



EUROGENTEST - creating confidence in genetic testing

Dear Colleague

The Network of Excellence, EUROGENTEST, funded by the European Commission, has started its activities on January 1, 2005.

Genetic services in Europe, while based on leading scientific know-how, suffer from important levels of technical and reporting errors together with poor standards of counseling. This is the direct result of a lack of structure and harmonization at the European level - diverse quality schemes, lack of reference systems and differing EU Member State regulations all contribute to the overall fragmentation of services.

Nevertheless, demand for existing genetic services continues to rise. In addition advances in technology mean widespread susceptibility and pharmacogenetic testing could soon become a reality.

EUROGENTEST aims to harmonize and improve the overall quality of these services by

- improving the organization and harmonization of external quality assessment schemes / quality assurance systems
- facilitating the development of guidelines
- supporting the accreditation/certification of the genetic services.
- promoting collaboration between academic centers and the private sector on technology development and validation
- encouraging uptake of better and more economical testing technologies
- creating a European Network of Excellence based on the four principles of medical ethics

We will also tackle the broader issues arising from testing, including legal, health policy and economics impact, intellectual property rights, ethical and social questions: confidentiality, informed consent, employment and insurance.

Underpinning all these actions will be education. With the help of Parent and Patient Support Groups, EUROGENTEST will create practical tools for the education of different stakeholders.

Finally, EUROGENTEST aims at becoming a model for similar initiatives in developing countries and will provide appropriate support for their development.

www.eurogentest.org



One of the practical aims of EUROGENTEST is to join forces with ORPHANET/ ORPHANPLATFORM for the management of information on genetic testing, rare diseases and orphan drugs.

ORPHANET is an EU funded database of services in the field of rare diseases, rare diseases including all mendelian genetic diseases, in addition to non genetic disorders.

ORPHANET website is freely accessible and receives currently more than 10,000 visits per day. It covers ongoing activities in 20 European countries.

www.orpha.net

In view of the existence of quality validated information on more than 1000 European genetic testing facilities already available in the ORPHANET database, and since ORPHANET is a participant in the EUROGENTEST NoE, we have elected to identify ORPHANET as the central European entrance port for information on all the genetic testing facilities for the public and the professionals.

The long-term aim of the collaboration is to provide a unified, complete and accurate information resource on genetic testing and testing services in Europe.

You or your national representative may receive requests from the ORPHANET – EUROGENTEST participants regarding additional information about your genetic testing facility. Please be assured that this is being done in consultation between the two organizations and that your information will be available, after validation, on the ORPHANET / EUROGENTEST website. The EUROGENTEST network will also collect information to be used within the various activities of the network, starting with information already available in ORPHANET. Any additional and relevant information collected will be passed on to ORPHANET to be posted on the website following the usual procedures.

We do hope that you will help and support us in creating this unique and absolutely necessary tool for our European community.

Thank you,

Jean-Jacques Cassiman
Coordinator of the EUROGENTEST NoE

Co-ordination: Prof. Dr. Jean-Jacques Cassiman
University of Leuven – Campus Gasthuisberg
Center for Human Genetics
Herestraat 49 – Box 602
3000 Leuven Belgium

Ségolène Ayme
Director of ORPHANET

Tel. +32 (0)16 345 860
Fax +32 (0)16 345 997
Email: jean-jacques.cassiman@med.kuleuven.be