

## welcome

Welcome to the latest TREAT-NMD newsletter. This edition features a friendly welcome to our new TREAT-NMD staff, information on our FP7 Marie Curie Initial Training Network submission (TRAIN-NMD), a meeting report from the Registries Training Course held in Montpellier last week and interviews with PTC and Prosensa.

As always, we hope you enjoy the newsletter and look forward to hearing your comments - write to [info@treat-nmd.eu](mailto: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, Rachel and Samantha: the Newcastle TREAT-NMD team

## at a glance...

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](#)



### Successful 2nd registry curators' training course takes place in Montpellier

Sixty participants from twenty different countries gathered in the Mediterranean resort of La Grande Motte near Montpellier for the second annual TREAT-NMD registry curators' training meeting, followed by the inaugural meeting of the Global Database Oversight Committee. The TREAT-NMD global database for DMD and SMA receives patient details from individual national registries across the world, and this meeting provided an opportunity for the individuals involved in setting up the registries and ensuring the quality of the data they contain (the "database curators") to come together to share experiences and learn new techniques.



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### TREAT-NMD applies for Marie Curie training network

11 partners from TREAT-NMD have submitted a proposal for a Marie Curie Initial Training Network (EU FP7). The name of this TREAT-NMD spin-off is "Training and Research to Accelerate Innovative treatments for neuromuscular disorders (TRAIN-NMD)". The aim of TRAIN-NMD is to train early stage researchers in the field of translational medicine for neuromuscular disorders through a combination of training courses and summer schools and 15 individual research projects focusing on therapeutic applications for neuromuscular disorders.



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### New TREAT-NMD staff

#### New TREAT-NMD Project Assistant at UNEW

We would like to welcome Samantha Cook to the TREAT-NMD team here in Newcastle. Following on from Rachel Thompson taking up her new role as PR & Communications Officer, we have appointed Samantha as our new Project Assistant who started 1st September. You can contact her at [samantha.cook@ncl.ac.uk](mailto:samantha.cook@ncl.ac.uk).

#### New TREAT-NMD Project Leader at the ENMC

We would also like to welcome Katelijne Senden to the TREAT-NMD team at the ENMC. Katelijne will take over the role vacated by Pauline Evers who left earlier in the summer. You can email Katelijne at [senden@enmc.org](mailto:senden@enmc.org)

### TREAT-NMD Interviews with PTC and Prosensa

In July 2008, Guenter Scheuerbrandt, on behalf of TREAT-NMD, conducted two interviews with two of TREAT-NMD's industrial contacts, PTC Therapeutics and Prosensa B.V. He has since produced two reports for the information of patients, their families, and care-givers which are now available for download via the TREAT-NMD website.

[Exon Skipping, a therapy for Duchenne muscular dystrophy.](#)  
[Interview with Dr. Gerard Platenburg, President of Prosensa B.V. Leiden, the Netherlands.](#)

[Reading through premature stop codons with PTC124.](#)  
[Project Catalyst to find more Duchenne drugs.](#)  
[Interview with Ellen Welch PhD., Diane Goetz, and Neil Almstead PhD.](#)



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### MDC Newsletter Launch

The first Muscular Dystrophy Campaign (MDC) in the North East newsletter was published on the 1<sup>st</sup> August 2008. The newsletter contains articles on the Neuromuscular Centre in Cheshire, UK, which has been running for the last 18 years and provides a model for the new scheme being established in Newcastle upon Tyne, UK. There is also a 'who's who' to introduce the partner organisations and the project manager and details on how to get involved.

If you would like to subscribe to the quarterly newsletters please e-mail  
Becky.Knox@ncl.ac.uk



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### TREAT-NMD Booth at 13th World Muscle Society Congress

TREAT-NMD will have a booth, near the registration desk, at the WMS in Newcastle from the 29th September - 1st October. If you are attending the meeting we would like to encourage you to drop in and speak to the coordination team to find out what is happening in the network. We would also be happy to discuss how you can become more involved in TREAT-NMD activities and events.

We look forward to seeing you there.



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