

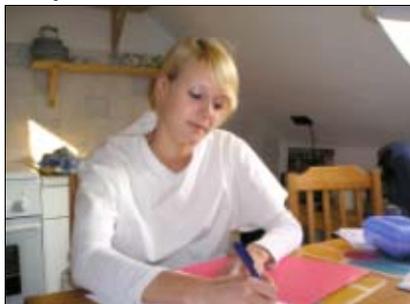
EuroGentest e-news

[edit this page](#) **Welcome to the EuroGentest Newsletter**

As is evident from many of the reports in this newsletter, EuroGentest has a role to play well beyond its initial 5 years. We are therefore playing a key role in the NoE sustainability group formed in 2007. Acting on behalf of more than 60 NoEs, the group aims at finding a solution for the numerous networks that have shown themselves capable of establishing lasting important service and research facilities at the European level. On February 13 J.J. Cassiman will be interviewed by the committee of experts from the EU commission looking at this issue. Then on February 26, MEP J. Buzek is organizing a dinner debate with representatives of the EU commission in the EU parliament on this issue. Please spread news of this initiative and encourage your contacts to visit the [website](#).

New paper highlights inequality in services

A timely new survey by Unit 3 members published in Community Genetics concludes that: "It is premature to mandate that genetic testing provided by clinical services meets professional standards regarding clinical validity and utility, because there is to date no consensus within the scientific community and among health care providers to what extent clinical validity and utility can and need to be assessed". A selection of divergent health care systems was reviewed and compared (e.g. Finland, Germany, Portugal, Sweden, UK, France, Italy, Spain, Czech Republic, Lithuania and Serbia/Montenegro) focusing on DNA-based testing for heritable disorders with a strong genetic component.



PGD report discovers major inconsistencies

The IPTS, ESTO and EuroGentest report on PGD in Europe has been released and again highlights the pressing need for EuroGentest's harmonization work. Commissioned in March 2005, the report surveyed 53 centres across Europe and

Newsletter February 2008

Accreditation workshops at ESHG 2008 now accepting registration

Although June seems a long way away, registration is now open for our workshops on "Accreditation in genetic testing services" and "Towards accreditation – managing the human side of change" to be held just before ESHG in Barcelona. [More](#)

EMQN and GfH EQA schemes to merge

Wherever possible EuroGentest seeks to encourage collaboration and we are therefore delighted to announce that the board of the German Society of Human Genetics (GfH) approved the merger of the EMQN External Quality Assessment Scheme with their own scheme [More](#).

CEQA continues to grow

Following a successful start, we are now issuing an open call for participation to all cytogenetic labs. According to Ros Hastings, the EQA repertoire is being expanded to include two full EQAs and two new Pilot EQAs for Oncology and Pre-implantation Genetic Diagnosis. Furthermore, as a result of a major EuroGentest member effort, the whole EQA process from registration to final laboratory report is also now online. Ros also relates one anecdotal example of how the project is catching on: "Milan Macek recently gave an East European Lab our contact details regarding CEQA. The lab really wanted some training in the first instance before participating in CEQA. We were able to suggest some courses and also that they apply for EUGT fellowship money. They did - they are on the course with fellowship funds from EuroGentest!" [Read more](#).

Workshop tackles Molecular Diagnostics reference material challenge

Molecular Genetic testing is evolving rapidly, with the introduction of new technologies such as MLPA, array CGH, ultra high throughput DNA sequencing and the possibility of genotyping over 1 million SNPs in a single experiment. EuroGentest has initiated this workshop to be held in Geel on April 24, to explore the challenges in developing reference materials for such technologies and the opportunities available for collaborative approaches to meeting these challenges. [More](#)

Latest additions to patient rights series

Hungary, Slovakia and Lithuania are the latest countries to be surveyed by EuroGentest experts regarding patient rights especially consent, privacy and discrimination [Download the reports from \[www.eurogentest.org\]\(http://www.eurogentest.org\)](#).

Patent Licensing in Medical Biotechnology in Europe

Invitations to participate in this major survey have been sent to professionals dealing with patenting and licensing in medical biotechnology. EuroGentest strongly encourages its Members to take part in this survey, so as to ensure that its results will accurately reflect the current situation and the needs of the genetic community. [More](#).

Patient Information Leaflets – New languages now available!

The highly successful EuroGentest patient information leaflets are now available in 8

highlights a number of issues for concern – quality assurance was found to be inconsistent and accreditation needs improving, genetic counselling is not being performed consistently, considerable work is needed to meet the requirements of the EU Human Tissue and Cells Directive and systematic longterm follow-up is only being carried out in one centre in Belgium. Lastly the regulatory situation differs in member states leading to large numbers of patients having to travel to Spain, Cyprus, Belgium and the Czech Republic for testing. [More...](#)



EuroGentest Harmonizing genetic testing across Europe

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languages: Bulgarian, English, Estonian, Icelandic, Polish, Romanian and Turkish with Arabic, Czech, Finnish, German, Greek, Hungarian, Italian, Portuguese, and Spanish to follow shortly. We hope to have these languages completed and available on the EuroGentest website by the beginning of June. A big thank you to everyone who has helped us with this work. [Download from www.eurogentest.org/patients](http://www.eurogentest.org/patients)

New topics commissioned

A series of new EuroGentest patient information leaflets is also underway and we aiming for the first to be ready by the end of the year. These will focus specifically on genetic tests and their emotional and social impact on patients and families. Leaflets currently in progress include: Carrier Testing, Predictive Testing, and Information For Parents When Genetic Testing Is Inconclusive. The content of these leaflets will again be developed with the help of patients and families to ensure that the information we provide is comprehensive, accessible and relevant.

70+ members already for new Genetic Nurses and Counsellors Network

While there are a growing number of non-medical genetic practitioners in clinical practice in Europe, there has not been any organisation dedicated to the needs of those professionals. In addition, nurses and counsellors may be working in situations with few colleagues, where peer support is hard to access. To address these needs, late in 2007, EuroGentest initiated a new European Network of Genetic Nurses and Counsellors with the support of the ESHG. So far, Heather Skirton reports: "we have 72 members in the network, from Netherlands, France, Spain, Portugal, Denmark, Sweden, Finland, Italy, Croatia, Bulgaria, UK, Czech Republic, Greece, Belgium, Cyprus, Ireland, Turkey, Israel, Switzerland, Poland and Iceland. "At present we are collecting basic data on members to determine their needs and plan to have a meeting in Barcelona in May, in conjunction with the ESHG/ EMPAG conference. Please disseminate information about the network to any interested colleagues." [More.](#)

Orphanet leaps ahead with revamped website

[Orphanet](#) is launching, a new version of its website to better serve its 20,000 daily users on February 29, 2008. This "rare" date was selected as an appropriate day to recognise the rare disease community in Europe. For researchers, the new version features an enhanced database of rare diseases with new information on the epidemiology of the diseases (prevalence in the European population, age at onset), on their mode of inheritance, and on related genes when applicable. In addition EuroGentest has provided [data on the quality management of laboratories](#) running tests to promote an increased standard of quality across Europe.

IVD response framed

Stuart Hogarth and David Melzer have prepared EuroGentest's proposals for an enhanced framework for the evaluation of new genetic tests before they are granted "CE marking", the seal of approval which allows IVDs to be placed on the market in the EU. [More.](#)

Consultation time

The important documents [IVD Directive](#) and [Genetic Testing Problems](#) and [Core competencies in genetics for health professionals](#) are on the website for comments

For an up to date list of upcoming events remember to visit the website [More...](#)