

NATIONAL ACADEMY OF SCIENCES *AND* NATIONAL ACADEMY OF MEDICINE

Committee on Human Gene Editing: Scientific, Medical and Ethical Considerations

Consensus Study Meeting #2

April 29, 2016

Académie Nationale de Médecine
(French National Academy of Medicine)
16 Rue Bonaparte, 75006
Paris, France

AGENDA

- 8:45 am **Registration**
- 9:15 am **Welcome**
Richard Hynes and Alta Charo, Committee Co-chairs
- 9:30 am **Integration of Social Perspectives into Science Policy**
Discuss views from several societal interest groups and how they intersect with science policy.
- Moderator John Evans
- Speakers (3) **Jackie Leach Scully** (disability ethics, feminist)
 Soren Holm (transhumanism)
 Kevin FitzGerald (Catholic, Jesuit)
 Thomas Landrain (DIY bio)
- 10:40 am *Break*
- 11:00 am **Making the Discussion Concrete: Hypothetical Case Examples of Germline Editing**
Discuss concrete examples, and why gene editing should or should not go forward, from various scientific, ethical, and regulatory perspectives.
- Moderator Jeff Kahn & Barry Coller
- Speakers (4) **Elizabeth Vroom** (DMD patient advocate)

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| George Dickson | (DMD scientist) |
| Yann Le Cam | (CF advocate) |
| Hans Clevers | (CF scientist) |
| ? | (Tay Sachs advocate) |
| ? | (Tay Sachs scientist) |

12:30 pm *Lunch (provided for all participants)*

1:30 pm **Principles Underlying Human Gene Editing Governance**

First session –Provide a basic grounding in what these principles represent and how they specifically apply to human gene editing.

Moderator Jennifer Merchant

Speakers (3) **Roberto Andorno** (Oviedo)
Bartha Knoppers (transnational)
~~**Stephanie Hennette-Vauchez**~~ (human dignity)

2:45 pm *Break (30 min)*

Second session – Obtain perspectives from permissive/neutral, precautionary, and preventive governance stances for human gene editing.

Moderator Gary Marchant

Speakers (5) **Guido Pennings** (Belgium)
Chen Zhu (China)
Anita Ho (Singapore)
Abdul Rashid Gatrad (Muslim)
~~**Daniel Strech**~~ (Germany)

4:30 pm *Break*

5:00 pm **Regulatory Orientations: Similarities, Differences, and Lessons Learned**

Moderated discussion among committee, speakers, and meeting participants based on the case examples presented and other points raised in discussion.

Moderator Ellen Clayton

6:10 pm **Public Comment Period**

6:30 pm **Adjourn**