

Report of the Public & Professional Policy Committee



ESHG

Milan

1st June 2014

Martina Cornel, MD, PhD

Professor of community genetics
& public health genomics

On behalf of PPPC

Quality of Care

Community Genetics, Dept Clinical Genetics
EMGO Institute for Health and Care Research



Society & GENOMICS
Centre for Society and Genomics

VU university medical center



VU University Amsterdam



emGO+
Institute for Health and Care Research

Activities 2013/14 (1)

- Prioritization & distributive justice (accessibility of genetic services) WS Nov 2012 Wolf Rogowski:
 - Online summer 2013 for consultation (inviting ESHG members and others to comment)
 - ESHG membership and other response integrated
 - Board approval March 2014
 - At Eur J Hum Genet (minor changes needed)

Activities 2013/14 (2)

- Whole Genome Sequencing in Newborn Screening (*endorsed by Board 30th May 2014*):
 - Developed together with P3G Consortium, HUGO Ethics Committee (agreed May 2014)
 - Endorsement (potentially) also by Australasian SHG, ISNS, ...
- PPCP/ESHG publications usually in EJHG; **also**
 - Several websites/newsletters?

- P3G consortium: international Population Project in Genomics and Society
- Human Genome Organisation (HUGO) Committee on Ethics, Law and Society (CELS)
- ISNS: International Society for Neonatal Screening

Activities 2013/14 (3)

- Whole Genome Sequencing:

Letter in Science: ESHG calls for restraint in use of WGS diagnostic testing

In a letter published in the journal Science on 30 August, Professor Martina Cornel, chair of the Professional and Public Policy Committee of ESHG and colleagues call for restraint in the use of diagnostic testing based on whole-genome sequencing. Wherever possible, such **testing should be restricted to those genome regions linked to the patient's indications**, they say, and wider testing needs to be justified in terms of necessity. Adding additional targets to a diagnostic test would be a violation of this, they say.

However, in the case of **unsolicited findings**, the patient's right not to know may sometimes have to be secondary to clinical geneticists' professional responsibilities, say the authors. The patient may not have foreseen a specific finding and in some cases the physician will have a moral duty to warn close relatives. Pending further debate, a cautious approach continues to be warranted, they say.

Activities 2013/14 (4)

- Press activities
 - New Scientist:

THIS WEEK

Meet your unborn child - before it's conceived

Virtual embryos will allow parents to screen out genetic disorders

Catherine de Lange

WILL my baby be healthy? It's a question that concerns every prospective parent. Now a service that creates digital embryos by virtually mixing two people's DNA will give a clearer glimpse

working in reproductive health. The priority should be medical problems, says Martina Cornel of the European Society of Human Genetics. This is what GenePeeks plans to do. It intends to use the system to identify rare conditions such as cystic fibrosis and Tay-

as part of the 1000 Genomes Project. GenePeeks then screened their virtual embryos and compared the incidence of predicated disease to that in the general population. "These studies confirmed the system's ability to accurately



New

- Collaboration with SIC-ASHG (Yvonne Bombard)
 - NIPT guidelines?
 - Joint session Building bridges? Testing minors?
update ASHG's 1995 Statement on Genetic testing in Children and Adolescence

Ongoing

- Discussed June 2014:
 - Preconception carrier screening
 - NIPT
 - Etc
- Next PPPC meeting Feb 2015 in Istanbul, to be combined with course on “genetics in health care: practice & policies”.

Members of the PPPC 2013-2014

	3-year term ends	Term
Pascal Borry (Leuven, Belgium)	2015	2nd
Anne Cambon-Thomsen (Toulouse, France)	2014	2nd
Martina Cornel (Amsterdam, The Netherlands) Chair	2014	3rd
Florence Fellmann (Lausanne, Switzerland)	2015	1st
Francesca Forzano (Genova, Italy)	2014	2nd
Heidi Howard (Nijmegen, The Netherlands)	2015	1st
Hulya Kayserili (Istanbul, Turkey)	2014	1st
Christine Patch (London, UK)	2016	3rd
Borut Peterlin (Ljubljana, SI)	2016	2nd
Dragica Radojkovic (Belgrade, Serbia)	2015	1st
Emmanuelle Rial-Sebbag (Toulouse, France)	Observer	
Maria Soller (Lund, SE)	2016	2nd
Aad Tibben (Leiden, The Netherlands)	2014	2nd
Lisbeth Tranebjaerg (Copenhagen, Denmark)	2015	6th
Wolf Rogowski (Munich, Germany)	2014	1st

DNA Day 2014: Online premiere of "The Animated Genome"

25.Apr.2014

Enjoy the online premiere of "The Animated Genome" in recognition of DNA Day.



<http://unlockinglifescode.org/learn/the-animated-genome>

Proposed amendments to EU Regulation on Medical Devices are counter to patients' interests and unworkable, says ESHG

07.Apr.2014



Recent amendments to the proposed Regulation on In Vitro Diagnostic Medical Devices (IVDs) currently before the European Parliament will restrict the rights of patients and doctors to carry out essential genetic testing, says the European Society of Human Genetics (ESHG) today (Monday 7 April 2014). Furthermore, an independent legal opinion now shows that the European Union (EU) has no competence to enact the Regulation as amended by the Parliament.



[More information](#)

EuroGentest-ESHG Satellite at ESHG 2014 in Milan

25.Mar.2014

Clinical and quality issues when introducing new technologies in genomics

Friday, may 30, 2014, MiCo, Milan, Italy

Separate registration is necessary!

[Programme information](#)

[Online registration form](#)



New ESHG-ASHG Joint Initiatives!

14.Mar.2014

The European Society of Human Genetics and the American Society of Human Genetics will provide **joint memberships at discount rates**, with on-line access to both societies' journals. Becoming a member of ESHG will get you a discount of 20% on the ASHG member fee.



[Conference Calendar](#)

Genetics in Europe

- National Human Genetics Societies
- Genetics in Europe
- Genetics as Medical Specialty in Europe
- Genetics as a Laboratory Specialty in Europe

Students and Trainees

- Training in Genetics
- Job opportunities
- ESHG Fellowships

Documents

- ESHG and Received documents
- Patient information
- Links - Resources

About ESHG

- Structure
- Committees and sub-committees
- Membership Information
- Member Area

European Board of Medical Genetics

- News
- Clinical Laboratory Geneticists
- Genetic Nurses and Counsellors
- Clinical Geneticists
- Documents
- Meeting Notes

Contact

- [Information and Contact](#)
- [Public Policy](#)