



Newsletter December 2012



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

- ATELIER - Validation des méthodes de diagnostic des tests génétiques 7-8 Feb
- [EuroGentest 3rd Scientific Symposium, 7-8 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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Best wishes for 2013

EuroGentest 3rd Scientific Symposium, registration deadline January 20th!



The final program is now available revealing the speakers for the 3rd EuroGentest meeting, co-organized by APOGEE-Net/CanGeneTest.

No admission fee, but [on-line registration](#) is required.

Register now and book your hotel for the best hotel rates!

News from the Quality in Genetic Counselling Work Package

[Guidance on Direct to Consumer \(DTC\) testing](#)

One of the goals of this Work Package was to produce guidance on the use of DTC testing for consumers. It is also planned to write guidance for health professionals who might be asked for advice by patients either before they purchased a DTC genetic test or after they received the results.

To prepare for this work, three systematic reviews were undertaken to assess the evidence on DTC testing. Following that, a workshop of experts was organised in Amsterdam in late August 2012. During discussion, it became clear that production of one set of guidelines to meet the needs of all stakeholders was more appropriate than multiple sets of guidelines.

Guidance on the use of DTC testing has now been produced. This is clinically-oriented and based on the reason(s) the patient might have for wishing to purchase a test: it can thus be used by either patients or health professionals. The guidelines will be published within the next few months.

[Training the trainers courses](#)

During the next year several Train the Trainers (TtT) courses will be advertised. These courses can be used by experienced health professionals who are willing to support the learning of other professionals in their own country.

The plan is to recruit 3-4 trainers from each country. Trainers will be recruited from countries where there is a demonstrable need for education and where the national society is prepared to support the trainers in their educational initiatives after the TtT course. This is essential to ensure that trainers can access other learners effectively.

We currently plan to offer the following courses:

Title	Logistics
Offering presymptomatic testing in a range of clinical contexts – good clinical practice	Offered via distance learning. Webcast 11.00hrs -12.30hrs (GMT+1). 19,26 April, 3,10 May Attendees can follow the course from their own PC or laptop.
Counselling skills for use in genetic healthcare contexts	Residential course of 3-4 days, date to be finalized. Late June or early July (TBC) 2013. Led by Heather Skirton and Aad Tibben.
Genomics developments and primary care workers	Offered via distance learning. Based on successful course offered in Netherlands. Led by Isa Houwink. Planned for November 2013.

Please contact Heather Skirton if you would be interested in attending any of these courses. Heather.skirton@plymouth.ac.uk.

! New Clinical Utility Gene Cards

Rothmund-Thomson syndrome – Nov 2012

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

Publications

By EuroGentest members:

- [Biomarker patents for diagnostics: problem or solution?](#) by Stuart Hogarth and others.
- [The EuroGentest Clinical Utility Gene Cards continued.](#) An editorial by Anna Dierking, Joerg Schmidtke, Gert Matthijs and Jean-Jacques Cassiman.
- [Non-invasive prenatal testing for single gene disorders: exploring the ethics](#) by Lyn Chitty, Celine Lewis and others.

For your interest:

- [Ethics panel urges cautious approach to DNA testing](#)
 - [Ethical dilemmas associated with genetic testing: which are most commonly seen and how are they managed?](#)
 - [The perspective from EASAC and FEAM on direct-to-consumer genetic testing for health-related purposes](#)
 - [Assuring the quality of next-generation sequencing in clinical laboratory practice.](#)
 - [Improving Newborn Screening Follow-up in Pediatric Practices: Quality Improvement Innovation Network](#)
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Other

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