

welcome

Welcome to the latest TREAT-NMD newsletter.

This week's edition includes:

- information about TREAT-NMD's next conference scheduled for November 2011
- initial information about the stakeholder consultation process for TREAT-NMD
- a report from the first Russian summer school of myology
- a call for research projects from SMA Europe
- details of a research opportunity studying biomarkers for DMD

This is our final newsletter before we take our summer break. We would like to take this opportunity to thank everyone who has contributed to the newsletter over the last year.

We will return on 3rd September, so if you have anything you wish to include in our newsletter on our return please get in contact at info@treat-nmd.eu

See you in September!

at a glance...

[30 Jul - 1 Aug 2010 The Biennial FSHD International Patient and Researcher Network Meeting - Las Vegas, Nevada, USA](#)

[13-15 Aug 2010 Empower 2010 - Myotonic Dystrophy Family Conference - Minneapolis, MN, USA](#)

[14 Aug 2010 Annual BMD Conference - Boston, MA, USA](#)

[14-15 Aug 2010 CMD Family and Affected Person Conference - Philadelphia, PA, USA](#)

[26 Aug 2010 - 04 Sep 2010 Advanced symposium and EMBO practical course - Kuopio, Finland](#)



SAVE THE DATE for next year's TREAT-NMD global conference!

Following the success of [last year's international conference, "Bringing Down the Barriers"](#), co-sponsored by TREAT-NMD and the US National Institutes of Health (NIH), we are delighted to announce a major follow-up conference to take place **8th - 11th November 2011** in Geneva, Switzerland.



Organised with logistical support from the Swiss patient organisation **Progena**, the conference will comprise a range of sessions addressing the challenges in the neuromuscular field, including:

- Delivery of future therapies
- Biomarkers
- Care considerations
- Neuromuscular diseases and society
- Regulatory issues, orphan drugs and the rare disease field

Please put the date in your diaries now and come back soon for further information!

MORE >

Public consultation on the future focus of TREAT-NMD

**Public consultation
3 September - 1 October**



TREAT-NMD is currently funded as a 'Network of Excellence' by the European Union and its activities for its initial 5 years (Jan 2007-Dec 2011) are clearly defined in a "Description of Work" approved by the EU. After 2011, the structure of the network will evolve as new funding sources are brought in and new partners have the opportunity to play a more active role in the network.

To make sure the future structure and activities of the network reflect the needs of all its stakeholders, we need your input. We will be holding a four-week public consultation which will open on Friday 3 September. A strategy document and detailed questionnaire will be made available online and all stakeholders will be encouraged to contribute their opinions. The results of this consultation will help TREAT-NMD to define its future structure, activities and objectives.

Further details will be provided in the TREAT-NMD newsletter when the public consultation opens on 3 September. If you have any questions in the meantime these should be addressed to TREAT-NMD's project manager [Stephen Lynn](#).

[29 Aug - 1 Sept 2010 European Meeting on Next Generation Sequencing - Leiden, Netherlands](#)

[9-10 Sept 2010 MD2010 - 4th conference for the Muscular Dystrophy Association of Western Australia - Perth, Western Australia](#)

[18 Sept 2010 Muscular Dystrophy Campaign Conference - Birmingham, UK](#)

[20-22 Sept 2010 Muscle Study Group Annual Meeting - Buffalo, NY, USA](#)

[01-02 Oct 2010 European Research Conference in Paediatric Neurology - Leuven, Belgium](#)

[4-5 Oct 2010 7th UK SMA Researchers' Conference - Llanwyddyn, Wales, UK](#)

[12-16 Oct 2010 World Muscle Society International Congress - Kumamoto, Japan](#)

[21-22 Oct 2010 FSH Society FSHD International Research Consortium Meeting - Watertown, MA, USA](#)

[12-13 Nov 2010 Action Duchenne 8th Annual Conference - London, UK](#)

[16 Nov 2010 Europlan Conference - Manchester, UK](#)

Please note: This is only a selection of upcoming meetings. To see all our listed meetings [click here](#).

First Russian Spring School of Myology initiates specialist training for Russian health professionals

From 17-20 May 2010 more than 60 Russian clinicians, scientists and health professionals with a special interest in neuromuscular disorders came together in St Petersburg for an update on the latest developments on diagnosis, standards of care, clinical management of symptoms and development of treatments. The four-day training course, branded as the "1st Spring School of Myology", was organised by TREAT-NMD and the ENMC in collaboration with the University of St Petersburg, AFM and GAOORDI, an umbrella organisation for parents of disabled children in St. Petersburg.



Considerable progress has been made in the last decade in the development of diagnosis and potential treatments for a number of neuromuscular conditions and keeping up to date with these advances is a significant challenge for many clinicians whose main concern is the day to day care of their patients. As most of the conditions are rare or ultra-rare, national and international collaboration between muscle centres is vital to ensure the speedy transfer of these advances into the clinic. Therefore the idea of the 1st Spring School of Myology was to initiate a training course in the style of the myology summer schools that are held in every year in London and Paris and to not only provide updates on different aspects of myology, but also encourage networking and communication between different muscle centres and disciplines, both within Russia and between Russia and other countries.

A scientific committee consisting of clinicians from Russia, France and the UK developed a stimulating programme with lectures that provided an overview of a broad spectrum of conditions including muscular dystrophies, metabolic and inflammatory myopathies and neuropathies. The presentations were given by expert clinicians from Russia and other European countries and gave the Russian participants the opportunity to compare their standards of diagnosis and clinical management nationally and internationally and also to voice the challenges they are specifically facing within their regions. There was agreement that a multidisciplinary team is essential for patients to benefit from the best possible care to improve life expectancy and quality of life. Emphasis was on improving diagnostic standards, particularly in view of the establishment of patient registries and the development of personalised medicine. The partnership with the GAOORDI patient organisation was also a very positive experience and the need for collaboration between doctors and patients was stressed during the course.

The lectures were given either in Russian or English and an excellent simultaneous translation service ensured that nothing was "lost in translation". At the end of each day a clinician from Russia presented a case study with a patient attending the course in person and a lively discussion followed that allowed the experts to share their knowledge and experience.

The feedback from the course has been tremendous and the hope is that in the coming years the "Spring School of Myology" will become an integral part of clinical training within the field of neuromuscular disorders in Russia. We are delighted to report that talks are already underway for a second course that will take place next year in Moscow.

Report by Marita Pohlschmidt, MDC

[MORE >](#)

Send us your meeting details

The meetings and events section of the TREAT-NMD website is one of its most popular, with over a thousand visitors in the last month alone. Our aim is to ensure it is a comprehensive list of all neuromuscular-related events worldwide to assist all our colleagues in diary planning and help avoid meeting clashes. As many of you are already making plans for 2011, we need your help now to complete our listing of meetings and events for the rest of 2010 and also 2011.



If you are aware of an event that should be listed, please send details to michael.hails@newcastle.ac.uk or telephone the TREAT-NMD coordination office on +44 191 241 8605.

Your contribution will not only help maintain the utility of this area of the website but also help promote your meetings to our many visitors.

[MORE >](#)

SMA Europe call for research projects

SMA Europe has announced its third international call for SMA research projects, following the successful calls in 2008 and 2009.

This third call for SMA Projects will be open to any research project aimed at finding a cure or therapy for Spinal Muscular Atrophy (SMA). Priority will, however, be given to projects concentrating on the following aspects/fields: basic research, gene and/or cell therapy, clinical trials, biomarkers and/or functional outcome measures and drug



development.

SMA Europe want this call for projects to foster both international collaboration between SMA researchers and to address potential bottlenecks in the search for cures and therapies for SMA. Preference may be given to applicants who address these concerns.

The screening of applications in 2010 will be provided by a scientific advisory board under the direction of AFM (Association Française Contre les Myopathies). If applicants need further information regarding the process or the make up of the selection panels, please contact AFM at sma-europe@afm.genethon.fr

The final choice of projects to be funded will be selected by the representatives of the partner organisations, based on the recommendations made by the advisory board.

SMA Europe has no central secretariat, and the selected projects will be allocated to member organisations of SMA Europe for funding. Contractual and financial responsibility for a project will be taken directly by the member organisation(s) on behalf of SMA Europe.

The application deadline for projects is **8th October 2010**.

Two types of research grants will be awarded Operating Grants and Postdoctoral Fellowships.

It is anticipated that notification of Awards will be made early in 2011 with funding to commence as soon as possible thereafter, subject to contracts being agreed between the relevant parties. It is recognised that time lines will be affected by project specifics, notably in the case of potential part or joint funding of a clinical trial.

Full details can be downloaded from [here](#).

MORE >

Job opportunity for senior scientific researcher - biomarker discovery

A position has arisen for a senior scientific researcher based at Leiden University Medical Centre. The successful candidate will be part of a team dedicated to the further improvement of a genetic therapy for Duchenne Muscular Dystrophy.

The project aims to discover new non-invasive protein biomarkers for the monitoring of disease progression and response to therapy. The appointed person will apply high dimensional liquid chromatography and mass spectrometry on serum samples. Additionally they will also be responsible for part of the biomarker discovery program in the department of Human Genetics.

Leiden University Medical Center is a center of medical innovation that will improve patient care through scientific research. The center boasts an impressive amount of state-of-the-art analytical equipment and has extensive experience with high-throughput biomarker research. The successful candidate will collaborate closely with other partners in the EU project BIO-NMD.

For further details please visit the [job opportunity](#) section of the TREAT-NMD website.

MORE >

www.treat-nmd.eu

Unsubscribe | [view this newsletter online by clicking this link](#)