Newsletter April 2012

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YOUR NEWS

Are you a EUGT2 participant? Let us know if you are involved in upcoming evens or have a new publication. We will publish this on the website and in the newsletter!

IN SHORT

EuroGentest2 is a European coordination action for the harmonization and further improvement of genetic services, especially genetic testing across Europe.

UPCOMING EVENTS

- Quality in Genetic Counselling : Prenatal diagnosis workshop, 2-3 May
- 25th Course in Medical Genetics, 20-24 May
- Bioinformatics for genetics scientists, 22-23 May
- 6th European Conference on Rare Diseases and Orphan Products 2012, 23-25 May
- BASIC WORKSHOP - Validation of diagnostic tests in clinical molecular genetics, 31 May- 1 June

PARTICIPANTS ONLY

Documents for EUGT2 participants are found on the participant page of the EuroGentest website.

If you cannot access these documents, make sure you are registered on the website and contact our webmaster for participant access.

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Do you wish to receive this newsletter and stay up to date with the activities of EuroGentest2? Please register on our website.

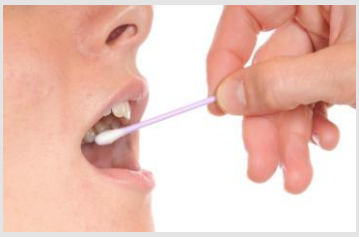
EuroGentest at the 6th European Conference on Rare Diseases and Orphan Products 2012

The European Conference on Rare Diseases & Orphan Products is the unique platform/forum across all rare diseases, across all European countries, bringing together all stakeholders - academics, health care professionals, industry, policy makers, and patients' representatives.

The conference will take place from **23rd until 25th of May 2012** in **Brussels** (Belgium) and EuroGentest will actively participate with posters, presentations and a joint booth with ESHG.

For more information click here.

Consumer Genetic Testing - POSTnote



Last month, the UK Parliamentary Office of Science and Technology published a POSTnote - *a short briefing note on current science or technology issues and its policy implications* - on **direct-to-consumer genetic testing** services.

"DNA sequencing is getting faster and cheaper. This has paved the way for the development of genetic tests for predisposition to diseases. These are now being marketed directly to consumers over the internet. This POSTnote explores the scientific, regulatory, and ethical issues related to such tests."

Click here to download the POST Note and read the report review by Dr Peter Border and Dr Ana Padilla on the Bionews website

! Newly published Clinical Utility Gene Cards for:

Proximal spinal muscular atrophy - 2012 Apr 18

Nemaline myopathy - 2012 Apr 18

Check the EuroGentest website for a full list of CUGC's.

Publications

By EuroGentest members:

- The changing landscape of genetic testing and its impact on clinical and laboratory services and research in Europe
- Development of an Evidence-Based Information Booklet to Support Parents of Children Without a Diagnosis
- Non-invasive prenatal diagnosis for fetal sex determination: benefits and disadvantages from the service users' perspective

For your interest:

- The clinical implementation of whole genome sequencing: a conversation with seven scientific experts
- Preimplantation genetic diagnosis (PGD) for Huntington's disease: the experience of three European centres.
- Managing incidental findings and research results in genomic research involving biobanks and archived data sets
- Exome Sequencing: Dual Role as a Discovery and Diagnostic Tool

Other

- Connect to EuroGentest on LinkdIn
- Read more about EuroGentest
- EuroGentest will hold its next steering committee meeting May 9th 2012.