



Newsletter January 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

- Data protection in an era of consumer targeted genome sequencing, 3-5 Feb
- ATELIER - Validation des méthodes de diagnostic des tests génétiques 7-8 Feb
- Rare disease Day 2013, 28 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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REGISTER

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

Registration closed for the EuroGentest 3rd Scientific Symposium



We would like to thank everybody for their immense interest in this symposium and look forward to welcoming you in Prague.

Practical information will become available soon on our website.

EuroGentest2 workshop on priority setting in genetic testing: short report

On the 28th and 29th November 2012 a group of invited patient representatives and experts in the field of genetics, ethics and health policy participated in a workshop held in Hohenkammer, Munich, Germany. The stakeholder workshop oriented at the principles of accountability for reasonableness was part of the activities of Work Package 6 in EuroGentest2 and conducted in collaboration with the ESHG's Public and Professional Policy Committee.

Harmonizing genetic testing in Europe is also an issue of consistently fair and reasonable prioritization of genetic health services in the face of limited budgets. Aim of the workshop was to develop a shared set of points to consider for prioritizing genetic tests for regional and local decision makers across Europe.

The focus of the discussion was on predictive and diagnostic testing in born individuals. Prenatal testing and population screening programs were excluded from the discussions as these are expected to involve a range of very specific ethical issues that have to be discussed separately. The following criteria were discussed for priority setting of genetic tests: risk for the disease, severity of the disease, purpose and timing of the test, evidence of medical benefit for the individual being tested, benefit for live decision making, benefit for other persons (apart from the testee), costs and budget impact of the test.

A draft document including further details is currently in preparation. Its final version will be circulated for commenting among interested stakeholders across Europe.

Rare Disease Day: 28 February 2013



The sixth international Rare Disease Day coordinated by EURORDIS and organised with rare disease national alliances in 24 European countries.

On and around this day hundreds of patient organisations from more than 60 countries worldwide are planning awareness-raising activities converging around the slogan "**Rare Disorders without Borders**"

Activities will take place across Europe, all the way to Russia, continuing to China and Japan, in the US and Canada, and as far as Australia and New Zealand!

Click [here](#) for more information.

! New Clinical Utility Gene Cards

[Dilated cardiomyopathy \(CMD\)](#) – Dec 2012

[Smith-Lemli-Opitz Syndrome \[SLOS\]](#) – Jan 2013

[Poikiloderma with neutropenia](#) – Jan 2013

[Lesch-Nyhan syndrome - update 2013](#) – Jan 2013

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

Publications

By EuroGentest members:

- [Public attitudes towards genetic testing revisited: comparing opinions between 2002 and 2010](#) by Martina Cornel, Lidewij Henneman and others.
- [Direct-to-consumer genomic testing from the perspective of the health professional: a systematic review of the literature](#) by Heather Skirton, Leigh Jackson, Lesley Goldsmith and others.
- [Building the Genetic Counsellor Profession in the United Kingdom: Two Decades of Growth and Development](#) by Heather Skirton and others.
- [What Counts as Effective Genetic Counselling for Presymptomatic Testing in Late-Onset Disorders? A Study of the Consultant's Perspective](#) by Jorge Sequeiros, Heather Skirton and others.

For your interest:

- [NSGC Practice Guideline: Risk Assessment and Genetic Counseling for Hereditary Breast and Ovarian Cancer](#) (*restricted access*)
- [Unravelling fears of genetic discrimination: an exploratory study of Dutch HCM families in an era of genetic non-discrimination acts.](#)

Other

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