

welcome

Welcome to the latest TREAT-NMD newsletter.

This edition includes:

- news of a new committee to oversee EU rare disease policy
- a call for transnational research programs from E-Rare-2
- the publication of the UK Muscular Dystrophy Campaign's research magazine for patients

We would like to thank those who have contributed to this edition. This newsletter relies on input from our readers. If you have anything you wish to be included in the next newsletter please contact us at info@treat-nmd.eu. This is the last edition of 2010 - we'll be back in January but in the meantime would like to wish you happy holidays and all the very best for 2011!

at a glance...

[21-22 Feb 2011 7th Annual Update Symposium on Clinical Neurology and Neurophysiology - Tel Aviv, Israel](#)

[24-26 Mar 2011 International Congress of the European Society of Magnetic Resonance in Neuropediatrics - Amsterdam, Netherlands](#)

[29-30 Mar 2011 The Fourth UK Neuromuscular Translational Research Conference - London, UK](#)

[7-8 April 2011 Chinese conference on translational research in DMD - Guangzhou, China](#)

[9-16 April 2011 63rd American Academy of Neurology Annual Meeting - Honolulu, Hawaii](#)

[9-13 May 2011 Myology Congress - Lille, France](#)

[18-22 Oct 2011 WMS Conference 2011 - Algarve, Portugal](#)



New European Union Committee of Experts on Rare Diseases (EUCERD) will oversee EU rare disease policy

The newly formed European Union Committee of Experts on Rare Diseases (EUCERD) convened for the first time on 9-10 December in Luxembourg. The committee is made up of experienced stakeholders in the field of rare diseases, including representatives from DG Sanco and DG Research funded projects, the rare disease patient organisations and the biopharmaceutical industry.



EUCERD is charged with aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, in cooperation and consultation with the specialised bodies in Member States, the relevant European authorities in the fields of research and public health action and other relevant stakeholders acting in the field.

At the kick-off meeting, Ségolène Aymé (Orphanet) was elected President of EUCERD for a two-year term. The Bureau will have three Vice-presidents: Yann Le Cam (Eurordis), Kate Bushby (TREAT-NMD) and Helena Kaariainen (National Institute for Health and Welfare Helsinki).

The committee will monitor and contribute to the implementation of existing European strategies towards rare diseases, including the European Project for national plans for rare diseases, the revision of the WHO International Classification of Diseases (ICD 11) in the field of rare diseases, and joint EU-US strategies towards the creation of an international rare disease consortium to prioritise and organise research in these conditions.

Three EUCERD Working Groups will be refined and will hold workshops in 2011. These will focus on Centres of Expertise and European Reference Networks for rare diseases; Registries; and Coding and Classification.

www.eucerd.eu

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Best wishes for the holiday season from all at TREAT-NMD

TREAT-NMD was established as a collaborative network and it is thanks to the tremendous efforts, goodwill and dedication of clinicians, researchers and patient groups across the world that the neuromuscular community is achieving so much. On behalf of everyone associated with TREAT-NMD we would like to take this opportunity to thank you all once again for your dedication and support, and to wish you a happy and peaceful holiday season and all the best in the coming year.



Kate Bushby and Volker Straub

TREAT-NMD Coordinators

8-11 Nov 2011 [TREAT-NMD International Conference - Geneva, Switzerland](#)

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

E-Rare-2 Call for Proposals 2011 - Transnational Research Projects on Rare Diseases

The Seventh Framework Programme project E-Rare-2 is calling for transnational research programs from research groups based in Austria, Belgium, France, Germany, Greece, Israel, Italy, Spain or Turkey.



Proposals must cover at least one of the following topics...

- Definition of new nosological entities, epidemiological studies, genotype/phenotype correlations, natural history of diseases
- Characterisation of the genetic/molecular basis of specific diseases
- Pathophysiological and genetic studies of rare diseases
- Diagnostic and therapeutic research (interventional clinical trials are excluded)

Proposals should demonstrate the clear potential for clinical application whilst the benefits of transnational collaboration in the form of gathering a critical mass of patients/biological material, harmonization of data, sharing of resources, sharing of specific know-how and/or innovative technologies should also be readily apparent.

The submission procedure is a two stage process and each submitted proposal must involve a minimum of 3 and a maximum of 6 research groups from at least 3 different countries participating to this call.

Funding is granted for a maximum of three years.

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UK Muscular Dystrophy Campaign publishes research update for patients

The UK charity the Muscular Dystrophy Campaign has published the third issue of Target Research - an annual magazine dedicated to neuromuscular research for patients, families and supporters. This issue features gene therapy, translational research and next generation DNA sequencing.



Inside you will also find summaries of this year's research and clinical trial news, interviews with Lord John Walton and Professor Alan Emery, details of the research that the charity funds and more. An [electronic copy](#) of the magazine can be downloaded from the Muscular Dystrophy Campaign website or contact research@muscular-dystrophy.org for a hard copy.

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