EASAC-FEAM Working Group on Direct-To-Consumer Genetic Testing: Announcement of new project and open Call for Evidence

Developments in genetic science are leading to an expanding potential for predictive screening of disease. Current methods in public health services enable the specific diagnosis of treatable diseases. But other tests, of questionable value, are being offered for complex disorders where interpretation of the result is more challenging. Tests are being offered through internet-based companies selling direct-to-consumer (DTC) and this provision is anticipated to grow rapidly world-wide.
It is important to clarify and communicate information about the opportunities, scientific uncertainties and risks of predictive genetic screening. The goal of this project – the first collaboration between the academies' networks EASAC and FEAM - is to enable academies to work together in providing the evidence to inform policy development to achieve a good balance between the increased use of responsible testing and protection against unsound testing; in particular, to form a view on developments in DTC genetic tests. This project focuses on issues both for the policy-maker and public, extending analysis and discussion beyond the professional genetics community and aims to build relationships between national and EU policy levels.

Members of the Working Group are:

Volker ter Meulen (Germany, Chairman)
Stefania Boccia (Italy)
Martina Cornel (The Netherlands)
Marc Delpech (France)
Anne De Paepe (Belgium)
Xavier Estivill (Spain)
Mats Hansson (Sweden)
Katia Karalis (Greece)
Andres Metspalu (Estonia)
Markus Nothen (Germany)
Peter Propping (Germany)
Jorge Sequeiros (Portugal)
Ron Zimmern (UK)
Robin Fears (secretariat)

Among key objectives of this project are:

- Compiling information on current status and expected developments in EU Member States – attitudes to genetic testing and to DTC provision.
- Identifying relevant key scientific advances in genetic testing for predisposition to disease.
- Discussing implications of advances in science and technology for consumer access to genetic testing for predisposition to disease.

- Reviewing current developments in Regulatory Agency views on DTC genetic tests.
- Clarifying issues for establishing clinical validity, utility, registries of DTC tests etc. Issues for managing provision of information (company advertising etc), for professional training and access to professional support etc.
- Developing recommendations for EU policy-makers (European Commission and European Parliament), taking account of work already accomplished by other bodies.
- Considering mechanisms for communicating benefits and risks relating to DTC testing to the general public.

Initial conclusions will be developed before the end of 2011 with a final report published by mid 2012. Evidence and inputs are now invited from individuals and organisations on any of the issues to be considered by the Working Group.
Please send your contribution to:
Christiane Diehl, EASAC (christiane.diehl@leopoldina.org) or
Laurence Legros, FEAM (laurence.legros@feam.eu.com)

Contributions will be particularly useful if received by 30 September 2011.