

Report of the Public & Professional Policy Committee



ESHG

Copenhagen

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& public health genomics
On behalf of PPPC

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



The Professional and Public Policy Committee aims:

- To **identify and discuss the ethical, social and policy issues** related to human genetics and its application in research, clinical practice and laboratory genetic services.
- To be informed of various research projects, conferences and events, as well as policy initiatives and actions relating to those issues
- To **inform and stimulate the discussion** around these issues at meetings
- To address these issues and **provide guidance** through background documents, policy statements, recommendations or other publications
- To **participate in the public debate** around these issues
- To inform, interact with and provide advice to national and international policy makers

Activities 2016/17

- Two “fast responses”: **NO to obligatory DNA testing** (*see newsletter*)
- **Gene editing**
 - Agenda setting paper submitted to journal
 - With ESHRE: Preliminary recommendations germline gene editing at ASHG and online Nov/Dec
 - In April/May consultation membership ESHG including background document.
- **Post mortem** genetics in sudden cardiac death

Endorsement

- Officially endorsed ESHG recommendations follow a procedure of
 - agenda setting,
 - preparation in a multidisciplinary setting,
 - consultation of ESHG membership and external experts,
 - integration of suggestions and
 - voting by Board for germline gene editing
- OK 26-5-2017

Recommendations Germline GE

- (see email May 19, 2017) WITH ESHRE
- Currently not allowed in many countries.
- This makes clinical applications in these countries impossible now, even if germline gene editing would become safe and effective.
- Categorical objections seem **unconvincing** when it comes to possible applications of Germline Gene Editing with a clear **therapeutic or preventive aim** (“not natural”; “identity”)
- Consequentialist arguments important (Is it safe? For child and future generations?)

Recommendations Germline GE

- Both **basic and preclinical research** regarding human germline gene editing can be justified on conditions.
- Furthermore, while **clinical germline gene editing** would be totally **premature**, it might become a responsible intervention in the future, but only after adequate preclinical research.
- **Safety** of the child and future generations is a major concern.
- **Priorities?** non-reproductive alternatives, such as preimplantation genetic diagnosis and somatic editing.
- The prohibition of human germline modification however needs **renewed discussion** among relevant stakeholders, including the general public and legislators.

Post mortem genetics

ch/fr/events/228/ethical-legal-an ↻ ↺ brocher geneva cardiogenetic... Fondation Brocher | Ethical,...

Événements

- Événements à venir
- Événements passés
- Conditions
- Appel à projets

Université d'été ou d'hiver

Appels à projets

23 - 25 novembre 2016

Ethical, legal and practical aspects of post-mortem genetic analysis for sudden cardiac death in young adults

Organisateurs:

- Cornel Martina
- Rial-Sebbag Emmanuelle, INSERM, UMR 1027, Inserm/Paul Sabatier University Toulouse, PhD, Permanent Research fellow
- Fellmann Florence, CHUV Lausanne, Dr. Medical Geneticist

During this workshop, we will discuss the ethical, legal and practical issues of conducting post-mortem genetic testing with the ultimate aim of drafting European recommendations. We will focus on the case of sudden cardiac death (SCD) in young adults (less than 40 years of age) and aim to elaborate recommendations to aid in the inclusion of such testing in autopsy procedures in Europe. To date, attempts at incorporating genetic testing for sudden cardiac death in autopsy procedures has faced a number of challenges, including legal and ethical challenges, as well as very practical issues such as financial questions (who will pay for this?) and (mis)communication obstacles (pathologists and geneticists being unaware of the issues and unable to discuss and find applicable solutions).

We will gather an international multidisciplinary group of experts to discuss these challenges in order to find potential solutions. Clear and constructive recommendations on post-mortem genetic testing for SCD will not only help in the context of this disorder but may also prove to be useful for other medical disorders.



L'utilité de ce genre d'institutions est incontestable. Car le monde moderne est sans cesse confronté à des innovations, médicales ou autres, qui s'appliquent à l'homme ou à son environnement proche. Ce lieu est donc nécessaire pour préparer la matière intellectuelle qui sera ensuite transférée aux citoyens afin que ceux-ci puissent en tirer profit.

Post mortem genetics

- Report to Brocher Foundation
- Autopsy procedures are generally well described in various European regulations, however, these often poorly integrate post-mortem genetic testing.
- Medicolegal autopsies should have a **dual aim**: not only to establish if a death was natural or caused by a criminal act or accident; but also to **establish the cause of a natural death**, and allow results to be used for health care purposes for the surviving **relatives**.

Post mortem genetics

- Report to Brocher Foundation
- Sudden cardiac death at a young age should be considered a **public health priority**,
- Public **funding** should be allocated for related relevant investigations.

- Next steps: develop BD&RC

New topics?

- Recontacting (ongoing, building on activities Exeter/Groningen groups as Background)
- Cascade screening/ informing relatives
- “56 ACMG genes” – when to provide additional information on actionable diseases?
- DTC: which responsibilities for professionals in clinical genetics to explain test results (Helena Kääriäinen)

Members of the PPPC

	3-year term ends	Term
Caroline Benjamin (Lancashire, United Kingdom)	2018	1st
Angus Clarke (Cardiff, UK)	2019	1st
Martina Cornel (Amsterdam, The Netherlands) - Chair	2017	4th
Guido de Wert (Maastricht, The Netherlands)	2018	1st
Florence Fellmann (Lausanne, Switzerland)	2018	2nd
Francesca Forzano (Genova, Italy) - Co-Chair	2017	3rd
Heidi Howard (Uppsala, Sweden)	2018	2nd
Hulya Kayserili (Istanbul, Turkey)	2017	2nd
Bela Meleg (Pecs, Hungary)	2018	1st
Alvaro Mendes (Porto, Portugal)	2018	1st
Markus Perola (Helsinki, Finland)	2019	1st
Dragica Radojkovic (Belgrade, Serbia)	2018	2nd
Emmanuelle Rial-Sebbag (Toulouse, France)	2017	1st
Carla van El (Amsterdam, The Netherlands) - Secretary General	2019	1st