



## Neurological Alliance — Neurology & Primary Care Report

This new report published by the Neurological Alliance has found that GPs in England lack confidence in the primary care pathway for people with neurological conditions. The report sets out eight recommendations aimed at improving the pathway including a pan-neurological “watch list” of the ten signs and symptoms GPs should be aware of. To find out more visit their website: [www.neural.org.uk](http://www.neural.org.uk)

## GP Practice Talks

- **Would your Practice team like to know more about neuromuscular conditions and our Network?**
- **Do you hold Practice Lunch time teaching sessions?**

**If Yes, then why not invite one of our Neuromuscular Advisors along to one of your team meetings? They can provide overview of the neuromuscular conditions we cover and how we can support your patients in the community.**

**Just call our office.....**

## Contact Us

South West Neuromuscular ODN  
Office 7, Gate 18, Level 1,  
Brunel Building  
North Bristol NHS Trust  
Southmead Hospital Bristol  
Westbury-on-Trym  
BRISTOL BS10 5NB  
Tel: 0117 41 41184

E-mail: [nbn-tr.neuromuscular-odn@nhs.net](mailto:nbn-tr.neuromuscular-odn@nhs.net)

Website: [www.swneuromuscularodn.nhs.uk](http://www.swneuromuscularodn.nhs.uk)

Twitter: [@SWNODN](https://twitter.com/SWNODN)

# GP Neuromuscular News

## The New Genetics—Transforming Research into Neuromuscular Disease

The next SW Interest in Muscles (SWIM) Conference will be held on **Thursday 1 December 2016 @ Bristol Marriott Royal Hotel** at 09.00 to 16.00. Topics covered will include:

- 100,000 Genome Project
- Genetic Manipulation to cure Neuromuscular Diseases
- Inclusion Body Myositis – Update
- Case presentations
- Physiotherapy in research

A full programme is available on our website: [www.swneuromuscularodn.nhs.uk](http://www.swneuromuscularodn.nhs.uk)

The event is **FREE** of charge to healthcare professionals. Refreshments and food will be provided. Places are limited, so to avoid disappointment please register to attend via: <https://swnodn-swim-dec16.eventbrite.co.uk> as soon as possible.

## Patient Engagement & Education

The Neuromuscular multi-disciplinary team in Bristol has been developing a programme of patient engagement and education. This consists of:

### Living Well with a Neuromuscular Condition

A six week course (2½ hr sessions per week) designed for people newly diagnosed or finding it hard to adjust to having a neuromuscular condition or needing further support in coping with their condition. The course is led by our Counselling Psychologist in conjunction with a Specialist Physiotherapist and Neuromuscular Advisor.

### Duchenne Muscular Dystrophy workshops

Our Neuromuscular Advisor, supported by a Clinical Psychologist, has developed three workshops for parents who have a child with Duchenne Muscular Dystrophy (DMD). They cover:

- Newly diagnosed with DMD — adjusting and coping
- Talking to your child about DMD
- Supporting parents to support their child on DMD journey

Feedback has been very positive and you can read further details about this in our latest [SW Neuromuscular News](#) newsletter which we send out to our service users.

If you have a patient or family that you think may benefit from either of the above, please contact our office.

## New NICE Guidelines

**Ataluren for treating Duchenne MD (DMD) with a nonsense mutation in the dystrophin gene.** <https://www.nice.org.uk/guidance/hst3>. Evidence-based recommendations on Ataluren (Translarna) for treating DMD with a nonsense mutation in the dystrophin gene in people aged 5 years and older who can walk.

**Transition from children's to adult services for young people using health or social care services.** <https://www.nice.org.uk/guidance/ng43>. This guideline aims to help young people and their carers have a better experience of transition by improving the way it's planned and carried out.

## SW Neuromuscular ODN awarded Muscular Dystrophy UK (MDUK) Network of Excellence

We are very pleased to report that MDUK and their Service Development Committee, led by Baroness Celia Thomas of Winchester, have recognised our Network as a Network of Excellence. The Network fulfilled all of the audit criteria and the Committee were particularly impressed with our level of patient engagement and involvement.



## Referrals to the SW Neuromuscular Network

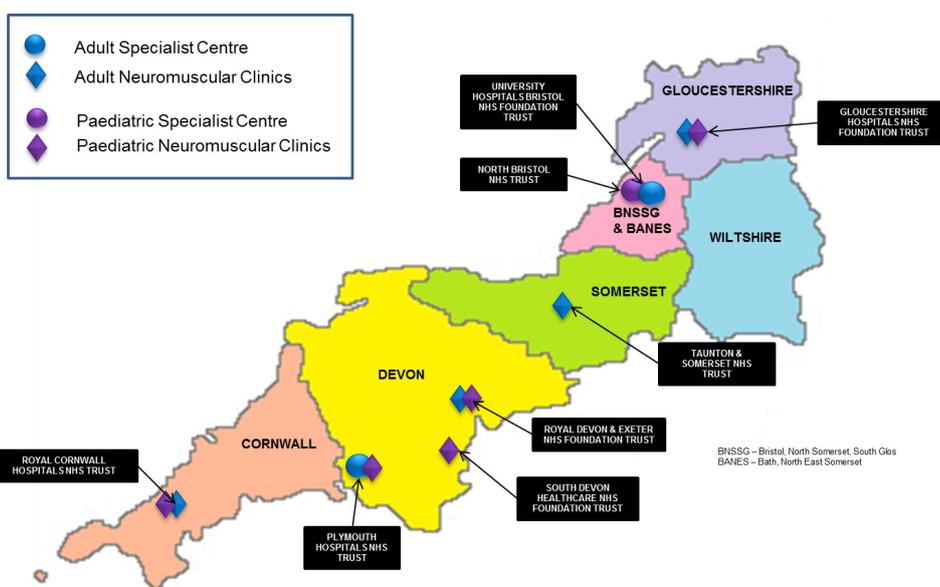
Did you know that you can refer directly to one of our Consultant Neurologists (paediatric and adult) who have a specialist interest in Neuromuscular conditions. If you suspect a patient has a neuromuscular condition covered by the Network (see our website for list of [conditions covered](#)), please refer in the normal way to the Consultant at their host Trust (see details below). We have specialist Neuromuscular Centres in Bristol and Plymouth and based around these consultants are multi-disciplinary teams of Specialist Paediatric and Adult Physiotherapists, Specialist Psychologists and Neuromuscular Advisors.

We run weekly MDT clinics in the main specialist centres and deliver monthly adult clinics outside of these centres (see map).

Our specialist Paediatric Neurologists, based at the Bristol Royal Hospital for Children, also provide a twice yearly specialist clinic with the local Paediatricians in Plymouth and Truro.

The service is fully funded by Specialised Commissioning so the only cost is for MDT clinic attendance (via tariff).

### SPECIALIST NEUROMUSCULAR CLINIC LOCATIONS



*(Please note the SW Neuromuscular Network does not cover Multiple Sclerosis, Parkinson's Disease or Cerebral Palsy)*

North Bristol NHS Trust	North Bristol NHS Trust	UHBristol NHS Trust	UHBristol NHS Trust	Plymouth Hospitals NHS Trust
<b>Dr Andria Merrison</b> Consultant Neurologist	<b>Dr Stefen Brady</b> Consultant Neurologist	<b>Dr Anirban Majumdar</b> Consultant Paediatric Neurologist	<b>Dr Kayal Vijayakumar</b> Consultant Paediatric Neurologist	<b>Vacant Post</b>
Holds MDT clinics at: <ul style="list-style-type: none"> <li>• Southmead Hospital</li> <li>• Gloucester Royal Hospital</li> <li>• Bristol Royal Infirmary (NIV clinic)</li> </ul>	Holds MDT clinics at: <ul style="list-style-type: none"> <li>• Southmead Hospital</li> <li>• Musgrove Park Hospital</li> </ul>	Holds MDT clinics at: <ul style="list-style-type: none"> <li>• Bristol Children's Hospital</li> <li>• Royal Cornwall Hospital (joint respiratory)</li> <li>• Plymouth Child Development Centre</li> </ul>	Holds MDT clinics at: <ul style="list-style-type: none"> <li>• Bristol Children's Hospital</li> <li>• Vranck House School Exeter</li> <li>• Torbay Hospital</li> </ul>	Dr Liz Househam, no longer works for the Network but still holds a Neuromuscular MDT Clinic at Mount Gould Hospital, Plymouth

More information about the clinics:

<https://www.nbt.nhs.uk/south-west-neuromuscular-operational-delivery-network/swnodn-clinics/how-access-a-neuromuscular>