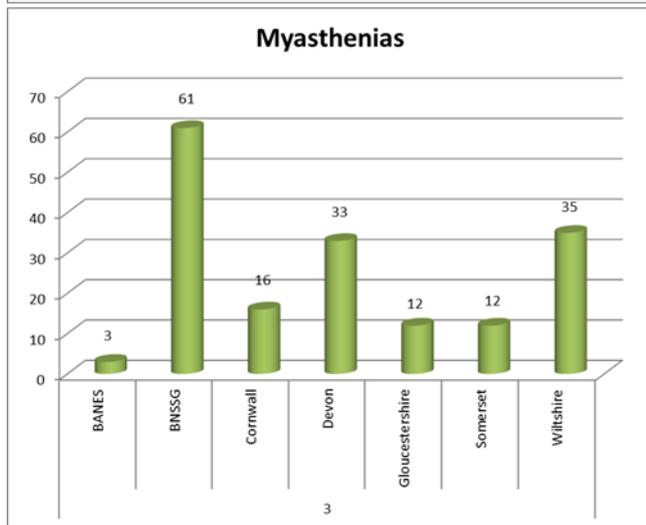
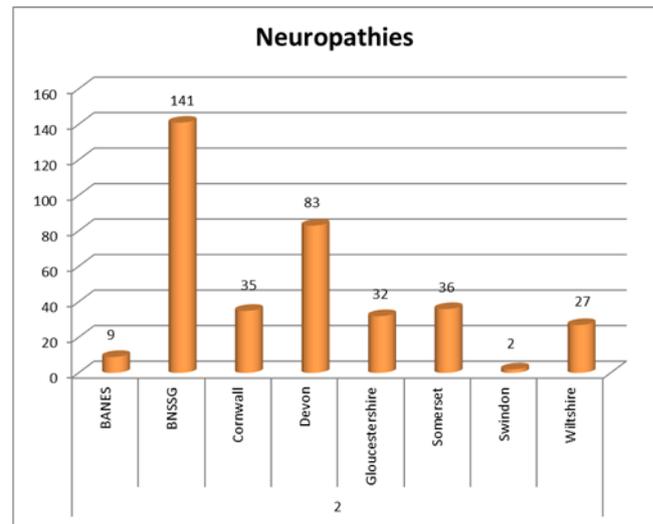
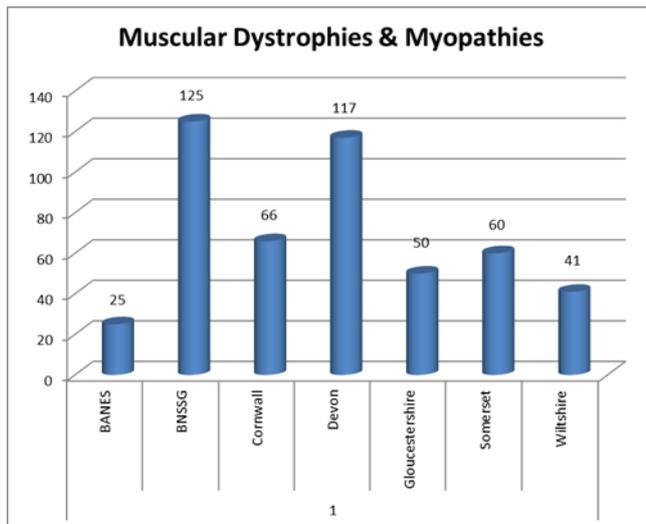
Paediatric Neurologists	Adult Neurologists
Dr Anirban Majumdar Bristol Royal Children's Hospital	Dr Andria Merrison Southmead Hospital Bristol
Dr Kayal Vijayakumar Bristol Royal Children's Hospital	Dr Liz Househam Derriford Hospital Plymouth
Paediatric Physiotherapists	Adult Physiotherapists
Bev Toms Bristol Royal Children's Hospital	Nicola Doran Southmead Hospital Bristol
Claire Eddy Royal Cornwall Hospital	Vicky Farrell (<i>nee</i> Flanagan) Peninsula Community Health, Cornwall
Claire Frimpong-Ansah Plymouth Child Development Centre	Geraldine Goldsmith (<i>nee</i> Lavallee) Mardon Neuro-Rehab Centre, Exeter
Neuromuscular Advisors	Ages and Areas covered
Elaine Burrows Southmead Hospital Bristol	Children & Adults: Glos, BANES, Swindon & Wilts. Adults: S Glos
Ann Morgan Southmead Hospital Bristol	Children & Adults: Bristol, N Somerset & Somerset. Children: S Glos
Vacant Post 1 Derriford Hospital Plymouth	Children & Adults: Devon
Vacant Post 2 Derriford Hospital Plymouth	Children & Adults: Cornwall
Neuromuscular Specialist Clinical Psychologists	
Dr Sadie Thomas-Unsworth Southmead Hospital Bristol	Dr Craig Newman Derriford Hospital Plymouth
SW Neuromuscular ODN Co-ordinators	
Sharon Standen Southmead Hospital Bristol Tel: 0117 41 41184 E-mail: Sharon.Standen@nbt.nhs.uk	Jane Kinney Southmead Hospital Bristol Tel: 0117 41 41185 E-mail: Jane.Kinney@nbt.nhs.uk

SW Neuromuscular ODN Patient Registry— Please tell your patients about us!



Below is a breakdown of the patients currently known to the Network. Unfortunately, this represents only about a 1/3 of what we would expect in the south west. We would appreciate it if you could inform your neuromuscular patients about the SW Neuromuscular ODN and encourage them to register their details with us so they can take advantage of our services. Our specialist Neuromuscular Advisors can support your patients throughout their lives, from diagnosis to end of life care, and guide them through the maze of local government and NHS services. The Network also organises a number of patient and public involvement (PPI) events across the south west. These events bring together patients and families for peer support, socialising and education.

For the Network to plan and influence service improvement across the south west we need to know the neuromuscular population. So please let your patients know about us and refer to our Advisors for extra support.



News & Events

SW Neuromuscular ODN Website



The Network has been without a functioning website for over a year now. Therefore, we are in the process of developing a new website for the South West Neuromuscular ODN. We aim to make this a useful resource for patients and professionals alike

across the south west.

We are planning a dedicated clinical section, to keep you updated on the latest developments in the neuromuscular world and locally, and will publicise events we are organising across the region for patients and professionals.

It's a very exciting project and we are really looking forward to launching this as soon as we can. We will notify you when it goes live.

Duchenne Muscular Dystrophy Project in Devon



Dr Craig Newman (Specialist Clinical Psychologist) and Geri Goldsmith (Specialist Adult Physiotherapist) are interested in gaining the views of adult patients with Duchenne Muscular Dystrophy in Devon, along with their families, to see how they are currently supported by the SW Neuromuscular ODN. The aim of this project is to ensure that families are aware of the services (including other local health and social care services) available to them, as well as how and when to access them. It will also provide an idea of what extra support would be most beneficial.

As part of the project, Craig and Geri will be liaising with local health and social care professionals. If you would like to know more please e-mail: nbn-tr.neuromuscular-odn.nhs.net.

Neuromuscular Transition Workshop

Dr Sadie Thomas-Unsworth, the Network's Specialist Clinical Psychologist, and members of the Network's Bristol Hub team will be running a Transition Workshop on Saturday 27 September 2014 at Southmead Hospital Bristol.

This will be the first of its kind in the region and the Network hopes to run these workshops yearly in both Bristol and Plymouth.

This workshop is by specific invite to families with young adults between the ages of 15 and 17. If you know of a family that may benefit from this, or want to find out more about the programme, please e-mail: nbn-tr.neuromuscular-odn.nhs.net.



Dr Sadie Thomas-Unsworth and Ann Morgan are running a "Living Well with Muscle Disease" course for adults who have a neuromuscular disease and are under the care of Dr Merrison, Consultant Neurologist, at Southmead Hospital Bristol.

With additional input from Nicola Doran, Specialist Adult Physiotherapist, the course aims to offer support to patients around adjusting and coping with their condition, especially if recently diagnosed, and offering practical support around managing their condition on a day-to-day basis. It will also provide the opportunity for patients with a neuromuscular condition to meet each other.

The course consists of four modules and starts in September 2014. To find out more, please e-mail: nbn-tr.neuromuscular-odn.nhs.net.

Find out more about the Specialist Physiotherapist role in Cornwall

Vicky Farrell (nee Flanagan) is probably well known to our affiliate members and patients down in Cornwall. However, if you would like to find out more about the role of one of the Network's Specialist

Physiotherapists who works with adult patients you may like to read this article "Way out West — A Profile of Vicky Flanagan" published by the Chartered Society of Physiotherapy in their Frontline magazine.

<http://www.csp.org.uk/frontline/article/way-out-west-profile-vicky-flanagan>



Devon & Cornwall Neuromuscular Advisors

We are pleased to inform you that the advert for the two Neuromuscular Advisors to cover Devon and Cornwall has now gone out. Please follow link below for further information.

https://www.jobs.nhs.uk/xi/vacancy/5568285abec609fc83eae5a7c09f70eb/?vac_ref=913468803

The closing date for applications is **10 August**. Please pass this round to colleagues. The Neuromuscular Advisors based in Bristol would be happy to give further information about the role. Just call 0117 414 1184/5.