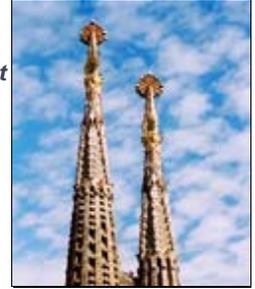


You can find the newsletter online here: [http://www.eurogentest.org/web/newsletter/data/may\\_2008.xhtml](http://www.eurogentest.org/web/newsletter/data/may_2008.xhtml)

# EuroGentest e-news

## Towards Barcelona

Welcome to the May issue as we get ready for ESHG in Barcelona. I am particularly pleased at recognition for the work of Unit 1. To take a couple of examples, Mike Morris reports that at a recent workshop in Copenhagen, we were introduced with the words "nobody knows more about accrediting genetics labs". In addition, David Barton has just sent us an article from the US praising our work on reference materials. We should also mention Gert Matthijs and Ségolène's work on gene patenting recommendations, a topic in which they were ably assisted by Jorge Sequeiros who launched our first [EuroGentest blog](#)!



## Quality focus at ESHG

EuroGentest will have a booth along with OrphaNet and ESHG and a series of workshops and other sessions, in particular driving forward our aim to make accreditation the norm. Places are going fast, but please enlist anyone you think might be interested:

- **Workshop on accreditation: 30-31 May in Hotel Hesperia del Mar, 2 places left, more information and [registration form](#)**
- **Workshop on motivation and change: 30-31 May in Hotel Hesperia del Mar, 7 places left, more information and [registration form](#)**
- **Case studies on quality assurance and quality control issues in genetic testing laboratories (round table format): compared to last year it is only one session of two hours instead of two sessions of one hour, Saturday 31 May, 13.30 -15.30 at the Congress Centre. No fee, but [registration](#) is required via the ESHG website or the EuroGentest website**
- **Els Dequeker and Mike Morris will chair, as in previous years, the quality control workshop at the ESHG, Sunday 1 June, 13.30-15.30, topics and speakers will be announced later on.**

## OECD Guidelines for Human Biobanks and Genetic Research Databases open for comments

Biobank initiatives across Europe and worldwide are struggling at the moment with a whole range of issues from best practice to informed consent. EuroGentest members Helena Kääriäinen, Jorge Sequeiros and JJ Cassiman have been involved in the working group trying to formulate this difficult document which is now open for public consultation. Comments are needed by May 16 via regular mail or email: [hbgrd.guidelines@oecd.org](mailto:hbgrd.guidelines@oecd.org)

## OrphaNet launch

The new quality database supplied and maintained by EuroGentest to allow patients all over Europe check the quality credentials of potential testing laboratories has now been running for a couple of months and is attracting widespread praise. [More...](#)

## No to patenting genes say ESHG

A committee of ESHG experts including EuroGentest members Gert Matthijs and Ségolène Aymé have published long awaited recommendations on patenting and genetic tests. Broadly speaking they concluded that patenting actual genes should not be allowed, but that in order to ensure availability of new tests, companies should be allowed to patent technologies. The news was released in conjunction with International DNA Day and led to significant media interest. [More...](#)

## "Core Competences in Genetics for Health Professionals in Europe" final consultation

The establishment of core competences is currently being used as a basis for health professional education in many other fields and settings groups. EuroGentest has discussed and modified them for the European context. After 1st and 2nd drafts is now on the web for the final consultation [More...](#)

## Danish success

Mike Morris and Els Dequeker were recently invited to the Danish Society of Human Genetics, for a special 1 day session on accreditation in genetics laboratories. According to organizers Marianne Schwartz and Lilian Jensen: "We have had a lot of positive comments about the meeting. I am sure that the audience got a lot of inspiration. I also think that the people who were not previously aware of the EuroGentest organisation and the work being done there will now benefit from that insight and hopefully use the various courses, programs, etc. in the future." [More...](#)

## European network of Genetic Nurses/Counsellors

The first European network of genetic nurses and counsellors has been set up, and almost 30 members have already registered for the first network meeting in Barcelona.



### **Take 15 minutes now!**

*This important survey, sponsored by the European Commission, has been sent to EuroGentest member laboratories to assess the role of patents in development and use of molecular diagnostics. The authors are working closely with EuroGentest and will share their results with laboratories and policy makers. Respond [here](#) to ensure the survey's success*

## **EuroGentest Harmonizing genetic testing across Europe**

**For more information visit [www.eurogentest.org](http://www.eurogentest.org)**

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### **Spreading the message**

EuroGentest has presented at a number of meetings recently, the latest being the third meeting of the European Network PHGEN - Public Health Genomics - "From Policy Development to Assurance", in Hinxton, January 23rd-25th 2008

### **More training**

Due to increasing demand, more and more training courses are being organized:

**National one day training on quality management** in Leuven, in Dutch (pilot), 26 May:

<http://www.eurogentest.org/web/db/event/380/index.xhtml>

**Workshop on specific topics such as management review, internal and external quality control.** To be held in Berlin, 9-10 October 2008, registration form is online [here](#).

**Workshop on validation of diagnostic tests in clinical molecular genetics,** 8-9 January 2009, programme and registration online [here](#).

### **US praise for reference materials work**

The May edition of key US journal Medical Laboratory Observer has a major feature on pharmacogenetic testing. As part of this EuroGentest collaborator Michael Murphy of ParagonDx writes on reference materials and praises EuroGentest's initiative.

[More...](#)