



EUROPEAN SOCIETY OF HUMAN GENETICS

# PPPC highlights 2019

Francesca Forzano, Chair  
Martina Cornel, Co-Chair

The Public and Professional Policy Committee (PPPC)

# Activities 2018/2019/2020



- Postmortem genetic testing in SCD
  - Germline Gene Editing
  - Forensic issues
  - Opportunistic screening
  - GDPR
  - Collaboration with SIENNA
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- Participation to WMA Medical Ethics Conference and General Assembly, October 2nd-4th 2018

# Activities 2018/2019/2020



- **Postmortem genetic testing in SCD**
  - Recommendations in press.
  - Endorsed by ESHG, European Council of Legal Medicine, European Society of Cardiology working group on myocardial and pericardial diseases, European Reference Network for rare, low prevalence and complex diseases of the heart (ERN GUARD-Heart), and Association for European Cardiovascular Pathology
  - Martina Cornel will represent PPC and ESHG in the development of the 2020 Asia Pacific Heart Rhythm Society (APHRS) and the Heart Rhythm Society (HRS), APHRS/HRS Expert Consensus Statement on Investigation of Patients with Sudden Cardiac Arrest and of Their Families

# Activities 2018/2019/2020



- **Germline Gene Editing**

- Contribution in drafting ESHG statement in support of a moratorium
- New activity: fetal gene editing. Angus Clarke, Guido de Wert, Wybo Dondorp with Dagmar Schmitz contributed to the book 'The fetus as a patient'.
- New activity: public/ stakeholder engagement. Collaboration initiated with teams in the Netherlands, aim to scale up to European level. Potential involvement EGE

# Activities 2018/2019/2020



- **Forensic issues**

- Publication [A response to the Forensic Genetics Policy initiative's report "Establishing Best Practice for Forensic DNA Databases"](#) in Forensic Sciences International Epub July 5 2018.
- Contribution to draft ESHG statements condemning the collection of DNA from individuals in China as part of an oppressive programme of surveillance and control of the Muslim Uyghur population in Xinjiang

# Activities 2018/2019/2020



- **Opportunistic screening**

- **Lead: Guido de Wert. In collaboration with Eurogentest committee (Sandi Deans)**
- Heidi Howard is leading on a European survey
- W16, Monday: Opportunistic or non-opportunistic genetic screening?
  - Organizers Francesca and Martina
  - Discussants:
    - Guido De Wert
    - Sandi Deans
    - Milan Macek
    - Heidi Howard
    - Pascal Pujol

# Activities 2018/2019/2020



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- **GDPR**

- **Lead: Emmanuelle Rial-Sebbag. In collaboration with Eurogentest Committee (Els Dequeker)**
- Scope: GDPR applications in genetics clinic and research practice.
- ERS and a subgroup of PPC has commented on behalf of ESHG to the United Nations International Consultation on Draft Recommendation on the Protection and Use of health-related data, to be discussed in Strasbourg on 11-12th June 2019. BBMRI has also responded with similar focus.
- Collaboration with ASHG. Derek Scholes (Director of Science Policy ASHG): concern regarding consequences of international and upcoming national regulations for research, especially South African Protection of Personal Information Act (POPIA)

# Activities 2018/2019/2020



- **SIENNA**

- **Lead: Heidi Howard**
- Stakeholder-Informed Ethics for New technologies with high socio-economic and human rights impact
- Funding [H2020 research and innovation programme](#)
- Will develop ethical protocols and codes for human genomics, human enhancement and AI & robotics.

<http://www.sienna-project.eu/>

<http://www.sienna-project.eu/genomics/elsi/>

# Future Joint activities



- **SIC-ASHG.** Joint sessions at international conferences.
- **Eurogentest,** Quality and Guideline committees. Reporting in prenatal setting.
- **ESHRE.** Embryo WGS. Lead: Guido de Wert

# Future Topics



- Recommendations on IVD Regulation that comes into effect as of 2022.  
Working group: Martina Cornel, David Barton, Alison Hall, Stuart Hogart, Helen Wallace
- Consent and Confidentiality. Lead: Angus Clarke.
- Iceland experiences with Decode return of BRCA results: what issues to consider for optimal return/recontact alongside this specific episode (Vígdis)
- How genetics services, research, technologies, DTC testing could add to health inequalities.
- Update previous PPC documents:
  - Pharmacogenomics (Dada)
  - Testing children (Christophe, Florence, Guido, Angus, Alvaro)
  - Cascade screening (Carla, Hülya)

# Members of the PPPC 2018/2019



**Francesca Forzano (London, UK) - Chair**

**Martina Cornel (Amsterdam, The Netherlands) - Co-Chair**

**Carla van El (Amsterdam, The Netherlands) - Secretary General**

**Christophe Cordier (Lausanne, Switzerland)**

**Angus Clarke (Cardiff, United Kingdom)**

**Guido de Wert (Maastricht, The Netherlands)**

**Florence Fellmann (Dudelange, Luxembourg)**

**Sabine Hentze (Heidelberg, Germany)**

**Heidi Howard (Uppsala, Sweden)**

**Hulya Kayserili (Istanbul, Turkey)**

**Bela Melegh (Pecs, Hungary)**

**Alvaro Mendes (Porto, Portugal)**

**Markus Perola (Helsinki, Finland)**

**Dragica Radojkovic (Belgrade, Serbia)**

**Emmanuelle Rial-Sebbag (Toulouse, France)**

**Vigdis Stefánsdottir (Reykjavik, Iceland)**

<https://www.eshg.org/pppc.0.html>

**The Public and Professional Policy Committee (PPPC)**