

## welcome

Welcome to the latest TREAT-NMD newsletter. As well as news of the updating of the Declaration of Helsinki, a reminder of tonight's Telethon on French TV and a job opportunity at Newcastle, this edition features news of three conferences, including an announcement about the major TREAT-NMD/NIH International Conference in November 2009.

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...

[06-09 Jan 2009 Workshop: The Multiple Faces of Lamins in Aging and Disease](#)

[02-04 Feb 2009 TREAT-NMD Governing Board meeting](#)

[28 Feb 2009 - 01 Mar 2009 First Asian conference on Duchenne muscular dystrophy \(DMD\)](#)

[26-27 Mar 2009 UK Neuromuscular Translational Research Conference](#)

[12-15 May 2009 The Nottingham Systematic Review Course 2009](#)

[21-23 May 2009 International conference in Ukraine: Recent standards in diagnosis, treatment and medical care for some rare neuromuscular diseases](#)

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

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



## TREAT-NMD - NIH International Conference 17-19 November 2009

TREAT-NMD / NIH International Conference

17-19 Nov 2009



### “Bringing down the Barriers - Translational Medicine in Inherited Neuromuscular Diseases”

17 – 19 November 2009  
Brussels, Belgium  
Crowne Plaza Brussels City Centre

TREAT-NMD is planning its first international conference in collaboration with the NIH. The aim of the meeting is to share progress in the area of translational medicine in inherited neuromuscular diseases and set the future collaborative agenda. This conference will build on achievements of the NIH and TREAT-NMD. It will be a highly interactive meeting with a strong focus on the key issues surrounding "trial readiness" in the neuromuscular field.

#### Pre-Clinical Environment

- High throughput screening, target and candidate identification
- Established protocols to validate animal models
- Disease targeted therapeutics - how do we triage for the most suitable candidates?

#### Clinical Tools for Trial Readiness

- Patient registries
- Clinical outcome measures – overview, dissemination and education
- Effects of long term treatment and combination therapeutics
- Paradigm shift and decision making process – design development programmes based on pre-defined traits for the final product
- Therapeutic misconceptions and ethical considerations for trials

plus case studies with expert panels and keynote lectures on basic science as well as clinical trial experience.

The programme committee includes Dr. Annemieke Aartsma-Rus, Prof. Peter van den Bergh, Dr. Serge Braun, Dr. Krzysztof Jagla, Dr. Stephen Lynn, Prof. Francesco Muntoni, Dr. Glen Nuckolls, Dr. Marie-Odile Ott, Dr. John. Porter, Dr. Stefanie Possekkel, Dr. Markus Ruegg, Mr. Peter Streng, Mrs Katelijne Senden, Dr. Jon Tinsley.

Please reserve the date in your diary for the TREAT-NMD / NIH 2009 conference. We look forward to welcoming you in Brussels in November 2009.

A conference website for registration will be available shortly. If you have any questions in the meantime please contact TREAT-NMD network manager [Dr Stephen Lynn](#). [Dr Stephen Lynn](#)

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## UK Neuromuscular Translational Research Conference 26-27 March 2009

UK Neuromuscular Translational Research Conference  
MRC Centre for Neuromuscular Diseases and the Muscular Dystrophy Campaign  
Thursday 26th – Friday 27th March 2009  
International Centre for Life, Times Square, Newcastle-Upon-Tyne, NE1 4EP



**DEADLINE FOR ABSTRACTS: Friday 12 December!**

To find out more or to register for the conference, click [here](#).

#### Provisional programme

##### Day 1 – Thursday 26th March

- 09:00 – 10:15 Registration
- 10.15 – 10:30 Introduction
- 10:30 – 12:30 Focus on peripheral nerve disease  
- Professor Kristjan Jessen, University College London

- Professor Hugh Willison, University of Glasgow  
- Dr Mary Reilly, Institute of Neurology, University College London  
12:30 – 14:00 Posters/lunch  
14:00 – 16:00 Focus on muscle disease  
- Professor Marinos Dalakas, Imperial College London  
- Professor Volker Straub, Newcastle University  
16:15 – 16:40 The MRC and translational research  
- Professor Chris Kennard, Chairman of the MRC Neurosciences and Mental Health Research Board  
16:40 – 17:30 Posters/tea  
17:30 – 18:30 The John Walton lecture introduced by Professor Doug Turnbull  
- Professor Dame Kay E Davies, University of Oxford  
19:00 - 20:00 Drinks reception  
20:00 onwards Dinner in the Scotswood Suite  
After dinner speaker: Professor John Burn, Institute of Human Genetics, Newcastle University

#### **Day 2 – Friday 27th March**

09:00 – 11:00 Exercise therapy and muscle disease  
- Dr Mike Trenell, University of Newcastle  
- Dr Ros Quinlivan, Robert Jones and Agnes Hunt Orthopaedic & District Hospital  
- Dr Margaret Phillips, University of Nottingham  
- Professor Baziel Van Engelen, University Medical Centre Nijmegen  
11:00 – 11:30 Coffee  
11:30 – 13:00 Molecular therapies  
- Professor David Rubinsztein, University of Cambridge  
- Jon Tinsley, Summit  
13:00 – 14:00 Posters/lunch  
14:00 – 16:00 Neuromuscular channelopathies  
- Professor David Beeson, University of Oxford  
- Professor Hanns Lochmüller, Newcastle University  
- Professor Mike Hanna, Institute of Neurology, University College London  
- Professor Martin Koltzenburg, Institute of Neurology, University College London  
16:00 Close

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## **First Asian Conference on Duchenne Muscular Dystrophy in Bangalore, India**

### **First Asian conference on Duchenne muscular dystrophy (DMD)**

**28 Feb 2009 - 01 Mar 2009**



United Parent Projects Muscular Dystrophy (UPPMD) are hosting a conference for parents of boys diagnosed with Duchenne and Becker Muscular Dystrophy and their clinicians in the Asian region.

The aim of this Conference is to empower and inform parents and clinicians about diagnostics, state of the art care, research and clinical trials.

This conference will be held in Bangalore on Saturday February 28 and Sunday March 1, 2009, in collaboration with NIMHANS and HCG, Bangalore.

Venue: St John's Auditorium, St John's National Academy of Health Sciences, Johnnagar, Sarjapur Road, Bangalore, Karnataka, India  
Convenors: UPPMD, HCG, NIMHANS

#### Speakers:

##### **Dr Annemieke Aartsma**

Sylvius Lab, Leiden University, Netherlands  
Research overview - Exon skipping

##### **Dr John Bach**

New Jersey, US  
Lung function - non invasive ventilation/cough assist

##### **Prof Doug Biggar**

Bloorview MacMillan, Toronto, Canada  
Use of steroids in DMD

##### **Prof Dennis Duboc**

Cochin, Paris, France  
Cardiology – Cardiac medication

##### **Dr Madhuri Hegde**

Emory University, Atlanta, US  
Genetics and genetic testing

##### **Dr Jos Hendriksen**

Kempenhaeghe, Netherlands  
Learning disorders and comorbidity/emotional coaching

##### **Dr Nathalie Goemans**

KUL, Louvain, Belgium  
Care – Standards of care - ongoing clinical trials

**Helen Posselt**

Brisbane, Australia  
Physiotherapy

**Dr Ajaikumar**

HCG Bangalore Institute of Oncology

**Dr Nalini**

Dept of Neurology, NIMHANS, Bangalore, India  
Scenario of DMD in India: Challenges

**Dr Anupam Gupta**

Dept of neurorehabilitation, NIMHANS, Bangalore, India  
Neurorehabilitation in DMD: An Indian Experience

**Dr Raghavendra Rao**

Health Care Global, Bangalore  
Role of Yoga in management of DMD

**Patient representatives speakers:**

Patricia Furlong, President Parent Project Muscular Dystrophy, USA  
Hafiz Issadeen, President Duchenne Parent Project, Sri Lanka  
Elizabeth Vroom, Chair United Parent Projects MD, The Netherlands

**Registration:**

(Pre) Register as soon as possible at [info@UPPMD.org](mailto:info@UPPMD.org)  
For more information and updates on this meeting, visit:  
[www.duchenne-community.org](http://www.duchenne-community.org)

The worldwide organisation UPPMD is dedicated to finding a cure and viable treatments for DMD, to promoting good standards of care and to informing parents and clinicians around the globe. There is a compelling need to ensure that wherever they are in the world, the children suffering from this disease can benefit from a standard of care that is informed by the best practice of the best clinicians from all over the world. It is equally important that the information available to parents is contemporary and is based upon the latest research.

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**Helsinki Declaration updated**

A revised version of the Declaration of Helsinki, which sets out ethical principles for medical research involving human subjects, has been adopted by the World Medical Association. The Declaration, while not legally binding, is widely regarded as the cornerstone of human research ethics. New paragraphs of the revised Declaration deal with consent for research on human material, such as blood, tissues, and DNA, and human data and require clinical trials to be registered in a publicly accessible database. The full text of the Declaration is available [here](#) and further information on the update can be found [here](#).



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**Web development job opportunity in Newcastle**

Salary: £27183 pro rata  
Closing date: 4 January 2009

Based in the Treat-NMD Coordination Centre in the Institute of Human Genetics, you will be an enthusiastic, self motivated team player who will provide expert technical support to the network team. You will assist in the development and maintenance of a web site, web based information delivery and communication systems using the most appropriate tools. There will be interaction with partners and collaborators across the world and a working knowledge of a modern European language would be an advantage. The post is a challenging one, working with a large number of people from different backgrounds and you will need to be flexible and able to work to deadlines. TREAT-NMD- a European initiative to accelerate treatments for neuromuscular diseases.

There is the possibility of the post becoming full-time in the future. Tenable until 31st December 2011 in the first instance.

Job Ref: A257A (IHG)

For further details click [here](#).

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**French Telethon starts tonight!**

TREAT-NMD partner the AFM (the French Muscular Dystrophy Association), has set itself two missions: curing neuromuscular diseases and reducing the disabilities they cause. To achieve these goals, AFM has organised an annual





"Telethon" on the first weekend in December every year since 1987. This major fund-raising operation, combining a 30-hour TV show and tens of thousands of local events across France, provides the majority of donations to the Association and also aims to raise public awareness of neuromuscular diseases.

With the investment of 845 million euros for its Cure mission between 1987 to the end of 2007, the AFM has become an indispensable actor in the field of research. In 2007, 66 million euros have been invested in almost 400 research programs.

**Tune in on France 2 at 1850 tonight!**

For more information, [click here](#).

[Make a donation now!](#)

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