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 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

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 Possekel, 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.

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
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 Baziel Van Engelen, University of Cambridge

11:00 – 11:30 Coffee

11:30 – 13:00 Molecular therapies
- Dr Madhuri Hegde, Emory University, Atlanta, US
- Dr Jos Hendriksen, Kempenhaeghe, Netherlands

13:00 – 14:00 Posters/lunch

14:00 – 16:00 Neuromuscular channelopathies
- Prof Doug Biggar, Bloorview MacMillan, Toronto, Canada
- Prof Dennis Duboc, Cochin, Paris, France
- Dr Madhuri Hegde, Emory University, Atlanta, US
- Dr Nathalie Goemans, KUL, Louvain, Belgium

16:00 Close
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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