



Newsletter September 2011

YOUR NEWS

Are you a EUGT2 participant? [Let us know](#) if you are involved in upcoming events 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

Molecular and Cellular Biology of the Epithelium in Health and Disease:

- [WS1. Membrane Signalling & Inflammation, 12-16 Sept](#)
- [WS2. Epithelial Cellular Differentiation & Physiology, 19-23 Sept](#)

[9th Balkan Congress of Medical Genetics, 15-17 Sept](#)

[Hereditary recurrent fevers \(HRF\) best practice meeting for genetic diagnostics, 18-19 Sept](#)

[2nd Course in Eye Genetics, 28 Sept -1 Oct](#)

[WORKSHOP - Accreditation for PGD laboratories, 3-4 Oct](#)

PARTICIPANTS ONLY

Documents for EUGT2 participants are found on the [EuroGentest website](#) (log on and go to the 'Participant' tab).

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Ancillary event ICHG2011: "Challenges in the Translation of Genomic Innovations into Clinical Care"

EuroGentest and CanGeneTest are jointly organizing an ancillary event Thursday 13 October 2011 at the [12th International Congress of Human Genetics \(ICHG\) and the 61st ASHG Annual Meeting in Montreal \(Quebec\), Canada](#).

Apogee/CanGeneTest and EuroGentest are 2 major networks, dealing with all aspects of genetic testing: Quality Management, Public Health, New Technologies and Education. The members of the network reach out to the colleagues in the genetic laboratories, practitioners in the genetic services, as well as to the patients, public and policy makers. The technological revolution enabling complete human genome sequencing at low costs will have a dramatic impact on our life and on our vision of life. This revolution challenges a broad spectrum of disciplines. Technological challenges include the development of infrastructure to handle the massive amount of data, to link the medical records with genetic information, to provide clinical validation and, last but not least, to prove the utility of full genome sequencing in a clinical context. In addition, ethical, social and legal questions need to be addressed before the massive introduction of this technology. Members of Apogee/CanGeneTest and EuroGentest have thought about these issues, therefore we would like to present different perspectives - and maybe a few solutions - during this session in Montreal.

More information on this meeting can be found [here](#).



Production of a WHO-certified panel of Reference Materials for Prader-Willi syndrome and Angelman syndrome testing

Medical Laboratory standard ISO 15189 requires that all assays should be calibrated by "use of suitable reference materials". EuroGentest and the UK's National Institute for Biological Standards and Control (NIBSC) are working to make such reference materials available for genetic tests.

EuroGentest supported NIBSC in the successful production of a WHO-certified panel of Reference Materials for Prader-Willi syndrome (PWS) and Angelman syndrome (AS) testing. NIBSC is the only centre in the world producing biological reference materials for the WHO. PWS and AS patient samples were supplied by EuroGentest partners (notably Rob Elles in Manchester) and EuroGentest provided seed funding for the project, as our surveys had identified these materials as high priority. Results of a world-wide collaborative validation study, as recently [published in EJHG](#), indicate that these materials are suitable for use in methylation-specific MLPA, methylation-specific PCR and *UBE3A* sequencing. The panel consists of genomic DNAs generated from cell lines, which can be renewed indefinitely. The PWS/AS panel joins the recently-approved Fragile X panel (also supported by EuroGentest) in the [NIBSC catalogue](#).

Workshop on Quality in Genetic Counseling and Best Practice Guidelines for Provision of Clinical Genetic Services

One work package within EuroGentest2 is focused on quality in genetic counseling (WP7) and another is aimed at developing best practice guidelines for provision of clinical genetic services (WP8). Because of the overlap in the goals of the two work packages and the expertise needed for their aims, we have decided to organize a meeting together on the 22nd and 23rd of November 2011 in the Netherlands. Invited are specialists from all over Europe from different fields as e.g. clinical genetics, oncogenetics, cardiogenetics, neurology, primary care, molecular genetics etc.

The aim is to explore the implications of recent developments in genetic testing to set the groundwork for writing the guidelines. [More information on this workshop can be found here](#).

Other news

- Connect to EuroGentest on [LinkedIn](#)
- EUGT2 was present at the ESHG 2011 conference in Amsterdam: read the workshop summaries of EUGT2 participants [here](#).
- September 30th the Steering Committee will have its two-monthly meeting by teleconference
- Unit 1 will have their unit meeting in London (UK) September 15th. A report will be posted on the [website afterwards](#).