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EuroGentest e-news

Newsletter Summer Edition 2008

Welcome to our summer edition, which follows upon the most successful participation to date by EuroGentest at ESHG. Barcelona provided an inspiring location and a big thank you to all EuroGentest members who submitted posters, presented, ran workshops and manned the booth. The Lab Quality Database in particular proved to be a major draw with some 50 new labs registering. Autumn will soon be with us, along with a new series of quality workshops, and presentations of EuroGentest in both Europe and further afield in South America.



ESHG Booth

This year EuroGentest shared a booth with ESHG and Orphanet to symbolize the close cooperation between the three organisations. There was a steady stream of visitors with the quality database and patient information leaflets in particular gaining attention from not only EU countries, but also Russia and further afield, including Iran, Canada, Mexico and India.



New initiatives

Workshop 'Gender and Genetics' to take place on 23 September 2008 - Based on the original project description EuroGentest has launched a distinct project on 'gender and genetics' in which sex and gender considerations in relation to genetic testing are analyzed in a broader perspective. A workshop taking place in Leuven on 23 September is the key element of this activity. Topics to be covered are grouped into 4 main categories:

- Sex and genetics research
- Gender and genetic counseling

New ESHG president

EuroGentest co-ordinator Professor Jean-Jacques Cassiman took over the presidency of the ESHG during the Barcelona meeting in June.

Quality issues

CEQA reaches 100 – The Cytogenetic European Quality Assessment scheme, which is strongly supported by EuroGentest, reached an important milestone recently with its 100th registration. CEQA aims to harmonize Cytogenetics EQA in Europe. [Read more](#)

Two new quality workshops - In response to major demand for more in depth coverage of topics related to quality management, EuroGentest has developed two new training workshops for genetic testing laboratories.

- Fulfilling the requirements of ISO 15189 for management review, internal quality control and external quality assessment: 9-10 October 2008, Berlin, Germany
- Validation of diagnostic tests: 8-9 January 2009, Prague, Czech Republic

Registration forms, contents and more detailed information for both workshops are available on the EUGT website. [More here](#)

Czech accreditation success - In a major achievement which is hoped will be followed across "New Europe", the Motol Hospital Institute of Biology and Medical Genetics laboratory in Prague in the Czech Republic (ublg.lf2.cuni.cz) has gained official laboratory accreditation according to ISO 15189. This important project took over two years and involved setting up quality procedures for all molecular and cytogenetic testing procedures. It was performed under the guidance of EuroGentest and is an important step in ensuring public confidence in what is often a complex and emotionally charged subject. It is also a further example of how EuroGentest is bringing real patient benefits.

In charge of the project was Dr. Alexandra Stambergova: "I am delighted that our laboratory has received accreditation. The two main factors in this success have been the enthusiasm of the 45 members of staff and the unfailing support and encouragement of EuroGentest. Key to staff motivation was showing that this was not merely a paper filling exercise, but something which would make a real difference to their work. This was helped by EuroGentest member laboratories sharing their experience. We now hope to follow this example and encourage other laboratories in eastern Europe to also seek accreditation."

EuroGentest on the international scene

Roadshow moves on - Latest stops for the roadshow were Pecs, Hungary where Prof. Jean-Jacques Cassiman introduced EuroGentest at the 7th congress of the Hungarian Society of Human genetics and Tartu, Estonia at Gene Forum 2008.

Reaching across the Atlantic - EuroGentest has forged strong links with Canada and Prof. Jean-Jacques Cassiman was invited to a recent Workshop entitled

- **Sex, gender and ethical decision-making**
- **Education and the profession**

Members of EuroGentest who are interested in the subject are welcome to participate in the workshop. At this stage 6 contributions are planned, four from Eurogentest members and 2 from external experts.

Read more, see the provisional programme and register [here](#)



“Supporting policy development in genetics/genomics” organized by CanGeneTest and the APOGEE-net network on July 6, in Montreal, Canada. Organiser Ingeborg Blanquaert commented: “I think that we managed to present an interesting scope of examples of translational research in genetics, as well as an overview of the challenges of moving this field of research forward and of ensuring that judicious choices will be made with respect to genetic applications. Your contribution was extremely important in circumscribing potential next steps and in identifying who else to involve. There were a number of policy-makers and professionals involved in HTA from across the world in the audience, which may help in spreading awareness of these issues ...”

Major presence at South America - EuroGentest will be well represented at the first congress of the Latin American Network of Human Genetics (RELAGH) in October with presentations on both the overall project and individual topics such as Quality Management in the Laboratory (Sarah Berwouts), Essential knowledge in Medical Genetics for Health Professionals (Domenico Coviello), Information for Patients (Celine Lewis), Presymptomatic diagnosis and predictive medicine (Jorge Sequeiros) and the Orphanet database (Jean-Jacques Cassiman). [More info](#)

Indian fellowship has immediate impact - Shivaram S. Shastri, a Research Associate from the Genetics Unit of the All India Institute of Medical Sciences in New Delhi, recently completed a EuroGentest fellowship at the Cystic Fibrosis Centre, Institute of Biology and Medical Genetics, Prague, Czech Republic under Professor Milan Macek Jr. According to Shivaram this has had an immediate impact upon his work back in India: “In those three weeks, I was able to learn some of the important and emerging techniques in the detection of pathogenic changes in the human genome that cause Cystic Fibrosis such as DNA sequencing, MLPA and HRMCA. The friendly and knowledgeable team at the centre taught me the intricacies of these techniques and it was possible to identify some of the mutations previously undetected by the SSCP (Single Strand Conformation Polymorphism) in a set of Indian patients' samples. The knowledge gained here will be invaluable in starting similar services for the Cystic Fibrosis patients in India.” More information on fellowships [here](#)

Upcoming news – more in next issue

- **New quality committee**
- **Patent debate continues**
- **New technologies**
- **Educational meeting in Brussels**

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