

welcome

Welcome to the latest TREAT-NMD newsletter. This edition features a report on the launch of the UK SMA patient registry, information about a TREAT-NMD ethics workshop at the WMS and a focus on Newcastle University.

As always, we hope you enjoy the newsletter and look forward to hearing your comments - write to info@treat-nmd.eu with anything you'd like to say. Feel free to forward this message to anybody you think might find it of interest, or invite them to sign up to receive the newsletter by visiting our website. Back-issues of this newsletter can be found on our website at <http://www.treat-nmd.eu/patients/news/ezine-archive/>

Best wishes,

Katie, Volker, Steve, Emma, Neville, Brigitta and Rachel: the Newcastle TREAT-NMD team

at a glance...

Meetings & Events

[12-14 Sep 2008
EAMDA/TREAT-NMD conference](#)

[03-04 Oct 2008 European Research
Conference in Paediatric Neurology](#)

[02-04 Feb 2009 TREAT-NMD
Governing Board and Science and
Technology Advisory Council
Meetings](#)

[09-12 Sep 2009 IDMC-7
International Myotonic Dystrophy
Consortium](#)



Partner Focus: Newcastle University

We continue our "partner focus" sections with a feature on Newcastle University, home to TREAT-NMD's coordination office and one of the UK's specialist neuromuscular centres. Click the link below to read about the Muscle Centre and the Newcastle staff.



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TREAT-NMD ethics workshop at WMS2008

If you are attending WMS 2008 we encourage you to attend a free workshop on ethical issues in neuromuscular diseases, which will take place immediately before the opening reception.



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Inherited Neuromuscular Diseases: Translation from Pathomechanisms to Therapies

TREAT-NMD will have an exhibition booth at the International Symposium on Rare Diseases. Inherited Neuromuscular Diseases: Translation from Pathomechanisms to Therapies in Valencia, Spain, November 16th-18th, 2008



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UK SMA patient registry launched

On 5th July 2008 the UK SMA patient registry was launched in the presence of more than 100 SMA patients and families at the Annual Conference of The Jennifer Trust.



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Patient rights in the EU

The Centre for Biomedical Ethics and Law of the Catholic University of Leuven in Belgium, in collaboration with the European Commission and EuroGentest, has added two more ethical-legal documents on patient rights in the EU to its collection.



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TREAT-NMD workshop report: preclinical testing for DMD

An international workshop on preclinical testing in DMD was held on June 30 and July 1, 2008 in Zürich. The aim of the meeting was to propose "standard operating procedures" (SOPs) for various methodologies/end points in animal models of DMD.

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