

# welcome

Welcome to our 62nd TREAT-NMD newsletter.

This week's edition highlights improvements to the TREAT-NMD Registry of Outcome Measures, including the implementation of a facility to quickly compare reports and also a systematic review tree to assist with a coordinated approach of reviewing outcome measures.

The Myotubular Trust is holding a second call for research projects with a closing date of 18th December 2009. The 2009 Myores Workshop is being held in Carmona near Seville, Spain from 14th to 18th November. King's College London's Neuromuscular symposium on November 27th is also highlighted.

The TREAT-NMD International Conference is fast approaching and registrations are still being accepted. Given its emphasis on two-way communication, we are currently encouraging anyone with an interest to submit questions for our panels of experts to consider. If you wish to submit a question please use the electronic form at the bottom of the [conference programme page](#) of our dedicated website. As always, we look forward to hearing from you.

Best wishes from Katie, Volker, Hanns, Steve, Emma, Rachel, Samantha and Michael, the Newcastle TREAT-NMD team

## at a glance...

[21-23 Sept 2009 Muscle Study Group Annual Meeting, Buffalo, New York](#)

[25-26 Sept 2009 SMA 'at the Eve of the Cure' conference, Warsaw, Poland](#)

[05-06 Oct 2009 6th UK SMA Research Conference, Edinburgh, UK](#)

[23-24 Oct 2009 Action Duchenne International Conference Holiday Inn Bloomsbury London](#)



### Enhancements to the Registry of Outcome Measures

The Registry of Outcome Measures has been undergoing upgrades to support and facilitate comparison and review of outcome measures. Two key upgrades are now ready for use.

**ROM Comparison Report** - You can now rapidly compare the recorded details of 2 to 4 outcome measures in minutes. You just select the outcome measures you wish to compare and then the fields you wish to review. You can include all fields or limit your selection to those of specific interest.

**Systematic Review Tree** - The systematic review tree is designed to support a co-ordinated approach to the review of outcome measures with respect to their application for a specific disease. It aims to record a range of information, from the outcome measures that are being considered in the review, to the final determination of the review.



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### Myotubular Trust Call for Projects

The Myotubular Trust was set up in 2006 to raise money for research to find a cure and / or treatment for myotubular myopathy.

The Trust is now holding a second call for research projects. Completed applications need to have been received by close of business Friday 18th December 2009 to be considered for the anticipated awards in April 2010.

The Trust is looking to fund further projects that will help find a cure and / or a treatment for any of the three types of myotubular myopathy (congenital X-linked recessive; congenital autosomal recessive; autosomal dominant), focusing on research that would not generally be funded by public or industrial funding sources. This call will be open to European research bodies only.



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### Deadline Approaches for MYORES Workshop on Mechanisms Involved in Muscle Atrophy and Hypertrophy

Gillian Butler-Browne and John C. Sparrow are organizing a workshop entitled "Mechanisms Involved in Muscle Atrophy and Hypertrophy" which will present the latest knowledge on the pathways involved in muscle mass regulation as well as the impact of these regulatory mechanisms on muscle homeostasis.

Scheduled to take place from 14th - 18th November 2009 this workshop will be held in Carmona close to Seville in Spain.

### King's College London 9th Annual Neuromuscular Symposium

King's College London's will be holding a Neuromuscular symposium which will take place on November 27th. This annual event is now in its 9th year.

Programme highlights include an educational programme on the clinical management of neuromuscular diseases. Topics include neuropathic pain, neuromuscular disease in pregnancy and also motor neuron disease.

This symposium will be of interest to clinicians working in general neurology, general medicine,

[14-18 Nov 2009 Mechanisms Involved in Muscle Atrophy and Hypertrophy, Carmona, Spain.](#)

[17-19 Nov 2009 TREAT-NMD / NIH International Conference](#)

[27 Nov 2009 King's College London Neuromuscular Symposium](#)

Deadline for registration is 1st October 2009.



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pain management, obstetrics, clinical neurophysiology, rehabilitation and paediatrics.



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