South West
Neuromuscular
Operational
Delivery Network

SWIM Bulletin

Issue 2 (July 2016)

South West Neuromuscular ODN is now on Twitter!

We have now set up a @SWNODN Twitter account. Please follow us to be kept updated on any ODN developments or other developments in the world of neuromuscular care, education and research.

You can also view our other newsletters (SW Neuromuscular News and GP News Bulletin) on our website as well as earlier issues of the SWIM Bulletin.

South West Interest in Muscles (SWIM) Conference – Thursday 1 December 2016 @ Bristol Marriott Royal Hotel

The next SWIM Conference is themed around "The New Genetics – Transforming Research in Neuromuscular Disease".

This event will run from 09.00 to 1600. Topics covered will include:

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

A poster detailing the highlights (please feel free to display and share) and a Provisional Programme is attached.

The event is FREE of charge to healthcare professionals and 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.

SWNODN – Consultant Neurologist post advertised for Devon & Cornwall

As you may know, Dr Liz Househam resigned from her post as SWNODN Consultant Neurologist in Plymouth Hospitals NHS Trust earlier in the year. Further details are available at: https://www.jobs.nhs.uk/xi/vacancy/9081f7ebb098210fd44e74674e7739ed/?vac_ref=914257814.
Closing date: 11 August 2016

Paediatric Neuromuscular Research Physiotherapist post advertised – UHBristol

An extremely exciting and rare opportunity for a physiotherapist to develop a clinical-academic career in neuromuscular research. Further details are available at: https://www.jobs.nhs.uk/xi/vacancy/4adab5859d5f0cd0e22f33c1feafa455/?vac_ref=914258984 .
Closing date: 11 August 2016

Muscular Dystrophy UK—Network of Excellence Recognition

We are pleased to report that Muscular Dystrophy UK's Services Development Committee, led by Baroness Celia Thomas of Winchester, has recently recognised the South West Neuromuscular ODN as a **Network of Excellence**. Their Audit Sub-committee consisting of Professor Martin Bobrow (Chair), Dr Ros Quinlivan (Consultant in NM Disorders, Dr Helen Roper (Consultant in NM Disorders), Sue Manning (Neuromuscular Care Advisor) and Phillippa Farrant (Parent) agreed that the SWNODN fulfilled all of the criteria to become a Network of Excellence. They were particularly impressed with our levels of patient engagement, which is work that we hope to build on in the future.

New NICE Guidelines

Ataluren for treating Duchenne MD 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 adults' 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.

North West Neuromuscular Network Education Event - Friday 30 September 2016 in Oswestry.

This event is offered **free of charge** to healthcare professionals, and further details can be found on the attached flyer. Or contact:
tracie.cousineau@alderhey.nhs.uk
0151 252 5308.

The SW Neuromuscular ODN are using the NICE Transition Guidelines in conjunction with the Ready Steady Go paperwork developed by Dr Arvind Nagra at University Hospital Southampton NHS Foundation Trust.

NEW Patient Information Videos

Muscular Dystrophy UK has recently released a number of patient information videos related to specific neuromuscular conditions. Each film features an individual explaining what it's like to live with a particular condition and how important it is to access specialist healthcare to maintain a good quality of life. The films also feature advice and information from specialist neuromuscular health professionals.

The videos listed opposite can be assessed via the Muscular Dystrophy UK website: http://www.musculardystrophyuk.org/news/news/new-information-video-on-charcot-marie-tooth-disease-launched/

Available:

- Charcot-Marie-Tooth
- Becker Muscular Dystrophy
- Duchenne Muscular Dystrophy
- Facioscapulohumeral Muscular Dystrophy
- Myotonic Dystrophies
- Best Practice Healthcare

Available soon:

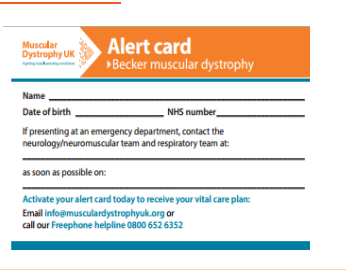
- Congenital Muscular Dystrophy
- Spinal Muscular Atrophy

Alert Cards

Muscular Dystrophy UK continue to develop their Alert Cards for patients to carry.

The cards listed opposite can be assessed via the Muscular Dystrophy UK website:

http://www.musculardystrophyuk.org/get-the-right-care-and-support/alert-cards-and-care-plans/alert-cards/



Alert card
Becker muscular dystrophy

Name ______

Date of birth ______ NHS number ______

If presenting at an emergency department, contact the neurology/neuromuscular team and respiratory team at:

______

as soon as possible on:

______

Activate your alert card today to receive your vital care plan:
Email info@musculardystrophyuk.org or
call our Freephone helpline 0800 652 6352

Available:

- Duchenne Muscular Dystrophy
- Becker Muscular Dystrophy
- Charcot-Marie-Tooth
- Limb Girdle Muscular Dystrophy
- Myotonic Dystrophies (1 and 2)
- Spinal Muscular Atrophy
- Congenital Muscular Dystrophy
- Facioscapulohumeral MD
- Undiagnosed muscle-wasting

Available soon:

- Oculopharyngeal MD
- Inclusion Body Myositis
- Myopathies