

EuroGentest e-news

[edit this page](#) **Welcome to the last newsletter of 2007/Year 3.**

At the recent AGM we turned our minds to sustainability, heartened by the news that the recent meeting involving EuroGentest and other NoEs in Brussels on the issue met with a favourable response. The message that we believe 5 years is simply not long enough was acknowledged; we now wait to see what is the way forward. However, we have not been idle and I am pleased that already we have identified a series of potential revenues streams for EuroGentest which we will be refining during the coming year. So my message to you all is that the key to success now is to focus! Wishing you all a Happy New Year!

AGM presentations on the web

All of the presentations from Leuven are now on the web in the events section, including reviews of unit activities and the excellent range of guest speakers.

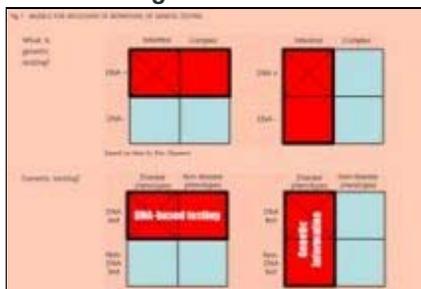
[Find them here](#)



Definitions draft published

EuroGentest has just published the third draft of a major report on definitions of genetic testing taking responsibility for a recommendation by a European Commission Expert Group in 2004. This huge and important task has involved reviewing over 153 documents from 65 organisations - international and local. Only by performing such a mass analysis can the next step towards a common consensus be taken, and the foundation for genetic services understood and trusted by all be laid.

Click the image to find out more



Newsletter December 2007

EU consults public about plans for Rare Disease policy

The European Commission has launched a Public Consultation on a European Action in the Field of Rare Diseases with a view to publishing in November 2008 a Communication on a European Action in the Field of Rare Diseases. This follows the prioritization of High-quality diagnosis, treatment and information for people suffering from rare diseases by European Commission as established in the new Health Strategy adopted last 23 October 2007. There may be opportunities for EuroGentest and so we encourage members to familiarize themselves with the proposals [here](#) with a view to EuroGentest submitting comments and suggestions by 14th February 2008 to sanco-rarediseases-consultation@ec.europa.eu

Towards accreditation – Managing the human side of change

This new topic in the highly popular series of workshops related to quality management will tackle the human side of change. To be held in Nice on February 8, the workshop will answer key questions such as: How do you motivate the laboratory to implement a new quality system? How do you manage the human side of this process of change? [More.](#)

Home genetic testing kits 'a waste of money'

Genetic tests that claim to predict the risk of developing life-threatening diseases are a waste of money and can frighten healthy people, experts including EuroGentest member Alastair Kent warned in a recent UK media briefing in the UK. This followed a sensationalist TV programme in which celebrities underwent genetic testing to discover their risk of potentially fatal diseases. The company Genetic Health claimed to have a test calculating the risk of contracting diseases including Alzheimer's, cancer and diabetes. However, the briefing pointed out the wrong genes are often tested in the £500, which makes the results almost meaningless. [Read more.](#)

EuroGentest to launch EQA scheme on genetic counselling

Over the last three years, EuroGentest has carried out pioneering research into the status of genetic counselling across Europe. This research has thrown up widespread variation in practice. When this is matched with growing public expectations, the need for guidelines has become more and more apparent. In addition to guidelines, there is a clear need for other ways to improve and harmonize the quality of genetic counselling. At the recent AGM, EuroGentest decided to take the lead in this matter and is now drawing up plans for developing a self-assessment tool for genetic counselling centres and even evaluating the possibility to develop a European-wide EQA scheme for this field where the quality is exceptionally difficult to measure.

Lab Data-base proves its value

Traffic both directly and via Orphanet to the new database showing the quality policies and status of genetic testing laboratories across Europe has grown steadily since its launch in the autumn. In November for example there were 150 unique visitors. Now containing details of some 240 laboratories, you can access the database

Patient rights expertise in demand

Following their work on surveying patient rights in genetic testing across the EU, Herman

Nys and his team have been asked by the Council of Europe to report on the factual situation of medical liability in Strasbourg in January. The issue of liability is becoming increasingly important as the level and scope of genetic testing increases and EuroGentest are also involved in the move to include a provision in the Biomedicine Convention on genetic testing.

Technology evaluations in demand

An increasing number of leading companies are enquiring about the EuroGentest technology evaluation service. Already Roche, Chemgen, Idaho Technologies have commissioned projects as they realize the value of the unique resource provided by the project's network. A fresh round involving automated DNA extraction systems is about to begin in the new year.

Patient leaflet translations well underway

From Bulgaria to Lithuania, the patient leaflet series has been a major success and is now being translated into some 13 languages by the end of this year, with a further 10 already scheduled for 2008. Furthermore, following feedback, a new set with a special focus on psychosocial issues is also due next year including :

- What does it mean to be a carrier?
- My child has a genetic condition: implications for parents, siblings and grandparents.
- Information for families when no diagnosis can be found, or results are inconclusive.

Translated versions along with the original English set can be downloaded [here](#).

EuroGentest Harmonizing genetic testing across Europe

For more information visit www.eurogentest.org

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And finally

Two dates to put in you diaries: February 29, 2008 Rare disease day;

April 25 DNA day – more information to come.