



TREAT-NMD

Neuromuscular Network

25th January 2008. Newsletter No. 25



Welcome to the latest newsletter. This edition features a brief report on our recent Governing Board meeting, plus information on a number of job advertisements, training opportunities, international meetings and calls for proposals.

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.

TREAT-NMD Governing Board Meeting, 14-16 January 2008, Milan

Last week the TREAT-NMD Governing Board met in Milan to discuss progress made in the network's first year and to look forward to the future as we continue to address the fragmentation and increase harmonisation in the neuromuscular field across Europe. The meeting also included the very first gathering of the Science and Technological Advisory Council (STAC) who advise the Governing Board. The network partners have worked extremely hard over the first year and have achieved an enormous amount in a relatively short period, a point STAC chair Marianne de Visser brought up in her closing remarks. From the setting up of patient registries in nineteen countries to international consensus on standards of care and the mapping of clinical trial sites across Europe, the collaborative infrastructure being built up by TREAT-NMD has begun to make a real impact on the neuromuscular field. It is important now for the network that we build on this successful first year and continue to make rapid progress in the coming years.



The Governing Board agreed on two major documents that were presented during the meeting. The first is the TREAT-NMD Registries Charter, which outlines the working relationship between TREAT-NMD, national patient registries and those wanting access to the TREAT-NMD global patient database. Secondly, the TREAT-NMD Members' Charter will allow us to work more formally with other groups, institutions and organisations to ensure the tools and products of TREAT-NMD are implemented outside the network. Both these documents will be posted to the TREAT-NMD web site in the next few days and we encourage you to visit our web site to learn more and to comment on these charters.

Finally, it was agreed by the Governing Board that TREAT-NMD would organise its own International Conference on translational research in neuromuscular disease to be held in November 2009. Further details will be released in the coming months.

The next TREAT-NMD Governing Board meeting will be held in Newcastle during the week of 23 June 2008. We look forward to welcoming all our partners to Newcastle!

TREAT-NMD Update on DMD and SMA

TREAT-NMD partners have produced two reports, one on DMD and the other on SMA, which describe some of the activities involving partners over the last six months. These reports give a very good account of the progress made by the international community and the involvement of TREAT-NMD in these two disease groups. The reports can be found on the TREAT-NMD web site by following the links below:

DMD: http://www.treat-nmd.eu/assets/documents/REPORT_DMD.pdf

SMA: http://www.treat-nmd.eu/assets/documents/REPORT_SMA.pdf

Current Use of Steroids in Practice

Kate Bushby and Berch Griggs are asking for help from clinicians who prescribe steroids to work out the current practice across the world in prescribing steroids in DMD. This is to inform the final planning phase of an international trial of steroid dosage regimes.

If you are able to help and have not already received an e-mail with questionnaire attached requesting your help, please click on the link below to download the questionnaire

<http://www.treat-nmd.eu/news/documents/CurrentUseofSteroidsinPractice-Blank.doc>

and return it to Berch Griggs at Griggs_robertresearch@urmc.rochester.edu before **30th January 2008**.

The questionnaire should take no more than a couple of minutes to complete, and we will let you know the results as soon as they are available.

Thank you very much indeed!

Calls for Proposals

New Calls for Proposals: EU-Canada and EU-US

EU-Canada Transatlantic Exchange Partnerships (TEP) Programme

The European Commission, together with Human Resources and Skills Development Canada (HRSDC), has published a new call for proposals to fund joint study and/or training programmes allowing transatlantic exchanges between European and Canadian education institutions.

This is open to higher education institutions and vocational education and training institutions. European eligible institutions must be established in one of the 27 Member States of the EU

Further information and application forms are available at the following link: http://eacea.ec.europa.eu/extcoop/canada/index_en.htm

EU-US ATLANTIS Programme

The European Commission, together with the US Department of Education, has launched a new joint call for proposals covering a series of actions grouped under the common title of "ATLANTIS", and covering the following actions:

- Transatlantic Degree Consortia Projects
- Excellence Mobility Projects
- Policy Oriented Measures.

Further information and application forms are available at the following link:

http://eacea.ec.europa.eu/extcoop/usa/index_en.htm

EU-Australia and EU-New Zealand

The Commission intend to publish a call in early spring for EU-Australia and EU-New Zealand.

New post available for a physiotherapist/ trials coordinator at the Newcastle Muscle Centre, UK



We have a post available from the beginning of 2008 until March 2011 for a physiotherapist with trials experience to work with the neuromuscular team in supporting clinical trials and clinical research activity, including standardised assessments of patients. Experience in trials and/ or research would be very useful, as would familiarity with the principles of good clinical practice, though training in these can be provided. The post holder would work under the direction of consultant physiotherapist Michelle Eagle, as well as interacting directly with the clinical trials co-ordinator and the TREAT-NMD team. The post will be advertised via the University of Newcastle website shortly, but in the meantime we would welcome any approaches from people who would like to discuss the post informally.

For further details contact the TREAT-NMD office (info@treat-nmd.eu), Dr Michelle Eagle (michelle.eagle@btinternet.com) or Prof Kate Bushby (kate.bushby@ncl.ac.uk)

Research Assistant: Social and ethical aspects of research in Neuromuscular disorders. Newcastle University, UK



This European funded Network of Excellence addresses the urgent need to address the treatment of neuromuscular disorders. This project will engage with many ethical and social issues including the ethics of clinical research, biobanks, patients' interests and public concerns. Based in the Policy Ethics and Life Science Research Centre you will be involved with researching the ethical issues associated with the nature and outcomes of research into the treatment of rare neuromuscular disorders many of which affect children. The project will involve literature searches and interviews with clinicians, scientists, patient groups and stakeholders from wider society across Europe.

This is a highly innovative international research programme working with partners across 11 European countries.

Candidates should have a good honours degree (2.1 or above) in a Social Science or cognate discipline and an M.A. / MSc/ in a relevant area is desirable preferably with social science or other relevant research experience. A language other than English is also desirable and you must be willing to travel.

In the first instance the post will be available until December 2011

Closing Date: To be announced.

Postdoctoral Research Assistant and Technical Assistant University of Oxford, Department of Physiology, Anatomy and Genetics.



Applications are invited for a Research Assistant and a Technical Assistant working under the supervision of Dr Matthew Wood on the development of a molecular therapy for Duchenne Muscular Dystrophy - DMD (Molecular Therapy, 2008, 16, 38-45). The project involves the investigation of antisense oligonucleotide technology for exon skipping of the dystrophin gene, which is defective in DMD. Both posts are funded for 18 months by a grant from the Action Duchenne.

Informal enquiries may be made to Dr Wood on tel. (01865) 272419 or on matthew.wood@dpag.ox.ac.uk.

Further information can be found at: http://www.dpag.ox.ac.uk/job_opportunities

Training Opportunities



Clinical Trial Methods Course in Neurology
August 17th-25th, 2008
Vail, Colorado

This is an intensive, interactive clinical trials training program for fellows and early faculty in the clinical neurosciences. The program will introduce early investigators to the essentials of effective clinical trial design and implementation. During the program, early investigators will develop their own pilot clinical trial protocol. The course will be held August 17-24, 2008 at the Vail Marriot Mountain Resort and Spa in Vail, Colorado. Applications are due by March 28, 2008 and accepted applicants will receive full scholarships for tuition and travel expenses.

To learn more about this course please review the brochure

<http://www.treat-nmd.eu/documents/NINDS-Clinical-Trials-Brochure.pdf>

or visit www.neurologytrials.org.

Meetings

American Academy of Neurology 60th Annual Meeting
April 12-19, 2008 in Chicago, Illinois

The deadline for late breaking science abstract submission is **February 15, 2008**

Online submission here:

<http://www.aan.com/go/am/science/latebreaking>

3rd International Congress of Myology
May 26-30, 2008 in Marseille, France

The deadline for abstract submission is **6 Feb 2008**

Online submission here:

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

American Society of Gene Therapy 11th Annual Meeting
May 28-June 1, 2008 in Boston, Massachusetts

The deadline for abstract submission is **28 Jan 2008**

Online submission here:

<http://www.call4abstracts.com/asgt/>

Partner-specific items

Future TREAT-NMD Governing Board Meetings

Newcastle, UK: June 2008

Budapest, Hungary: February 2009

Helsinki, Finland: Summer 2009

Barcelona, Spain: February 2010

Call for WMS 2008 Abstracts

All partners are encouraged to submit abstracts for the upcoming WMS meeting in Newcastle based on their work within TREAT-NMD. A specific TREAT-NMD poster session can then be scheduled for the WMS meeting. The deadline for abstract submission is 31st March 2008. You can access the online abstract submission web page at <http://www.worldmusclesociety.org/>



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