

EuroGentest e-news

[edit this page](#) **Welcome** to our new e-newsletter which will keep you up to date with EuroGentest activities. Midway through our 5-year project, the results of our various members' hard work are becoming increasingly evident in form of guidelines, recommendations, databases and other activities.

Reaching across the Atlantic

EuroGentest is helping Ecuadorian geneticists create a framework for improving their country's genetic services and convince their government of the need for investment. The project was launched at a recent meeting arranged by EuroGentest member Dr Peter Chedraui, which was also attended by representatives of other Latin American countries including Argentina and Columbia where a similar meeting is planned for 2008. See the programme [here](#)



New website

The new EuroGentest website has been live for a couple of months and been well received. However we will be contacting some of you in the near future ahead of the AGM for your comments and would be grateful if you could give us your feedback.



Patient information leaflets translations underway

Newsletter October 2007

NoEs join forces to lobby for sustainability

EuroGentest is among a group of leading NoEs which have joined forces to lobby the Commission over the issue of sustainability. Coordinator Jean-Jacques Cassiman is among those presenting at a debate on November 20 in Brussels hosted by MEP Prof Jerzy Buzek to convince the Commission on the unique role NoEs play in the European Research Area and on the need for flexibility to achieve this goal. Already we have had many indications of support from over 40 other NoEs and numerous MEPs and hope to take this successfully forward. For more information visit <http://www.supportresearchnoes.eu>.

First roadshow held in Poland on the OECD guidelines for genetic testing

EuroGentest held the first of a series of roadshows intended to encourage adoption of the new OECD guidelines in Warsaw recently at the Polish National Society of Human Genetics meeting. Hosted by EuroGentest member Prof Michal Witt, the roadshow featured presentations by David Barton, Helena Kääriäinen and Alastair Kent. Attended by a wide range of stakeholders including government, the roadshow led to encouraging discussions and was welcomed by the organizers. The venue for the next roadshow will be announced shortly. [Click here for the guidelines.](#)

QAu database launched

Until now, there has been no simple or reliable way to identify, for a particular diagnostic test, a laboratory with a quality system, nor conversely to determine for a given laboratory what is included in its QAu system. In June, to respond to this need, EuroGentest launched the European QAu database in close collaboration with [Orphanet](#). Already there have been 5200 unique views of the search engine and it is the number 1 landing page for the entire website apart from www.eurogentest.org itself. The majority of visitors have been from Belgium, United Kingdom, France and Switzerland.

Portuguese TV to report EuroGentest

Portuguese national television are preparing several news reports concerning health in the European Union to explore and explain to the Portuguese people the advantages of being a part of the Union. As part of this they are looking at genetics and the way in which samples are sent across borders for analysis using the laboratory of EuroGentest member Rob Elles in Manchester as an example.

New AGM format

The annual EuroGentest General Assembly 2007 will this year be held from Wednesday November 21st to Friday November 23rd in the Faculty Club in Leuven. The new format will see three panels on the first day discussing Accreditation, Counselling, and EQAs, featuring stakeholders and moderated by a EuroGentest participant. In the afternoon there will be presentations on the EuroGentest Roadshow and EuroGentest activities. This first day is open to non Members. The next day has talks by leading invited external experts including Christine Tarrajat from EDMA and Erik Tambuyzer of Genzyme. For the full programme click [here](#).

Motivation and change workshop filling up fast

Four months away and the next Quality workshop on motivation and change taking place in February has only three places left. So far 8 workshops have been run, with 155 participants from 85 institutes in 72 different cities in 27 different countries! Cytogenetic specialist Javier Sánchez from the Unidad Clínica de Genética y Reproducción Hospitales Universitarios Sevilla Spain recommends the workshops wholeheartedly: "Sessions were very well planned and the case study approach was the best way to learn

The EuroGentest patient information leaflets launched in June have been an immediate success – at ESHG Celine Lewis and her team were inundated with requests for language versions.

Fortunately, we have also had numerous offers of help with the translations and now the huge task is well underway. 13 languages – including Romanian, Bulgarian, Turkish, Polish, German and Portuguese are planned for the near future, with another 7 scheduled for next year. Download them by clicking the image.



all about auditing." For more workshop information click [here](#).

Next call for new technologies open

EuroGentest offers a unique evaluation service through its member laboratories for new technologies to speed their adoption. Already two calls for projects have resulted in evaluations of high-resolution melting curve analysis (HR-MCA), Pyrophosphorolysis Activated Polymerization (PAP) technology, mutation scanning technique 'Conformation sensitive capillary electrophoresis' (CSCE) in collaboration with the NGRL in Wessex and multiplex testing methodologies. Now industry is being invited to submit further requests as the pace of technology innovation continues to increase in the sector. [Read more.](#)

Patient rights booklets well received

The latest in the series of EuroGentest guides to patient rights have just been published for Estonia and Greece. Feedback from the first two has been extremely positive according to Herman Nys: "We have received a lot of mails from residents of the particular member state but also from others ("when will you finish a report on our country") expressing their thanks/enthusiasm about the booklets. The European Society for Medical Oncology has invited me for the ESMO Cancer Patient Advocacy Forum in Brussels from 26 to 27 November to give a speech on " How do policy makers take decision" , explaining the different approaches on protection of patient rights. The Council of Europe has invited me as rapporteur in preparation of a multilateral seminar on medical liability in Europe to be held in June 2008 in Strasbourg. My report will give "an overview of the factual situation of medical liability in the member states of the Council of Europe". The preoccupation with patient rights in Europe is constantly growing and the booklets have clearly contributed to this integration process which requires time and patience." The latest leaflets can be downloaded [here](#).

Recent ERNDIM events

The annual ERNDIM Workshop was held in conjunction with the Annual Symposium of the Society for Inborn Errors of Metabolism in Hamburg on September 4th. This workshop included parallel meetings for participants in the five different schemes for Diagnostic Proficiency Testing (DPT) allowing thorough and sometimes provocative discussions of samples and results from the 2007 distributions ([view](#) a brief description of the schemes) This was followed by a combined workshop open to participants in all ERNDIM schemes as well as other SSIEM attendees. The workshop included presentations on new developments in the ERNDIM schemes and in the EuroGentest project as well as clinical pointers, methodology and EQA for diagnosis of peroxisomal disorders (presentations available [here](#)). The meeting proved highly popular with approaching 200 attendees. Bearing in mind the educational nature of our activities a section of the ERNDIM website on "Training Resources for Laboratory Scientists in Biochemical Genetics" has also been developed.

IVD Directive impact under discussion

A EuroGentest workshop was held to explore issues around the provisions of the EUs IVD Directive (or IVDD), and how they might impact on the practice of genetic testing. Participants included representatives of the major stakeholders in genetic testing: directors of molecular genetics diagnostic laboratories, diagnostic device manufacturers, the European Commission, regulatory authorities, reference material producers and public health experts. It was agreed by all that although there were no issues around the IVDD which were unique to genetic testing, genetic testing brought to light issues which affected specialist testing in general, and that the special focus on all matters involving genetic testing served as a useful channel for discussion of such issues. Such a discussion is particularly timely because the Commission is considering future approaches to the medical devices directives, including the possibility of a proposal in 2008 to simplify and strengthen all the medical device directives, possibly amalgamating them into a single Directive. A full report on the workshop, and copies of all the presentations can be found [here](#).

Open call for best practice meetings for molecular genetic testing

A new series of meetings to discuss best practice in clinical diagnostic molecular genetic testing have been announced by EMQN and EuroGentest and supported by [CanGèneTest](#) . This activity links to EQA schemes which show many differences in the approaches taken to molecular genetics testing. Best Practice guidelines help to harmonise methods and the materials used and raise the standards of testing. The 2007 series kicked off with a meeting in Paris to draft guidelines for MODY a genetic form of diabetes affecting children. Meetings for the Spino Cerebellar Ataxias (Porto) and familial breast cancer (Würzburg) are scheduled for October. EuroGentest and EMQN have issued an open call for meetings in 2008 and suggestions are invited. Disease service based topics will be related to EQA schemes but technical areas may also be considered; previous guidelines have included; best practice in reporting, internal (laboratory bench level) quality control, mutation scanning, sequencing and other techniques. [Find out more.](#)

**EuroGentest
Harmonizing genetic
testing across Europe**

For more information visit www.eurogentest.org

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