



Newsletter February 2013



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

- EuroGentest 3rd Scientific Symposium, 7-8 Mar
- Next Generation Sequencing: Bioinformatics and Data Analysis - Workshop & Symposium, 12-13 Mar
- 13th Annual meeting of the Belgian Society of Human Genetics, 15 Mar



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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REGISTER

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

March 7-8, 2013: 3rd EuroGentest International Scientific Symposium



We would like to thank everybody for their immense interest in this symposium!

Please [check the website](#) for practical information and for an updated program.

We look forward to welcoming you in Prague next week!

Report: EuroGentest/NGRL Workshop: 'The challenge of getting clinical data into databases'

This workshop was organised by NGRL (www.ngrl.org.uk/Manchester) as part of the EuroGentest2 project and aimed to identify the most important aspects of achieving the collection of clinical genotype and phenotype data into databases. The objective of the workshop was to facilitate discussion on key topics and reach consensus agreement that could be translated into guidelines for the clinical genetics community and the developers and owners of databases, to support the effective and sustainable gathering of actionable clinical data into accessible or shared databases.

Key topics discussed were: data collection, system implementation, standardisation and quality control.

Click [here](#) for the report.

Train the Trainers Course: Offering presymptomatic and prenatal genetic testing in a range of clinical contexts

- Offered via distance learning (via your own computer)
- Four 90 minute teaching sessions, held on **26 April and 3,10,17 May 2013**
- Led by Professor Heather Skirton, Plymouth University (heather.skirton@plymouth.ac.uk)

The course is offered free to any health professional who has a role in mentoring, training or educating others in this topic.

After the course, all course attendees are asked to provide some training to colleagues, this can include providing an informal teaching session for clinical colleagues, teaching professionals in formal settings or running a study day or seminar at a conference or other professional meeting.

To join this course, you will need a computer connected to the Internet, with speakers and a microphone.

Click [here](#) for more information on the content of the **four sessions** and on how to register for the courses.

EuroGentest Network Response to the European Commission Proposal for a Regulation on IVD Medical Devices

Ensuring the quality of genetic testing is at the heart of EuroGentest's mission. EuroGentest maintains that only high-quality, clinically and analytically valid diagnostic tests should be performed in clinical laboratories. We believe that IVD device regulation is an important part of the governance framework for ensuring the safety and effectiveness of genetic tests. We welcome the Commission's new proposal for a regulation to replace the current Directive 98/79/EC on in vitro diagnostic medical devices. We are pleased that the proposal takes up a number of reforms which we have advocated, and we believe the draft regulation represents a major advance on the IVD Directive as a mechanism for ensuring the safety and effectiveness of IVD devices. However, we believe that some changes are required in order to enhance the proposal. In this briefing we outline what those changes are.

Click [here](#) to read the full report.

! New Clinical Utility Gene Cards

[Joubert syndrome - update 2013](#) – Feb 2013

[Gorlin syndrome - update 2013](#) – Feb 2013

Click [here](#) for the full list of CUGC's.

Publications

By EuroGentest members:

- [Relevance of Genomics to Healthcare and Nursing Practice](#) by Heather Skirton and others.
- [Proposed roadmap to stepwise integration of genetics in family medicine and clinical research](#) by Martina Cornel and others.
- [The Ethical Introduction of Genome-Based Information and Technologies into Public Health](#) by Jean-Jacques Cassiman and others.
- [The practical implications when finding chromosome abnormalities](#) by Ros Hastings.

For your interest:

- [Noninvasive Prenatal Testing/Noninvasive Prenatal Diagnosis: the Position of the National Society of Genetic Counselors](#)
- [Cystic fibrosis testing in a referral laboratory: results and lessons from a six-year period](#)

Other

- Connect to EuroGentest on [Linkdln](#)
- Read more [about EuroGentest](#)

