

PRESS RELEASE

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Project Enquiries	Professor Jean-Jacques Cassiman Leuven Tel +32 16 34 58 60 Email: jean-jacques.cassiman@med.kuleuven.be		
Media enquiries	Richard Hayhurst, Hayhurst Media Tel +44 (0) 7711821527 Email: richard@hayhurstmedia.com		

EuroGentest publishes first in series of European genetic patient rights reports

Major differences highlighted in Denmark and Czech Republic

Leuven, April 5, 2007: On the 10th anniversary of the signing of the European Convention on Human Rights and Biomedicine, the first in a series of reports of genetic patients rights in the EU highlights major variations and anomalies across the community. Produced by EuroGentest, an EU-funded project aimed at harmonising genetic testing across Europe, the first two reports focussed on Denmark and the Czech Republic. Despite the two countries ratifying the Convention, the authors discovered significant differences between patient rights on issues such as informed consent, confidentiality, access to records, insurance and employment. However, they also cautioned that the two countries had very different starting points, and that the Czech Republic was making significant progress in its transition from the paternalistic communist era.

EuroGentest member, Herman Nys, from the University of Leuven commented; "As genetic testing increases across the EU, it is essential that patient rights are protected through modern legal frameworks. Through these surveys, EuroGentest aims to encourage this process. Some idea of the task can be gained by looking at the differences between Denmark and the Czech Republic. In Denmark, although a fairly comprehensive new act on patient rights came into force on 1 January 2007, with excellent provisions for privacy and insurance and employment matters, we consider there are still gaps in certain areas such as rights of minors. In the Czech Republic, on the other hand, a comprehensive legislative framework of patient rights does not exist at

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the moment. Important patient rights such as the right to informed consent and the right to information about his or her health status, the right to protection of private life and confidentiality have only been incorporated fragmentally and incompletely into legislation. Instead patient rights are in the hands of the so called Czech Public Defender of Rights or Ombudsman and individual judges. Drafts for an act on patient rights have been announced several times after the ratification of the Biomedicine Convention but until now none succeeded to pass the legislative process. Also the draft Act N° 1151/0 on health care has been repealed after the parliamentary elections held in 2006. However, to the extent that we had the opportunity to become acquainted with the contents of this draft, it looked promising. We dare to express the hope that in the near future a modern legal framework for the protection of patient rights will be elaborated.”

The Czech Society for Medical Genetics welcomed the publication of the Czech report and endorsed it in its review as a first important step towards mapping the situation in the Czech Republic.

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Notes to editors

EuroGentest is an EU-funded project (10 million Euro for 5 years) that aims to establish an NoE (Network of Excellence) in genetic testing. Started in January 2005 the project is coordinated by Professor Jean-Jacques Cassiman, an acknowledge world expert in CF testing who holds the Arthur Bax and Anna Vanluffelen chair of Human Genetics at the Center for Human Genetics in Leuven, Belgium. The project is divided into 6 units each with a number of working parties.

More information is available at www.eurogentest.org

Facts and figures

No of testing centres in Europe – 1500

Number of conditions tested >1000

Annual growth in testing - 100-300%

Number of people in the EU suffering from genetic disease > 30 million

Cost to EU health sector – EUROS 500 million