

**TREAT-NMD Partner Newsletter No. 15
and Club of Interest Newsletter No. 9**

15th June 2007

Welcome to the ninth newsletter for the TREAT-NMD Club of Interest. This week's edition features information about our upcoming Governing Board meeting plus a proposed FP7 application that may be of particular interest to network members.

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.

Best wishes,

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

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1. About this newsletter

This is a weekly newsletter sent to all members of TREAT-NMD's "Club of Interest" worldwide. We are receiving new subscriptions all the time, so if you've missed the earlier editions of the newsletter and would like to catch up, please visit our newsletter archive online at <http://www.treat-nmd.eu/news/newsletter/> where you will find all back-issues. If you have received this letter from a friend or colleague and would like to subscribe directly, please visit our website at <http://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.

2. 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

3. TREAT-NMD news and reports

TREAT-NMD Governing Board meeting, 1–3 July 2007

A personal note by Stephen Lynn, TREAT-NMD Project Manager (stephen.lynn@treat-nmd.eu)

The TREAT-NMD Governing Board first officially met at the "kick-off meeting" held at the inauguration of the network in January this year. In two weeks time it will hold its highly anticipated second meeting, which is the first time all partners have had the opportunity to come together to discuss the impressive progress made in the first 6 months of the network and the impact we are having not only across Europe but worldwide. This is due in no small part to the work and dedication of the TREAT-NMD partners who are working hard to ensure the network is seen as an all-inclusive forum for the whole of the neuromuscular community.

The TREAT-NMD Governing Board is composed of representatives from each of the 21 partners that currently make up the network, and it is their responsibility to define the strategy that will define the network and the creation and integration of the TREAT-NMD Coordination Centre (TNCC). The Governing Board is also responsible for deciding on allocations of budgets, incorporating new members, and the creation of spin-off companies. It is supported by a number of advisory councils that will cover issues such as ethics, intellectual property and research activities.

This meeting will hear from partners involved in each of the three Joint Programmes of Activities, which cover integration and communication, research, and dissemination of information. This will be an opportunity for the Governing Board to hear first-hand from those partners who are working hard on these activities. A major challenge for the Governing Board will be to discuss the ongoing work on communicating the aims and objectives of TREAT-NMD to neuromuscular communities across Europe. This is an important goal of the network that will ensure everyone with an interest in neuromuscular disorders is able to contribute to and participate in the network. We will also discuss plans to reach out to groups outside Europe and involve them in various activities – probably in the form of an international conference hosted by TREAT-NMD – watch this space for further updates.

In the first 6 months, the network has drawn huge interest from other countries and organisations that are keen to be involved with the network and see this initiative addressing a number of important bottlenecks and hurdles. We have received interest and support from the Czech Republic, Bulgaria, Ukraine, Turkey, Japan,



Australia and the US. The Governing Board will begin to discuss how we can best serve these interested parties and how they can become associated with the network activities in future.

Finally, the Governing Board will begin the process of shaping and defining the future sustainability of the network, once the initial EU funding runs out in 2011. It is never too soon to be thinking about long-term plans for any venture, so this will be the first of many sessions in which the Governing Board and partners will have the opportunity to shape the future structure of the network. This will be vital if we are to ensure that the global neuromuscular community is best served regarding new and cutting edge treatments and therapies for their patients long after 2011.

Therefore, I look forward with great anticipation to the TREAT-NMD Governing Board meeting and the opportunity to move forward with the process of developing and sustaining a network for all interested parties around the world.

4. Other news

From Orphanews:

EuroGentest solicits feedback for its genetic counselling recommendations

EuroGentest, the European Network of Excellence for genetic testing, is busy developing a set of Recommendations destined for those whose role involves counselling genetic testing patients. EuroGentest is thus requesting feedback on its second draft of these guidelines. All concerned parties are strongly encouraged to take the time to read the Recommendations and offer comments.

See http://en.eurogentest.org/files/public/unit3/Draft_genetic_%20couns_1.6.2007.pdf for details.

OECD issues quality assurance guidelines for genetic testing

The Organisation for Economic Cooperation and Development (OECD) has developed and published a set of quality assurance guidelines for international genetic testing. Observing that "research laboratories play a valuable role in the development and validation of new tests particularly in the provision of genetic testing for rare diseases", the OECD asserts that the unique features of molecular genetic testing "place an enhanced duty on laboratories to assure the quality of their services...while governments, regulators and professional bodies have a responsibility to ensure that all genetic testing services are offered within a quality assurance framework that retains the confidence of the public."

The Guidelines thus consist of "Principles and Best Practices for quality assurance in molecular genetic testing for clinical purposes" and are available to assist both OECD and non-OECD member countries in the development and introduction of appropriate quality assurance procedures. The OECD guidelines contain the following objectives:

- Promoting minimum standards internationally for quality assurance systems and molecular genetic testing laboratory practices.
- Facilitating mutual recognition of quality assurance frameworks.
- Strengthening international co-operation and facilitating, where appropriate, the cross border flow of samples for clinical purposes in accordance with recognised principles for their handling, storage, safety, privacy and confidentiality.
- Increasing public confidence in the governance of molecular genetic testing.

The Principles are designed for governments and those involved in the regulation of genetic services, while the Best Practices are primarily aimed at "professional associations, directors of molecular genetic testing laboratories and others involved in the provision of molecular genetic testing". The OECD states "the ethical and legal principles set out in international declarations and agreements and the diversity of systems and jurisdictions within and between countries have been recognised during the development of these Guidelines." The Guidelines address particular aspects of genetic services, particularly, "molecular genetic testing offered in a clinical context, and the quality assurance practices of laboratories that carry out such tests. They do not address testing carried out only for research purposes". The publication of these guidelines will help contribute to providing equitable and uniform genetic testing practices for rare disease patients and their families across the world. See <http://en.eurogentest.org/files/public/QAGuidelineseng.pdf> for further details.



5. Calls for proposals

FP7 HEALTH Work Programme (Call FP7-HEALTH-2007-B)

The full text of the 2007 Health call document is available at ftp://ftp.cordis.europa.eu/pub/fp7/docs/a_wp_200701_en.pdf and last week's newsletter contained a summary of those we regarded as potentially most interesting to TREAT-NMD partners and Club of Interest members. If you are interested in applying for any of these calls, please notify Stephen Lynn at stephen.lynn@treat-nmd.eu so we can put you in touch with other partners interested in the same call.

A number of partners are interested in putting together an application for the call below, for the same disorders as those covered in TREAT-NMD, i.e. DMD, SMA, and LGMD/CMD, and an email was sent out to partners today requesting feedback on this suggestion. We would be very interested in hearing from anyone outside the network (from both academic institutions and SMEs) who would be interested in working with us in this area. Interested parties should contact Thomas Sejersen at thomas.sejersen@ki.se.

HEALTH-2007-1.2-6: High throughput molecular diagnostics in individual patients for genetic diseases with heterogeneous clinical presentation. The project should lead to the development of new diagnostic tools exploiting the knowledge of the human genome in combination with advanced read-out technology. Deliverables must be the development of a high throughput, sensitive, reliable and especially cost effective diagnostic test per disease category, which displays clear advantages over currently available diagnostic strategies. Special attention should be given to disease categories with heterogeneous clinical presentation, and/or locus heterogeneity, such as primary immunodeficiencies, muscle disorders, growth deficiencies, hearing or vision impairments and hemoglobinopathies. The project must address quality assurance issues and validation aspects, and should offer opportunities for industrial exploitation, preferably through SMEs.

Funding scheme: Collaborative projects (Small or medium-scale focused research projects).

Marie Curie individual fellowships:

Intra-European Fellowships (IEF), Incoming International Fellowships (IIF) and Outgoing International Fellowships (OIF)

DEADLINE: 14th August 2007

DETAILS: Marie Curie individual fellowships in FP7 are aimed at experienced researchers with more than four years' research experience or a PhD and cover all areas of research, including the socio-economic sciences and humanities. The researcher and the host institution jointly submit a proposal for a research project on a topic of their choice.

Nationals of EU Member States or Associated Countries can go to a European country other than their country of origin (IEF), or to a country outside Europe (OIF), for a period of 1-2 years (in the latter case, there is a mandatory return period in Europe of at least one year)

Third country nationals may come to a host institution in a Member State/Associated Country for 1-2 years and if they are nationals of a developing or emerging economy, there is an optional grant to aid return to their country of origin (IIF).

DOCUMENTS FOR SUBMISSION

Intra-European Fellowships (IEF)

http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.PeopleDetailsCallPage&call_id=44

Outgoing International Fellowships (OIF)

http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.PeopleDetailsCallPage&call_id=45



Incoming International Fellowships (IIF)

http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.PeopleDetailsCallPage&call_id=46

Please note: If you are interested in any of these fellowship opportunities, we can offer some documents that have been created to provide further details and support to potential applicants – please contact Rachel Thompson at rachel.thompson@treat-nmd.eu if you would like to receive these documents.

6. Partner-specific items

Governing Board meeting

All Governing Board members should have received the agenda for the upcoming Governing Board meeting in Naarden. If you require a copy, please write to Stephen Lynn at stephen.lynn@treat-nmd.eu. This will be a very busy and productive meeting and many partners have been asked to prepare items in advance. If you would like clarification on any issue, please do not hesitate to contact Stephen at the address above. Various discussion documents and other papers will be distributed in advance of the meeting.

TREAT-NMD 6 month activity report

The 6 month activity report is due TODAY!

1. The Activity Leader should ask each **Work Package Leader** from her/his Activity to complete the information on her/his WP (i.e. Work Package objectives, Progress towards objectives, Ethics, Deviations from project work program, deliverable and milestones and dissemination of knowledge). WP leaders can do this by updating their 3 month report and sending it to their Activity Leader **as soon as possible**.
2. The Activity Leader **consolidates** information from the Work Packages of her/his Activity, and provides an overview of actions undertaken.
3. The Activity Leader **sends** the consolidated report to ACIES (eu-new@acies.fr) no later than the **Friday 15th June**

Cost-Effort forms

Today is also the deadline for the cost-effort forms!

The first overview on costs and resources spent during these 6 first months of TREAT-NMD is required before the Governing Board meeting at the end of June. Therefore, could you please send ACIES your cost and efforts follow-up sheets before the **15th June**? These sheets, designed for each partner, are **downloadable** from the private part of the website (<http://www.treat-nmd.eu/private/> under "Cost forms").

Posters and presentations for Governing Board meeting

Partners have been asked by Stephen Lynn to prepare and present posters and/or presentations for the Governing Board meeting. Templates are available to download from the private section of the website <http://www.treat-nmd.eu/private/>.

As a general guide, can we please request that all posters should be printed A1 size (594x841 mm or 23.4x33.1 inches). The poster template page setup is set at A1 size. The posters will be on display from the evening of Sunday 1st July until the close of the meeting on Tuesday 3rd July. The UNEW team are very happy to help you in preparing the content for these posters, so please feel free to contact us.

You will also find on this web page a template for producing PowerPoint presentations related to the network. Please use this template when designing presentations that you intend to give on your activities within the network. We hope you find these templates useful.

Reimbursement guidelines

As the number of TREAT-NMD activities are increasing across the network reimbursement guidelines have been drawn up to help simplify your planning and implementation of TREAT-NMD related meetings and workshops. These guidelines have been posted on the private section of the web site and will be incorporated into the next version of the TREAT-NMD Project Management Manual. Please print-out and read these guidelines – they will help you to correctly identify the source for reimbursement when attending workshops and meetings.



Discussion forums / lists

Would you like us to set up a discussion forum for you on the TREAT-NMD website?
If so, please e-mail rachel.thompson@treat-nmd.eu.

Calls for proposals / funding opportunities

Please forward to us at the Coordination Office any calls for proposals and funding opportunities you receive within your institution. We will then advertise these in the newsletter and on the website.

7. Send us your news and views!

We 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

