



TREAT-NMD Partner Newsletter No. 10 and Club of Interest Newsletter No. 4

11th May 2007

This week's newsletter contains information about plans for the Standards of Care pages of the website and some interesting calls for proposals, including some FP7 calls.

The TREAT-NMD Club of Interest is growing on a daily basis – thank you all for your support and please keep spreading the word!

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. Much 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. Patient databases: online discussion / comment facility

Hanns Lochmüller and Christophe Beroud, the leaders of the TREAT-NMD activity on creating international patient databases, are inviting comments from specialists via an online comment form at <http://www.treat-nmd.eu/biobanks/>. A number of useful comments and documents have already been received and can be viewed at the aforementioned address. Please feel free to visit this website section, read Christophe's letter, and send your comments via the online form. **A meeting has been arranged for specialists to discuss issues relating to the TREAT-NMD databases in Paris on the 11th June – we therefore encourage you to submit your comments before then.**

4. Standards of care and diagnosis

Over the coming months TREAT-NMD will be working with experts worldwide to review standards of care for DMD and SMA with the aim of producing a consensus document that will hopefully become the "gold standard" of recommendations for the best way of caring for patients. We plan to develop the TREAT-NMD website into a comprehensive reference site for standards of care, which physicians and patients internationally can turn to for advice. Our work will be based on the valuable existing documents that are already available, and wherever we can gain the appropriate permissions we will publish the care standards that are in use in various countries or regions or that have been proposed at expert workshops such as the ENMC workshops, together with summaries of the most important conclusions.

We therefore welcome submissions of key papers / reports for uploading or summarising to arron.scott@newcastle.ac.uk

This area will see a lot of activity over the coming weeks – watch this space for news.



5. Latest news / research

Cooperation is key, say neuromuscular-disease researchers

The Lancet Neurology Vol 6 April 2007 p 298-299

We mentioned a few weeks ago that the TREAT-NMD network was highlighted in a recent edition of The Lancet Neurology. We have now very kindly been given permission by the article's author and the journal editor to upload the article to the TREAT-NMD website.

It can be viewed here: http://www.treat-nmd.eu/assets/documents/TREAT-NMD_Lancet_Neurology.pdf

This two-page article contains interviews with several partners and club of interest members and provides a valuable introduction to the network.

6. Calls for proposals

We regularly publish calls for proposals that might be of relevance to TREAT-NMD in this section of the newsletter. The network has ambitious plans in areas such as training and education, and since these are not covered by our initial funding from the EU, we have to seek funds from elsewhere. We strongly encourage anyone outside the network who is interested in developing links with us to look through these calls and see if there is anything of relevance to you. We also encourage partners to consider possibilities for academic exchanges via these proposals. We would ask anyone considering submitting a proposal for any of these funding opportunities to contact Stephen Lynn at stephen.lynn@newcastle.ac.uk – we will be happy to provide help and support if you require it, and it will help us to get an overview of the funding being applied for.

EU-US Call for Proposals 2007 - ATLANTIS

Deadline

31st May 2007

Details

The European Commission has published a new call for proposals under the ATLANTIS programme (Actions for Transatlantic Links and Academic Networks for Training and Integrated Studies). This call is launched jointly with the US Department of Education, Fund for the Improvement of Post Secondary education (FIPSE) in the framework of the 2006-2013 EU-US agreement in higher education and vocational training.

The general objective of the call for proposals is to promote better understanding and interaction between the peoples of the EU Member States and of the US, including a broader knowledge of their languages, cultures and institutions, and to improve the quality of higher education and vocational education and training in the EU and in US. There three types of action under this call:

Transatlantic Degree Consortia Projects

This Action provides support for consortia of EU and U.S. higher education institutions (hereafter called 'consortium') to implement dual/double or joint degree programmes referred to in the present document as 'Transatlantic Degrees.' Support may include mobility grants for students and faculty.

Excellence Mobility Projects

This Action provides funding for international curriculum development projects that involve short term transatlantic mobility not directly related to award of a joint or dual/double degree. Consortia applying for such a project must be able to demonstrate a proven track record in transatlantic cooperation and exchanges including those funded under preceding EU-U.S. agreements. Support includes mobility stipends for students and faculty.



Policy-oriented Measures

This Action provides support to multilateral EU-US projects and activities designed to enhance collaboration in the higher education and vocational training field.

Further Information

http://ec.europa.eu/education/programmes/eu-usa/call_en.html

http://europa.eu.int/comm/education/programmes/calls/callg_en.html

EACEA-EU-US@ec.europa.eu

Sources

OJC 83 (17.04.2007), p.21

http://ims.ukro.ac.uk/NR/rdonlyres/D6A90F5B-6721-4F87-9E36-2B1E56CDFE38/4181/070417_OJcp21.pdf

British-Italian Partnership Programme 2007: Call for Proposals

Deadline

20th July 2007

Details

The British Council Italy invites proposals for support within the British-Italian Partnership Programme, which promotes the development of British-Italian scientific cooperation between universities and public sector research institutes in Italy and the UK.

The Partnership Programme key objective is to focus on new or recently initiated collaborative links offering international experience to young researchers, with preference being given to projects which provide research training opportunities in the partner country. Proposals must fall within one of the following subject areas:

INFORMATION TECHNOLOGY IN HEALTHCARE has the potential to improve the quality, safety and efficiency of healthcare. Proposals should address viable solutions to support the ever increasing problem of ageing populations.

THE INTERACTIONS OF LIGHT AND NANOSTRUCTURES FOR APPLICATION IN SENSORS Among its many other applications, nanotechnology offers the opportunity for the sensing of chemical or biological entities in a number of different areas. They are particularly interested in projects that use the features of nanostructures as they interact with light to produce novel sensors for any practical purpose.

Note: The Programme provides a contribution towards travel and living expenses, but does not cover research costs.

Further Information

<http://www.britishcouncil.org/italy-science-partnership-programme.htm>

or contact jrp.italy@britishcouncil.it

Science in Society (SiS): Promotion of excellent trans-national research and science communication by the means of popular prizes



- Descartes prizes for transnational collaborative research
- Prizes for science communication

Deadline

17th July 2007

Details

Description of Topic: The European Research Awards have been created with a view to contributing to the Community policy which aims to stimulate European collaborative research, ensuring the general public's interest and understanding of its results. The European Research Awards complement each other and serve as a major awareness-raising tool. Making good science and communicating it efficiently are indeed essential ingredients in developing the European knowledge society.

The annual European Research Awards are a public recognition of outstanding achievements in (i) transnational collaborative research (Descartes prizes) and in (ii) science communication

The prizes are awarded respectively as follows:

(i) SiS-2007-3.0.5.1 European Research Awards - Descartes prizes for transnational collaborative research:

Prizes will be awarded to transnational teams that have achieved outstanding scientific or technological results from European collaborative research in any field of science, including the economic, social and human sciences. Each proposal received in response to this call will be allocated by the Grand Jury to one of four categories which will cover the various fields of science. In principle, in each of these categories one prize will be awarded, and one finalist selected. Proposals may be submitted by the research teams themselves, or by research organisations and institutions.

(ii) SiS-2007-3.0.5.2 European Research Awards - Prizes for science communication: Prizes awarded to organisations or individuals that have achieved outstanding results in science communication and which have been selected as winners of awards by European and/or national organisations. In principle, prizes will be awarded in the following categories:

- The communicator of the year: scientists or professionals engaged in communicating science to the public.
- The writer of the year: popularising science through the written word (e.g. newspaper articles, popular science books, editorial policies, innovative actions).
- The audiovisual documentary of the year: popularising science through audiovisual and electronic media (e.g. scientific television or radio documentaries, websites, editorial policies, innovative actions).

Proposals must be submitted by the organisation which has awarded the prize to the candidate.

NB: For all of the above mentioned prizes, there can be not more than one laureate per category and not more than one finalist per category.

Funding Scheme: Co-ordination and support actions (supporting)

Expected Impact: Increased standards and prestige of European collaborative research and of Science communication. Greater awareness among scientists of the importance of science communication. Better understanding of European research and of European research policies by the scientific and science communication communities. Increased knowledge about scientific research and science communication by the public at large. Feed the public debate on scientific research issues. Encourage scientific careers. Entice young people to an increased interest in science.

Further Information

http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.CapacitiesDetailsCallPage&call_id=48



eContentplus Work Programme

Deadline

The 2007 call for proposals is expected to be launched in June, with a provisional deadline of 4th October this year.

Details

The European Commission, DG Information Society, has published the 2007 draft work programme for eContentplus. eContentplus is a multiannual programme to make digital content in Europe more accessible, usable and exploitable (2005-2008). [Note that this programme is outside FP7, but intended to be complementary to it.](#)

The 2007 call for proposals is expected to cover the following areas:

Geographic information

- Best practice networks for geographic information

Educational content

- Best practice networks for educational content
- Targeted projects for educational content

Digital libraries

- Best practice networks for digital libraries
- Targeted projects for digital libraries
- Targeted projects for scientific/scholarly content

Reinforcing cooperation between digital content stakeholders

- A thematic network on language resources.

Further information

http://ec.europa.eu/information_society/activities/econtentplus/calls/proposals/index_en.htm

Information Day, Luxembourg, 24th May

http://ec.europa.eu/information_society/activities/econtentplus/events/lux_info_day_2007/index_en.htm

7. TREAT-NMD website proforma: please return as soon as possible

To all activity leaders: the TREAT-NMD website proforma deadline has now passed. We would like to thank all who have returned their completed proformas: they have provided valuable content for the website, and this will be appearing online shortly. We encourage those who have not yet done so to complete and return your contributions as soon as possible to r.h.thompson@newcastle.ac.uk

8. Fact-finding Questionnaire

Thank you to everyone who returned their fact-finding questionnaire.

Individual partners will receive feedback on the questions relating to their specific work packages next week and a short overview report for all partners and interested supporters will appear in a future newsletter.

9. Acknowledge TREAT-NMD

We would like to encourage all TREAT-NMD partners to recognise the support they receive from the TREAT-NMD network in papers, on posters and at conferences and workshops, whether that be through direct funding or via the support they receive from its members. It is not only good for the growth of the network but also fulfils one of our deliverables!



10. Upcoming conferences, meetings and workshops

TREAT-NMD meetings

TREAT-NMD National Database Curators Meeting

Date: 11 June 2007
Venue: Paris, France

TREAT-NMD Outcome Measures Workshop

Date: 30 June–1 July 2007
Venue: Naarden, The Netherlands

TREAT-NMD Governing Board Meeting

Date: 2–3 July 2007
Venue: Naarden, The Netherlands

TREAT-NMD Project Ethics Council Meeting

Date: 3–4 July 2007
Venue: Naarden, The Netherlands

TREAT-NMD Governing Board and Science and Technology Advisory Council Meetings

Date: 14–16 January 2008
Venue: Milan, Italy
(more details will be provided closer to the time)

Other meetings

IV Congress of the Spanish Society of Gene and Cell Therapy.

Date: 19–21 September 2007
Venue: Madrid, Spain
More details: <http://www.setgyc2007.com/>

As new upcoming conferences only appear once in the newsletter we have decided to provide a full overview of all upcoming conferences under the news and events section of the TREAT-NMD website. This will appear within the next few weeks.

If there is an event you would like us to publicise in future newsletters and on our website, please send details to r.h.thompson@newcastle.ac.uk.

11. 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@newcastle.ac.uk. What else would you like us to include in the newsletter? Write to Emma with your feedback. Please e-mail us with any information you have on upcoming education and training opportunities including workshops, conferences, funding, exchange programmes, clinical placements, visiting professorships and lectureships.

12. Publicising TREAT-NMD

If you plan on attending any conferences, workshops or other meetings please download the TREAT-NMD double-sided colour flyer http://www.treat-nmd.eu/assets/documents/TREAT-NMD_Flyer.pdf and hand it out



to interested parties. You also have the option of downloading an editable version in Microsoft Publisher format (higher resolution, better for large batch printing) http://www.treat-nmd.eu/public_html/private/docs/TREAT-NMD_Flyer.pub. We have had a limited quantity of flyers printed, therefore if you would like some to be posted to you for a specific event, please write to r.h.thompson@newcastle.ac.uk detailing the event you plan to attend and the numbers you require.

13. TREAT-NMD link from your website

In an effort to increase the profile of TREAT-NMD, supporters and members of the Club of Interest are warmly invited to link to the TREAT-NMD website. To download a web-friendly TREAT-NMD button for your website please click on the following link and copy the appropriate line of code to your website: <http://www.treat-nmd.eu/link.htm>

Alternatively the TREAT-NMD logo is available to partners via the website at <http://www.treat-nmd.eu/private/> for you to create your own hyperlink. Those without a partner login should write to r.h.thompson@newcastle.ac.uk if they would like a copy of the logo.

