



## “Send me your saliva and I’ll predict your fate”

STOA Workshop on “Direct to Consumer Genetic Testing”

organised by

**ETAG**

European Technology Assessment Group  
ITAS · DBT · viWTA · POST · Rathenau

Tuesday 3 March 2009, 2.30 – 5.00 p.m.

European Parliament, Brussels

Room ASP 5 G 3

Rue Wiertz 60, B-1047 Brussels, Belgium

At the end of the 1990s, genetic testing offered directly to consumers came onto the market as a new “business model”. Up until then, genetic testing had been carried out by specialised institutes in the medical sector upon referral by a medical doctor. In recent years, new companies offering direct-to-consumer genetic testing (DCGT) via the internet alone are emerging constantly. DCGT has given rise to concerns regarding an uncontrolled growth of the market for genetic testing. Tests are offered whose clinical validity and utility is doubtful and thus could do harm to consumers who might be misled and insufficiently informed by DCGT providers.

The STOA project - completed with the final report in November 2008 - provides an overview of the current discussion on DCGT among experts and public authorities and on the current status of DCGT offers on the internet. Guided by an analysis of the market development and the pros and cons of DCGT, possible options and needs for political intervention such as an amendment of the European Directive for In-Vitro-Diagnostic Devices are discussed. At the workshop central results of the project will be presented and discussed with a group of distinguished experts.

### Programme:

Chair: Ria Oomen-Ruijten, MEP and member of the STOA-panel

- Results of the STOA project “Direct to Consumer Genetic Testing”, Leonhard Hennen, ETAG/ITAS, Research Centre Karlsruhe

Expert Statements:

- Perspective of providers of DCGT, Linda Avey, 23andme (to be confirmed)
- Validity of tests and quality of counselling, Jean Jacques Cassiman, University of Leuven
- Ethical and social aspects, Helen Wallace, Gene Watch U.K.
- DCGT – the patients’ perspective, Alastair Kent, Genetic Interest Group
- Future perspectives of genetic testing, Stuart Hogarth, University of Loughborough
- Options for policy making, Frances Flinter, Human Genetics Commission, U.K.
- DCGT and the amendment of the European Directive for In-Vitro-Diagnostic Devices, Aurélien Perez, European Commission

For **further information** please contact Mr. Leonhard Hennen ([hennen@tab.fzk.de](mailto:hennen@tab.fzk.de), +49-228-3081834) or Mr. Marcelo Sosa ([marcelo.sosa@europarl.europa.eu](mailto:marcelo.sosa@europarl.europa.eu))

For **registration**, send an email to Nicole Lacourt-Pensis ([nicole.lacourt@europarl.europa.eu](mailto:nicole.lacourt@europarl.europa.eu)) with indication ‘workshop genetic testing’, and including the following information: name, address, nationality and date of birth (for participants from outside the parliament).

The European Parliament’s **STOA-panel**: [http://www.europarl.europa.eu/stoa/default\\_en.htm](http://www.europarl.europa.eu/stoa/default_en.htm)