



Jörg Schmidtke, Hannover

NHGS Meeting

European Human Genetics Conference 2012

Nürnberg, Germany, June 23-26, 2012

ESHG Highlights



ESHG 2012



NATURE | NEWS

Genome test slammed for assessing 'racial purity'

Hungarian far-right politician certified as 'free of Jewish and Roma' genes.

Alison Abbott

12 June 2012



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EUROPEAN SOCIETY OF HUMAN GENETICS

Press Releases

ESHG condemns use of testing to establish 'racial purity' (abbrev.)

Wednesday, June 13, 2012

The use of genetic testing to establish racial origins for political purposes is not only scientifically foolish, but also unethical and should be condemned, the European Society of Human Genetics (ESHG) said today The society, ..., said that the use by a member of parliament from the Hungarian far-right Jobbik party of a genetic test to attempt to prove his 'ethnic purity' was ethically unacceptable.

The company Nagy Gén scanned 18 positions in the MP's genome for variants that it said were characteristic of Roma and Jewish ethnic groups and concluded that Roma and Jewish ancestry could be ruled out.

Professor Joerg Schmidtke, President of ESHG, said on behalf of the Executive Board: "This is a gross distortion of the values of genetic testing, which is intended to be used to diagnose disease rather than to claim racial purity. ... I am sure that clinical geneticists worldwide will join me in condemning this scandalous abuse of a technology that was developed to help the sick, rather than to promote hatred."

Professor Béla Melegh, President of the Hungarian Society of Human Genetics added: "We were shocked to hear that a laboratory authorised to carry out genetic analysis for diagnostic purposes carried out such a test. Not only does it not serve a diagnostic purpose, but it has been used to create tension between people of different ethnic origins."

The 2012 European Genetics Conferences in Nuremberg, Germany (June 23-26) will provide a further opportunity for the ESHG to denounce such an unethical perversion of genetic science, and insist, at the same time, on the importance of genetic testing in the medical or scientific context of good practice.



ESHG 2012



ESHG Scientific Programme Committee



Brunhilde Wirth, Cologne
Chair



ESHG 2012



The people

Jantje de Roos, Director
 "My former experience includes conference and exhibition management, setting up the congress department of the Congress Centre in The Hague and a short time with an international trade show organiser. This is where the idea for my own specialised company was born. Running Rose International means more work than ever, but also more satisfaction and definitely the best opportunity to develop and deliver the quality that I personally stand for. Moreover, Rose International stands for team work. I am proud and happy to work with such wonderful young people."

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Jantje de Roos, den Haag
 Rose International



Nürnberg: the largest exhibition ever with

- 1,579 m² (1,241 m²)
- 132 (104) exhibitors (2011)

Jérôme del Picchia
 ESHG EO, Vienna



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...from EU-wide (+) recognition of clinical genetics as a medical specialty to ...

EU-wide (+) recognition of laboratory geneticists and genetic counsellors/nurses

- on the basis of the EU Professional Qualifications Directive

- by ESHG- „in house“ activities: an envisaged European Board of Medical Genetics



Heather Skirton, Plymouth
Chair



Marie-Antoinette Voelckel
co-chair



Thomas Liehr, Jena
chair



Egbert Bakker
co-chair

Ad-hoc-Committee for Accreditation for Genetic
Nurses/Counsellors

Ad-hoc-Committee for Accreditation for
Laboratory Geneticists



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EUROPEAN SOCIETY OF HUMAN GENETICS

2'

ESHG

2'

European Board of Medical Genetics

Division A: Clinical Geneticists

Division B: Nurses/Counsellors

Division C: Lab Geneticists

2'

European Board Certificate

+ MOC (maintenance of certification)

through European Board Exam



ESHG 2012



orphanet



Helena Kääriäinen, EUCERD vice chair



ESHG 2012



Public and Professional Policy Committee

Major issues

- Whole genome sequencing
- Newborn Screening
- Paediatric Biobanking



Martina Cornel, chair

Genetic Services Quality Committee

Major issues

- Changing landscape of genetic testing
- Laboratory performance in EQA
- Clinical Genetics
- Best practice guidelines
 - reporting guidelines
 - cytogenetic generic guidelines
 - molecular genetics guidelines
- Rare Variants
- Newborn screening



Ros Hastings, chair

European Journal of Human Genetics

Major achievements

- IF risen to 4.38 (from 3.56)
- top 4 articles received an average of 27 citations per year
- Clinical Utility Gene Cards, as a new strong asset (37 # in 2011)



GertJan van Ommen,
editor-in-chief



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IFHGS

Proposed changes of Bylaws

Key changes:

- IFHGS promotes and helps to organise ICHG (every 5 years)
- Exec more narrowly defined
- ICHG location determined at least 10 years in advance
- ICHG-SPC: 2 per each full member + 6 of hosting society
- ICHG President: hosting society
- ICHG financial obligations: within the responsibility of host



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Outlook:

- Reorganisation of ESHG
 - EBMG
 - EuroGentest
- Opening of ESHG: full membership globally
- Addressing inequalities in genetic health care
 - underserved populations
 - underserved countries in Europe (South and East, Ireland)
 - emerging economies world-wide



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EUROPEAN SOCIETY OF HUMAN GENETICS

Outlook: Disparities in Genetic Services

Potential actions in Paris, 2013,

- Symposium
- Satellite

- (1) underprivileged populations within countries (e.g. Roma in Hungary)
- (2) Migrants and displaced persons
- (3) underprivileged countries in (North-)Western, Southern, and Eastern Europe,
- (4) emerging economies world-wide,
- (5) potential roles for patients' organisations,
- (6) role of the media,
- (7) innovative forms of financing services (PPPs),
- (8) EU resources for health services research.



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Outlook:

ESHG is approaching its 50th birthday (2017)

Time to become more conscious of its own history



Peter Harper, Cardiff



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