

## 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

- [7th International Meeting on CNVs and Genes in Intellectual Disability and Autism, 13-14 Apr](#)
- [Basic and Advanced Course in Genetic Counselling in Practice, 14-20 Apr](#)
- [2012 Golden Helix Symposium Genomic Medicine: Translating Genes into Health, 18-21 Apr](#)
- [GENETICS: SPECIALTY AND QUALITY IN HEALTH CARE. What does being a geneticist mean for the time being?, 20 Apr](#)

## 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.

## UNSUBSCRIBE

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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.

## IRDiRC: Top experts guide international effort in rare diseases research

Chaired by the European Commission, the Executive Committee of the International Rare Diseases Research Consortium (IRDiRC) appointed today 31 class-leading experts to help guide its members' future research efforts. This brings IRDiRC one step closer to the initiative's objective of developing 200 new therapies for rare diseases and to be able to diagnose most of the currently known 6-8000 rare diseases by the year 2020.

The experts appointed today come from various fields including patients' organisations, academia and industry. They will serve on 3 scientific committees to advise the IRDiRC members on how to maximise the benefits of their investments in rare diseases research. Their recommendations will be crucial for the success of the initiative and ensure a better return on investment for the participating organisations.

We are pleased to announce that among the experts are EuroGentest participants **Gert Matthijs**, **Alastair Kent** and **Milan Macek**.



Click [here](#) for more information.

## NIH Launches Genetic Testing Registry



The National Institutes of Health has launched a new web resource aimed at providing consumers and healthcare providers with information about all of the genetic tests that are currently on the market.

The Genetic Testing Registry (GTR) provides a central location for voluntary submission of genetic test information by providers. The scope includes the test's purpose, methodology, validity, evidence of the test's usefulness, and laboratory contacts and credentials. The overarching goal of the GTR is to advance the public health and research into the genetic basis of health and disease.

Click [here](#) for more information.

## EUCERD news

- The 4<sup>th</sup> Meeting of the European Union Committee of Experts on Rare Diseases took place on 26-27 January 2012 in Luxembourg. Click [here](#) for the executive summary.
- EUCERD Joint Action kick-off meeting reviews the work plan designed to help implement the Council Recommendation on an action in the field of rare diseases. Click [here](#) for more information.

## ! Newly published Clinical Utility Gene Cards for:

[Abetalipoproteinaemia – 2012 Feb 29](#)

[Biotinidase deficiency – 2012 Feb 29](#)

Check the [EuroGentest website](#) for a full list of CUGC's.

## Publications

- [The wide variation of definitions of genetic testing in international recommendations, guidelines and reports](#)
- [Factors accounting for a missed diagnosis of cystic fibrosis after newborn screening](#)
- [Use and non-use of genetic counseling after diagnosis of a birth defect](#)
- [Risky Business: Risk Perception and the Use of Medical Services among Customers of DTC Personal Genetic Testing](#)
- [A profile of the genetic counselor and genetic nurse profession in European countries](#)
- [Advances in Whole-Genome Genetic Testing: From Chromosomes to Microarrays](#)

## Other

- Connect to EuroGentest on [LinkedIn](#) 
- In the participant section of the EuroGentest website, some interesting general documents from the [EC website](#) are highlighted
- Read more [about EuroGentest](#)

