German policy documents on the regulation of genetic testing

In April 2013, two policy documents on the regulation of genetic services have been issued in Germany, one by the German Ethics Council and one by the Genetic Diagnostics Commission. The first one expresses recommendations on genetic diagnosis in general, firstly for improvement of the provision of information for the public and in training. The second document, is the Tri-annual Report of the Genetic Diagnostics Commission.

Click here to read a commentary on both documents, written by Jörg Schmidtke (Hannover) and Clemens Müller (Würzburg).

ACMG guidelines for genetic counselling

A Working Group of the ACMG (American College of Medical Genetics and Genomics) has spent a year developing a set of recommendations for reporting incidental findings. While the situation with regard to notifying patients of incidental findings arising from exome and genome sequencing (defined by the ACMG as clinical sequencing) requires clarification, it seems that the ACMG has gone well beyond the issue of incidental findings with these recommendations. From my perspective some of the guidance appears to contravene ethical practice.

Click here to read the full comment written by Heather Skirton.

Visit EuroGentest at the booth in Paris ESHG2013

June 8-11, 2013 the European Society of Human Genetics is organizing its yearly conference in Paris (France) and as previous years EuroGentest will be there with a joint booth with the ESHG and Orphanet (booth # 460).

There will also be several workshops organized by EuroGentest during the meeting, please take a look at our webpage for an overview of our activities during ESHG2013.

We look forward to welcoming you at our booth in Paris!

! New Clinical Utility Gene Cards

Johanson-Blizzard syndrome – May 2013
Alström syndrome - update 2013 – Apr 2013

Click here for the full list of CUGC's.

Publications

By EuroGentest members:
- Whole-genome sequencing in health care by Martina Cornel, Pascal Borry, Ros Hastings, Hans Scheffer and others.
- Non-invasive prenatal diagnosis for single gene disorders: experience of patients by Celine Lewis, Lyn Chitty and others.
- Noninvasive prenatal testing: the paradigm is shifting rapidly by Lyn Chitty and others.
- A framework to start the debate on neonatal screening policies in the EU: an Expert Opinion Document by Martina Cornel, Tessel Rijgers and others.
- The clinical implementation of non-invasive prenatal diagnosis for single-gene disorders: challenges and progress made by Lyn Chitty and others.

For your interest:
- Next generation sequencing (NGS) strategies for the genetic testing of myopathies
- Best ethical practices for clinicians and laboratories in the provision of noninvasive prenatal testing
- Noninvasive Prenatal Molecular Karyotyping from Maternal Plasma
Do you wish to receive this newsletter and stay up to date with the activities of EuroGentest2? Please register on our website.

Other

- The EuroGentest website has transferred to a new server. We have done many efforts to maintain the look and feel of the website as it is, so you as a user will notice as little as possible of this change. However, the url's of the internal pages are changed and some pages will look a bit different. Please contact us if you experience any problems.
- Connect to EuroGentest on LinkedIn.
- Read more about EuroGentest.