



16 January 2009

TREAT-NMD newsletter no. 46

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welcome

Happy New Year and welcome to the first TREAT-NMD newsletter of 2009. This edition features information about our major joint conference with the NIH in November of this year, and the last opportunity to sign up for a free training course taking place in Budapest at the beginning of February.

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...

[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](#)

[09-11 Jul 2009 "Therapeutic Targets in CMD", Emory University, Atlanta, Georgia](#)

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

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

update

TREAT-NMD/NIH international conference 17-19 November 2009

"Bringing down the Barriers - Translational Medicine in Inherited Neuromuscular Diseases"

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



Planning for our joint conference with the US NIH in November this year is well underway and working groups have been established for each of the main areas the conference will address. This will be a major event in the international neuromuscular calendar for 2009 with a strong focus on translational research and "trial readiness". Up to 500 delegates are expected to attend.

Sessions will focus on:

- Target and candidate identification
- Animal model assessment
- Developing novel, disease-targeted therapies and addressing the challenges of systemic delivery
- What have we learnt from registry development?
- Clinical outcome measures
- Long-term treatment and combination therapeutics/learning from completed proof of principle trials
- Making clinical trials in neuromuscular disease a reality
- Therapeutic misconceptions and ethical considerations

Much of the preparatory work for the conference will take place via focused international working groups made up of specialists representing the various areas who will then give presentations representing the "state of the art" during the conference.

The conference will also feature poster sessions focusing on the science behind the therapeutics and we encourage any interested participants to submit abstracts.

Registration for the conference will be open shortly via a dedicated conference website - look out for details in subsequent newsletters. In the meantime, please save the date in your diaries and we look forward to welcoming you to Brussels in November!

For more information see <http://www.treat-nmd.eu/healthcare/events/events/401/>

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Sign up for the free TREAT-NMD clinical training course in NMDs - Budapest 4-5 Feb 2009

Doctors from across Central and Eastern Europe are invited to this training course, which is due to take place immediately following the TREAT-NMD Governing Board Meeting in February. There is no charge for attendance. Some financial support for travel may be available from ENMC (for details please contact [Annette Boersen](mailto:Annette.Boersen@enmc.nl)).



The goal of the course is to raise awareness about NMDs (SMA, DMD) among Central-Eastern-European healthcare professionals and the research community, and distribute new information on the latest developments in therapy and standards of care. The training lectures will be given by leading professionals in the field, who are members of the

TREAT-NMD consortium or work as specialists on patient care.

To register for the course, please complete the [registration form](#) and return it directly to the hotel. For further information on the course please contact [Dr Veronika Karcaji](#).

Satellite meeting of the TREAT-NMD Governing Board meeting
(February 4-5, 2009, Budapest - Hungary)

Meeting starts after closing of the Governing Board meeting on 4th February and ends on 5th February

Scientific programme

Lectures will last for 30 minutes followed by 10 minutes of discussion

4th February

Opening of the Training Course – Professor Kate Bushby

15:00-15:40 Volker Straub: Networking for neuromuscular disorders for clinicians
Professor of Neuromuscular Genetics, Newcastle University, joint coordinator of the TREAT-NMD network

15:40-16:20 Kate Bushby: Diagnosis and standards of care in DMD
Professor of Neuromuscular Genetics, Newcastle University, joint coordinator of the TREAT-NMD network

16:20-17:00 Thomas Sejersen: Outcome measures and assessment tools in neuromuscular disorders. Clinical trials on DMD
Associate Professor of Neurology, Karolinska University Hospital, Stockholm

17:00-17:40 Enrico Bertini: Genetic background, standards of care and clinical trials in SMA
Neurologist, Unit of Molecular Medicine, Dept. of Laboratory Medicine, Ospedale Bambino, Rome

Dinner

5th February

9:00-9:40 Hanns Lochmüller: Patient registries in DMD and SMA, global registries
Professor of Experimental Myology, Newcastle University

9:40-10:20 Ria Broekgarden: Neuromuscular disorders and respiratory care in the Netherlands
VSN - Dutch NMD Organisation, ENMC chair

10:20-11:00 Hervé Laouenan: Reference centre from concept to reality - A history of rare disease plans and initiation of reference centre model for gold standard implementation of care, registry to facilitate involvement in clinical trials.
European Project Manager, AFM, Institute de Myologie

11:00-11:40 Jes Rahbek: Social aspects, transfer from paediatrics to adulthood - Rehabilitation of patients (not confirmed yet)
Chief consultant, Muskelsvindfonden, Århus, Denmark

11:40-12:20 Bitte Ahlborg: Oral and dental care in NMD patients
DDS, Senior Consultant, Mun-H-Center, Göteborg, Sweden

Closing remarks by Professor Volker Straub

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Job opportunity: Clinical Trials Coordinator, London

Closing date: 30 January 2009

Applications are invited for a Clinical Trials Co-ordinator in the Dubowitz Neuromuscular Centre at the UCL Institute of Child Health (ICH). This is a new position funded by the Muscular Dystrophy Campaign and is available immediately.



This post is the outcome of a collaborative application between the Dubowitz Neuromuscular Centre, specialised in paediatric neuromuscular diseases, and the adult Muscle and Nerve centre located in the adjacent Institute of Neurology. The paediatric and adult centres have recently initiated a wide range of collaborations on clinical and research aspects related to neuromuscular disorders and further information can be found on: www.cnmd.ac.uk/.

The post holder will support the ongoing clinical trials held in the paediatric and adult centres. The main focus will be that of providing expert support to Senior Scientific staff in the Neuromuscular Centre in a clinical trials environment. The post holder will be involved in recruiting and following up patients for a number of ongoing clinical trials. You will also provide care for patients and their families through a process of support, information and counselling throughout trial inclusion and in-patient treatment. The trial coordinator will work collaboratively with the lead consultants and the MRC trial administrative coordinator.

Applicants must have a nursing qualification, first degree or equivalent relevant vocational experience. You must have experience of working in clinical research and managing or co-ordinating a similar project. The successful candidate will have excellent organisational and time management skills and the ability to communicate with people at all levels. Experience of working with children with neurodisability is also desirable.

For an informal discussion regarding this vacancy please contact Professor Francesco Muntoni at f.muntoni@ich.ucl.ac.uk

Salary will be on Grade 7 of the UCL Salary Scales which ranges from £28,839 - £35,469 per annum, depending upon skills and experience, plus £2,781 London Allowance per annum. This post is funded until 31 March 2011.

For further information and to apply see the following website:

http://www.ich.ucl.ac.uk/ich/humanresources/jobvacancy_00772

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International conference in Ukraine: Recent standards in diagnosis, treatment and medical care for some rare neuromuscular diseases

Registration is open for this international conference which begins on May 21 2009. The goal of the conference is to raise awareness about NMDs (SMA, DMD) among Ukrainian healthcare professionals and the research community, obtain support at government level, and educate involved families on the latest developments and standards of care.



The agenda will address the following topics:

- Spinal muscular atrophy. Modern and newest approaches to diagnostics and treatment.
- Duchenne muscular dystrophy. Modern and newest approaches to diagnostics and treatment.
- Other rare (1:4000) neuromuscular pathologies. Modern and newest approaches to diagnostics and treatment.
- Management of respiratory system at neuromuscular disorders.
- Orthopedic aspects of neuromuscular disorders.
- Orthotic/prosthetic rehabilitation and neuromuscular disorders.
- Anesthesia and neuromuscular disorders.
- Non-invasive methods of diagnosis for rare neuromuscular disorders (MRI, EMG etc.).
- Nutrition aspects of neuromuscular disorders.
- Care and quality of life of patients with neuromuscular disorders.
- Organization of medical service for rare neuromuscular disorders (diagnosis, registering, conducting of clinical trials and research in compliance with principles of GMP).

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