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# Global Forum on Bioethics in Research (GFBR): Genome Editing for Human Benefit: Ethics, Engagement and Governance

Singapore, 12 – 13 November 2019



## Agenda

Tuesday 12 November 2019

07:30	<b>Planning Committee breakfast meeting</b> (Room: Ginger – located in the main restaurant)
08:00	Registration (Sky Ballroom Foyer)
08:30	<b>Welcome and introduction</b> Teck Chuan Voo, National University of Singapore, Singapore
08:45	<b>Keynote presentations</b>  <b>Ethics, governance and policy aspects of human genome editing research</b> Maneesha Inamdar, Jawaharlal Nehru Centre for Advanced Scientific Research, India  <b>Gene drives in the face of uncertainty: Hype, hope, and duty</b> Claudia Emerson, McMaster University, Canada
<b>Theme 1</b> 09:30	<b>Human germline editing: Jiankui He case</b> Chair: Michael Selgelid, Monash University, Australia
10 min	<b>Introduction to the theme</b>
15 min	<b>Gene-edited babies: The political, governance and cultural issues and why China?</b> Yonghui Ma, Xiamen University, China
15 min	<b>Public participation and regulation of human germline gene editing in China</b> Qi Chen, Xiamen University, China
15 min	<b>Silence and complicity in the case of the first gene-edited babies</b> Owen Schaefer, National University of Singapore, Singapore
15 min	<b>Discussion</b>
35 min	<b>Breakout group discussion</b>
11:15	Tea/coffee break

**Theme 2** **Human germline editing: Regulatory and policy responses**  
11:45 Chair: Fabiana Arzuaga, Ministry of Science, Technology and Productive Innovation, Argentina

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10 min **Introduction to the theme**

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20 min **'Societal consensus' as a requirement for germline gene editing**  
Markus Labude, National University of Singapore, Singapore

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20 min **Is prohibition a solution? A reflection on embryo gene editing in the Civil and Commercial Code of Argentina**  
Ana Palmero, National Ministry of Health, Argentina

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15 min **Discussion**

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30 min **Breakout group discussion**

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13:20 *Lunch*

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**Theme 3** **Governance of genome editing: National and regional perspectives**  
14:30 Chair: Teck Chuan Voo, National University of Singapore

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10 min **Introduction to the theme**

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15 min **Research governance of heritable genome editing rooted in salient value sharing**  
Mika Suzuki, Kyoto University, Japan

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15 min **Prudence in germline gene editing: The urgent need for collaborative partnerships in Africa**  
Gerald Ssebunnya, Africa Institute for Human Dignity, Botswana

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15 min **Readiness level of the Brazilian regulatory framework: Can we face genome editing?**  
José Ricardo Jensen, Instituto Butantan, Brazil

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15 min **Policy on gene editing and gene drive research in the Caribbean**  
Derrick Aarons, Caribbean Research Ethics Education Initiative, Turks & Caicos Islands

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20 min **Discussion**

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16:00 *Tea/coffee break*

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16:30 **Breakout group discussion (Theme 3 continued)**

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17:05

**Pecha Kuchas**

Chair: Carla Saenz, Pan American Health Organisation, USA

- **Governance of gene editing in Africa**  
Syntia Nchangwi, University of Cape Town, South Africa
- **Pathway to genome editing in Nigeria**  
Simisola Akintola, University of Ibadan, Nigeria
- **“Mirror, mirror on the wall...who is the most ethical of us all?”  
Decoding genetic studies from Pakistan: A review of international, regional and local guidelines and compliance**  
Natasha Anwar, Aga Khan University Hospital, Pakistan
- **Articulation between an Argentine patient organization, the Argentinian state and researchers from the University of Huazhong (China) for inclusion of 10 Argentine patients in a ND4 gene therapy trial for Leber hereditary optic neuropathy**  
Marcela Ciccioli, Stargardt APNES-Retina, Argentina
- **Analysis of China’s CRISPR babies using the Emanuel Framework**  
Sofia Salas, Clínica Alemana Universidad del Desarrollo, Chile
- **Challenges of a Latin American startup using CRISPR for diagnosing sub-tropical diseases**  
Federico Pereyra-Bonnet, National Council of Science and Technology, Buenos Aires University, Argentina

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17:45

*Meeting close*

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18:30

**Meet in the venue reception for departure for dinner**

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Wednesday 13 November 2019

07:30

**Steering Committee breakfast meeting**  
*(Room: Ginger – located in the main restaurant)*

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08:30

**Summary – key themes from day 1**  
Samantha O’Loughlin, Imperial College London, UK  
Anant Bhan, Sangath and Yenepoya University, India

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**Theme 4**

09:00

**Engagement and social acceptability**  
Chair: Lucy Carter, The Commonwealth Scientific and Industrial Research Organisation, Australia

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10 min

**Introduction to the theme**

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20 min

**An unprecedented outreach event in Argentina to raise awareness about gene editing: A communication challenge to engage the general public**  
Sebastián Barbosa, Ministry of Science, Technology and Productive Innovation, Argentina

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20 min	<b>Co-developing community-wide acceptance model with affected stakeholders for genetic approach of vector control</b> Léa Paré Toé, Institut de Recherche en Sciences de la Santé, Target Malaria, Burkina Faso
20 min	<b>Public engagement towards eliciting public views and promoting dialogues on genomic research in India</b> Manjulika Vaz, St John's Research Institute, India
20 min	<b>Discussion</b>
40 min	<b>Breakout group discussion</b>
11:10	<i>Tea/coffee break</i>
<b>Theme 5</b> 11:45	<b>Governance of gene drive research</b> Chair: Jantina De Vries, University of Cape Town, South Africa
10 min	<b>Introduction to the theme</b>
20 min	<b>Providing sound policy frameworks for responsible gene drive research: An analysis of the governance landscape and priority areas for further work</b> Isabelle Coche, Outreach Network for Gene Drive Research, Portugal
20 min	<b>Guiding community acceptance processes for gene drive research – available guidance, gaps, and experiences from Mali, Burkina Faso and Uganda</b> Delphine Thizy, Target Malaria, Imperial College London, UK
15 min	<b>Discussion</b>
40 min	<b>Breakout group discussion</b>
13:30	<i>Group photo and lunch</i>
14:45	<b>Panel discussion: Key themes arising from the meeting</b> Chair: Michael Parker, Oxford University, UK <b>Panellists:</b> <ul style="list-style-type: none"> <li>• Maneesha Inamdar, Jawaharlal Nehru Centre for Advanced Scientific Research, India (ethics of human genome editing)</li> <li>• Teck Chuan Voo, National University of Singapore, Singapore (engagement and social acceptability in human genome editing)</li> <li>• Lucy Carter, The Commonwealth Scientific and Industrial Research Organisation, Australia (engagement and social acceptability in gene drive research)</li> <li>• Katherine Littler, World Health Organisation, Switzerland (governance of human genome editing and gene drive research)</li> </ul>
16:00	<b>Presentation of awards and announcement about next year's meeting</b> Phaik Yeong Cheah, Mahidol Oxford Tropical Medicine Research Unit, Thailand Ross Upshur, Toronto University, Canada
16:15	<i>Meeting close</i>