



TREAT-NMD

Neuromuscular Network

8th February 2008 · Newsletter No. 26



Welcome to the latest newsletter. This edition sees the launch of the **TREAT-NMD members' charter** (see the following page) and we are hoping that many of you will be interested in joining us in membership of TREAT-NMD!

We also have an update on the work of the Cochrane Group and an announcement about the TREAT-NMD regulatory affairs database, plus a number of meetings and training opportunities.

Please forward any items that you would like to be included in future editions of the newsletter to info@treat-nmd.eu.

Best wishes,

Katie, Volker, Stephen, Emma, Arron and Rachel – the TREAT-NMD coordination team

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About this newsletter

This is a fortnightly newsletter sent to all members of TREAT-NMD's "Club of Interest" worldwide. Earlier editions of the newsletter can be found online at www.treat-nmd.eu/news/newsletter/index.htm.

If you would like to subscribe directly, please visit our website at www.treat-nmd.eu/ where you will find a subscription form at the bottom of the homepage. You can also use the same form if you no longer wish to receive this newsletter – just select the unsubscribe button.

Working with us

TREAT-NMD aims to be an inclusive rather than an exclusive network, and you do not have to be based in Europe or be a partner to be involved. International collaboration with experts from all over the world is already taking place, and new links are being developed.

If you are involved in any of TREAT-NMD's areas of interest and have something you'd like to say or a suggestion of where we could work together, we encourage you to get in touch by writing to us at info@treat-nmd.eu. The coordination team in Newcastle will be happy to put you in touch with the person most relevant to your particular interest.

Become a member of TREAT-NMD!

The TREAT-NMD network already has 21 partners covering 11 European countries, but we recognise that there are many other organisations, institutions, companies and individuals who are doing valuable work in the neuromuscular field and who might benefit from closer links with TREAT-NMD. While “partnership” in the network is restricted to those who have signed a contract with the EU to perform specific tasks within the network, “membership” is open to all suitably qualified applicants who are willing to adhere to our “Members’ Charter”. Essentially, members will help us accelerate work on neuromuscular diseases worldwide, and members will have access to the network’s tools and resources to help implement the network’s goals in their country.

In our last newsletter, we reported that the TREAT-NMD Governing Board had ratified the Members’ Charter. We are now pleased to announce that the Charter is now available on the TREAT-NMD web site, along with an application form for those of you interested in signing up. The charter and application form can be found on the web site by following the link below:

http://www.treat-nmd.eu/news/item/?members_charter

We hope the TREAT-NMD Members’ Charter will help us to work together more closely to ensure that resources developed by TREAT-NMD will be made widely available to patients, researchers and industry, with the express aim of bringing new and promising therapies and treatments to patients with neuromuscular disease worldwide. Your participation in this endeavour is vital if we are to realise the goals of the network.

We look forward to receiving your completed application forms for membership of TREAT-NMD and hope that you will find being a member beneficial in your activities.

European Network of DNA, Cell and Tissue Banks for Rare Diseases



6th ANNUAL NETWORK MEETING

PARIS, 5-6 May 2008

at **EURORDIS**, Hôpital Broussais, Plateforme Maladies Rares, Bâtiment François de Gaudart d'Allaines (secteur jaune) – 96, rue Didot – 75014 Paris, France

The meeting will focus on quality control and is open to members of EuroBioBank and TREAT-NMD WP4.1.

For further details please e-mail: ambodin@eurordis.org

WP 10.2 Systematic reviews of interventions for NMD

Within the TREAT-NMD work on harmonising standards of diagnosis and care, TREAT-NMD partners at Kings College London are responsible for Cochrane systematic reviews of interventions for neuromuscular diseases. The following is an update regarding an existing Cochrane review, and interested parties are also invited to consider authoring a review or to submit further topics suitable for the Cochrane review process.

Important Update to Cochrane systematic review Glucocorticoid corticosteroids for Duchenne muscular dystrophy published in January 2008

Supported by a bursary from the Association Française contre les myopathies, this review incorporates additional evidence from one new randomised controlled trial and adds a further twelve new non-randomised studies. The review authors conclude:

“There is evidence from randomised controlled studies that glucocorticoid corticosteroid therapy in DMD improves muscle strength and function in the short-term (six months to two years). The most effective prednisolone regime appears to be 0.75 mg/kg/day, given daily. In the short term, adverse effects were significantly more common but not clinically severe. Long-term benefits and hazards of glucocorticoid treatment cannot be evaluated from the currently published randomised studies. Non-randomised studies support the conclusions of functional benefits but also identify clinically significant adverse effects of long-term treatment. These benefits and adverse effects have implications for future research studies and clinical practice”.

Manzur AY, Kuntzer T, Pike M, Swan A. Glucocorticoid corticosteroids for Duchenne muscular dystrophy. Cochrane Database of Systematic Reviews 2008, Issue 1. Art No: CD003725.

<http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD003725/frame.html>

This review provides the basis for the proposed trial of corticosteroid regimens in DMD submitted to the NIH and currently under revision.

Topics seeking authors

- Corticosteroids for limb girdle muscular dystrophies
- Cardiac management for Emery Dreifus muscular dystrophies
- Cough assist machines for spinal muscular atrophy
- Interventions for muscle weakness and wasting in myotonic dystrophy

Training and support from the Cochrane Neuromuscular Disease Group editorial base is available throughout the review process. Access to training courses on systematic reviewing run by the UK Cochrane Centre is also provided.

If you would be interested authoring a systematic review please contact us at: cochranenmd@kcl.ac.uk. To learn more about the work of the group please visit our website: www.kcl.ac.uk/cochranenmd.

Topics being sought

Please let us know if you think that there are other topics relevant to TREAT-NMD which have not yet been covered, especially but not only if you would like to contribute.



Regulatory Affairs Database

Regulatory Affairs Database is ready for use

The CTCC is delighted to present the first production version of the TREAT-NMD Regulatory Affairs Database.

This database should provide a valuable source of advice to people who are involved in the planning of mono- or multi-centre clinical trials within different European countries. The database contains the contact addresses of national authorities as well as national legislation and documents.

Additionally, *European regulations* and other important international documents and guidelines are provided (e.g. from ICH and EMEA). The database is open for public use and can be accessed online, a login/username is not required:

<http://www.treat-nmd.eu/regulatoryaffairs>

At the moment, the database solely contains European regulations and information from Germany. From June 2008, information from other countries will also be available.

If you can provide the CTCC with valuable sources of information or contact persons regarding the legal regulations in your country please contact us. We also welcome any technical suggestions. Your help would be very much appreciated and further accelerate the development of this valuable database.

For technical issues please contact Adrian Tassoni (adrian.tassoni@uniklinik-freiburg.de)

For content please contact Sebastian Geismann (sebastian.geismann@uniklinik-freiburg.de)



Funding Calls

Public Health Programme

The Public Health Programme is the European Commission's main instrument for implementing the EU's health strategy. The programme aims, via a number of projects it funds, to improve the level of physical and mental health and well-being of EU citizens and reduce health inequalities throughout the Community. In particular, the programme supports health-promoting and preventive actions that address the major health determinants.

The first call for proposals within the new Public Health Programme 2008-2013 will be published at the end of February.

An Infoday will be organised on 12 March 2008. Should you wish to participate, please register as soon as possible by clicking on the following link: <http://ec.europa.eu/phea/>.

As the number of places is limited, participation will be ensured on a first come first serve basis. Registration closes on 3 March 2008. For further information please visit:

http://ec.europa.eu/phea/programme/programme_en.html#php2

Scholarship for the Summer School of Myology

TREAT-NMD can offer one scholarship for the Summer School of Myology organised from 19 till 27 June, 2008 in Paris. The Institute of Myology offers a condensed 7-day course open to foreign students, with special attention to those posted in the French Overseas Territories (DOM-TOM) and those working in developing countries. Most aspects of Myology are addressed during the course: from basic science to cutting-edge therapies, clinical and genetic approaches of muscle diseases are taught. This is achieved by a series of lectures and interactive workshops in English.

The TREAT-NMD scholarship, covering summer school fee and hotel costs up to a maximum of €1000 in total, is aimed at young physician specialising in neuromyology and coming from the former Eastern part of Europe, including accession countries, Western Balkan and Turkey. Candidates should send their Summer School application form to andoni.urtizbera@hnd.aphp.fr with copies to s.miffre@institut-myologie.org and their TREAT-NMD scholarship application form to evers@enmc.org before May 1st 2008.

You can download the application forms via the TREAT-NMD website here:

<http://tinyurl.com/38bc27>

For additional information, please visit the TREAT-NMD website:

http://www.treat-nmd.eu/activities/training_educ.htm

or the Summer School of Myology website:

<http://tinyurl.com/yv63gz>



Abstract submission for the 3rd International Congress of Myology has been extended until February 18, 2008.

Please click on the link below to submit an abstract. It's easy and it takes only a few minutes.

<http://tinyurl.com/2ys5vg>

The 5th International Congress of Rehabilitation

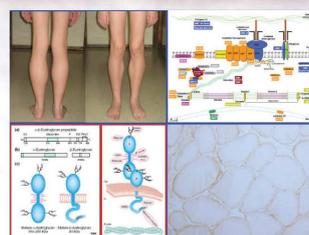
**May 30th, 31st and June 1st, 2008.
Marseille (France)**

The congress will be dedicated to the neuromuscular disorders and for the first time will follow the International Congress of Myology (see <http://www.myology2008.org/>)

On Friday 30th May myologists, rehabilitation physicians and physiotherapists will discuss the various therapeutic evaluations.



Enfermedades Musculares en la Infancia y Adolescencia (V)



Salón de Actos. Planta 0 centro
Hospital Ramón y Cajal
13 y 14 de Marzo de 2008

Please contact glorenzo.hrc@salud.madrid.org for further information and registration.

Send us your news and views!

We strongly encourage all partners and supporters to send their own news and updates and we will be happy to include them in future editions of the newsletter. Please send your contributions to emma.heslop@treat-nmd.eu