Report of the Public & Professional Policy Committee

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

ESHG

Paris

9 June 2013

Centre for Medical Systems Biology

Society & GENOMICS Centre for Society and Genomics

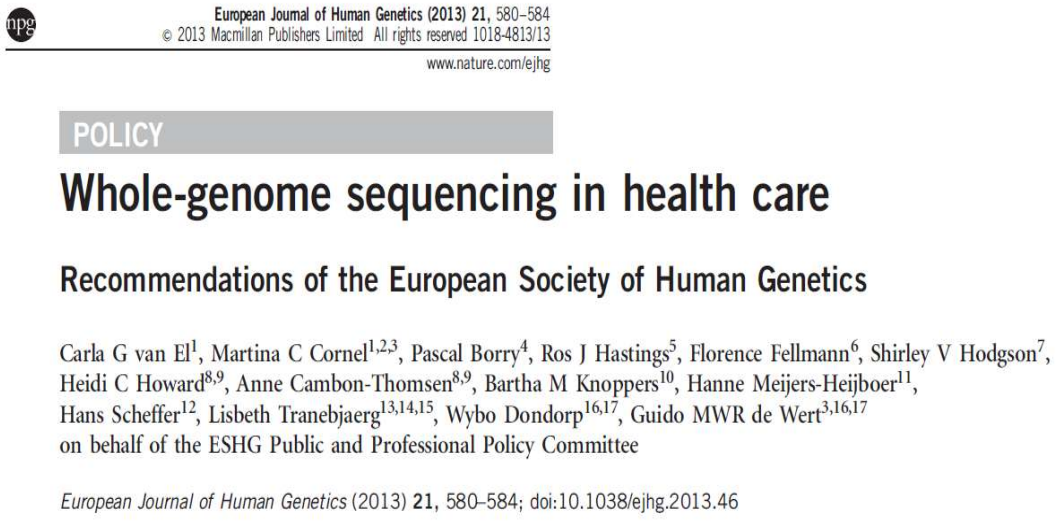
VU university medical center

VU University Amsterdam

EMGO+ Institute for Health and Care Research

Activities 2012/13 (1)

- Whole Genome Sequencing and Analysis recommendations:
  - Online summer 2012 to invite for comments
  - ESHG membership response integrated
  - Board approval dec 2012



European Journal of Human Genetics (2013) 21, 580–584

www.nature.com/ejhg

POLICY

Whole-genome sequencing in health care

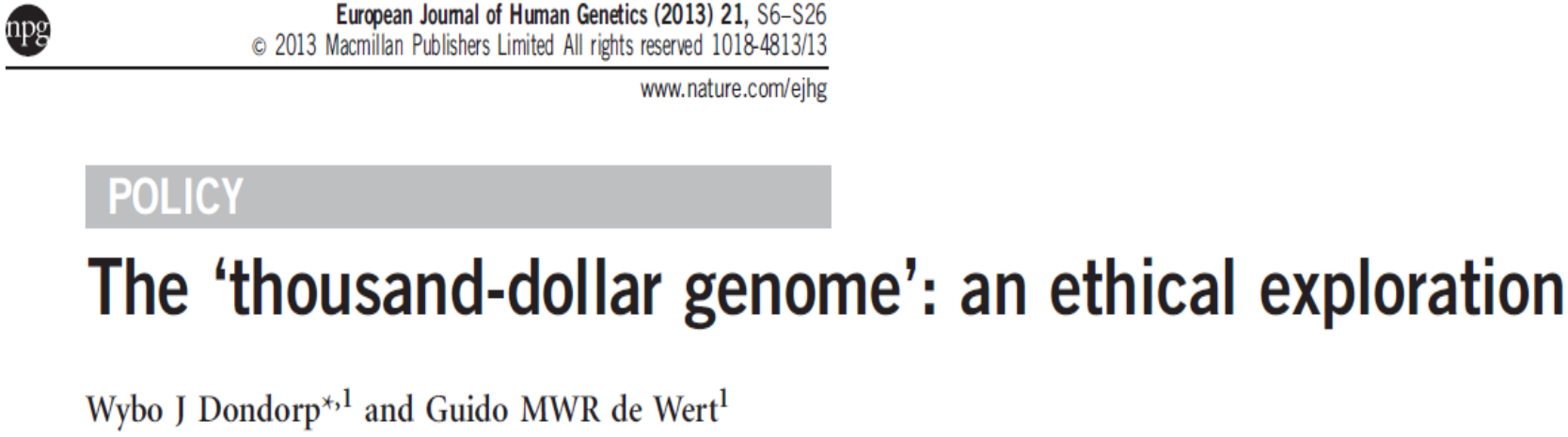
Recommendations of the European Society of Human Genetics

Carla G van El[1], Martina C Cornel[1,2,3], Pascal Borry[4], Ros J Hastings[5], Florence Fellmann[6], Shirley V Hodgson[7], Heidi C Howard[8,9], Anne Cambon-Thomsen[8,9], Bartha M Knoppers[10], Hanne Meijers-Heijboer[11], Hans Scheffer[12], Lisbeth Tranebjaerg[13,14,15], Wybo Dondorp[16,17], Guido MWR de Wert[3,16,17]
on behalf of the ESHG Public and Professional Policy Committee

European Journal of Human Genetics (2013) **21**, 580–584; doi:10.1038/ejhg.2013.46

Activities 2012/13 (2)

- Whole Genome Sequencing and Analysis Background document:



European Journal of Human Genetics (2013) 21, S6–S26

www.nature.com/ejhg

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The 'thousand-dollar genome': an ethical exploration

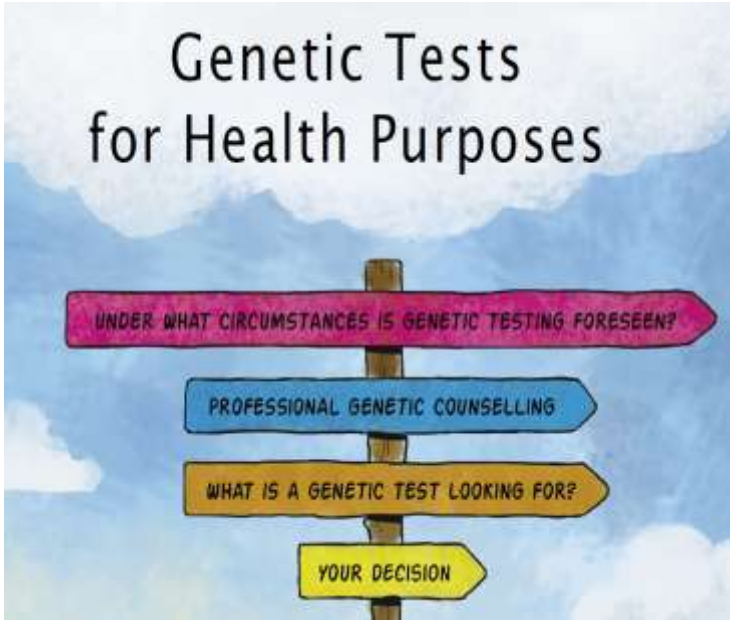
Wybo J Dondorp*,[1] and Guido MWR de Wert[1]

Activities 2012/13 (3)

- Press coverage
- What is next in the sequence…..???
  - Several ESHG related activities to further develop guidance (esp. Laboratory protocols VUS, informed consent-EUGT)
  - **Debate**
  - **Public awareness**
  - **Education**

Activities 2012/13 (4)

- **Translation *Genetic Tests Information Brochure Council of Europe,*** *developed with Pascal Borry & PPPC; together with EUROGENTEST;* distributed to public at large: Nat Soc Hum Genet websites, patients & parents organisations, secondary school teachers organisations, …
- http://www.coe.int/t/dg3/healthbioethic/Activities/07_Human_genetics_en/Brochure/default_en.asp



Activities 2012/13 (5)

Myriad using clinical data to extend monopoly position

Privately owned genetic databases may hinder diagnosis and bar the way to the arrival of personalised medicine: ESHG reacts to today's report in the European Journal of Human Genetics

Wednesday, October 31, 2012

In response to the on-line publication by the European Journal of Human Genetics today (Wednesday) of an article by US researchers led by Dr. Robert Cook-Degan, a former member of the US Office of Technology Assessment, showing that Myriad Genetics, providers of the BRCA1/2 genetic test in the US, has amassed vast quantities of clinical data without sharing it, Professor Martina Cornel, chair of the European Society of Human Genetics' Professional and Public Policy committee, said:

"We are very concerned that such important data is being withheld from those who most need it. Etc.

Ongoing

- To be discussed June 2013:
  - Data sharing/patenting/business models
  - Preconception carrier screening
  - Post mortem genetics
  - Mental health
  - Prioritization & distributive justice (accessibility of genetic services) *WS Nov 2012 Wolf Rogowski*
  - NIPT
  - etc

Your involvement….

- Policy making is never finished
  - Discuss WGA/S paper in your country, city, laboratory

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POLICY

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Your involvement….

- Policy making is never finished
  - Discuss WGA/S paper in your country, city, laboratory
  - Some older policy documents remain relevant:
  - Newborn screening (supported by ESHG Board Oct 2011):

A framework to start the debate on neonatal screening policies in the EU: an Expert Opinion Document

Martina C Cornel, Tessel Rigter, Stephanie S Weinreich, Peter Burgard, Georg F Hoffmann, Martin Lindner, J Gerard Loeber, Kathrin Rupp, Domenica Taruscio and Luciano Vittozzi

Eur J Hum Genet advance online publication, May 8, 2013; doi:10.1038/ejhg.2013.90