

## Agenda for the Third International Summit on Human Genome Editing

### Monday 7 March 2022

09:30 – 10:10 Introduction and History of Summits

- Royal Society representative
- David Baltimore, The California Institute of Technology
- Robin Lovell-Badge, The Francis Crick Institute
- Victor Dzau, United States National Academy of Medicine of the United States National Academy of Sciences

Moderator: David Baltimore

10:10 – 12:50 Scientific, Historical and Ethical Context of Human Genome Editing

Scientific and ethical considerations:

- Alena Buyx, German Ethics Council & Technical University of Munich
- Jennifer Doudna, University of California, Berkeley
- Jennifer Merchant, Université Panthéon-Assas Paris 2
- Cor Oosterwijk, VSOP (Association of Cooperating Parent and Patient Organisations)
- Ambroise Wonkam, University of Cape Town

Moderator: Robin Lovell-Badge

International perspectives panel:

- Jantina Devries, University of Cape Town
- Sergio Pena, Universidade Federal de Minas Gerais
- Natacha Salomé Lima, National Scientific and Technical Research Council (CONICET) & Universidad de Buenos Aires
- Ping Yan (in collaboration with Lu Gao, Yang Yang, Wenlong Lu and Wei Zhang), Dalian University of Technology

Moderator: Charles Rotimi, National Human Genome Research Institute, USA  
National Institute of Health

12:50 – 13:50 *Lunch*

13:50 – 15:40 Sickle Cell Disease: a case study on promoting innovation and providing the best therapeutic options to patients

Overview and clinical context of Sickle Cell Disease:

- Alexis Thompson, Children's Hospital of Chicago in Chicago & Northwestern University

Patient perspectives panel:

- Melissa Creary, University of Michigan
- Arafa Salim Said, Sickle Cell Disease Patients Community of Tanzania
- Natasha Thomas, Individual with Sickle Cell Disease
- TBC

Clinician's perspective on treating underserved population:

- Marina Cavazzana, Necker-Enfants Malades Hospital & Paris Descartes University

Moderators: Julie Makani, Muhimbili University of Health and Allied Sciences & Mayana Zatz, University of São Paulo

- 15:40 – 16:00 *Afternoon break*
- 16:00 – 18:00 Sickle Cell Disease: a case study on how to navigate between promoting innovation and providing the best therapeutic options to patients – continued
- Gene therapy as a benchmark for clinical management of gene-based treatments:
- John Tisdale, National Heart, Lung and Blood Institute, USA National Institute of Health
- Therapeutic innovation by gene editing: the growing number of precise engineering options and early clinical findings:
- Dan Bauer, Boston Children's Hospital, Dana-Farber Cancer Institute & Harvard Medical School
- Bioethicist considerations panel:
- Kofie Anie, London North West University Healthcare NHS Trust & Imperial College London
  - Daima Bukini, Muhimbili University of Health and Allied Sciences (Muhas)
  - Keith Wailoo, Princeton University
- Moderators: George Daley, Harvard Medical School & Jennifer Doudna

## **Tuesday 8 March 2022**

- 08:30 – 10:30 Clinical Research Involving Somatic Editing
- Update on the clinical research:
- Julian Gilmore, University College London
  - Rachel Haurwitz, Caribou Biosciences
  - Sonja Schrepfer, University of California San Francisco & Sana Biotechnology Inc.
  - Amy Wagers, Harvard University
- Moderator: David Altshuler, Vertex Pharmaceuticals
- Accessibility and price:
- Mike McCune, Bill & Melinda Gates Foundation
  - Steve Pearson, Institute for Clinical and Economic Review
  - Joni L Rutter, National Center for Advancing Translational Sciences, USA National Institute of Health
- Moderator: Chris McCabe, Institute of Health Economics
- 10:30 – 11:00 *Morning break*
- 11:00 – 13:15 Update of Science and Techniques in Somatic and Epigenetic Editing: non-therapeutic uses and current barriers to clinical applications
- Update of core technologies:
- Yuija Cai, Shanghai JiaoTong University & Aarhus University
  - David Lui, Broad Institute, Harvard University & Howard Hughes Medical Institute
  - Tippi Mackenzie, University of California, San Francisco
  - Feng Zhang, Broad Institute, McGovern Institute for Brain Research, Massachusetts Institute of Technology & Howard Hughes Medical Institute

Epigenetic editing for therapeutic and non-therapeutic uses:

- Angelo Lombardo, San Raffaele - Telethon Institute for Gene Therapy & Vita-Salute San Raffaele University
- Renee Wezgryn, Ginkgo Bioworks

Moderators: Luigi Naldini San Raffaele Telethon Institute for Gene Therapy & San Raffaele University School of Medicine & Lily Paemka, University of Ghana

13:15 – 14:15 *Lunch*

14:15 – 15:30 Role of Non-scientists in Setting Research Agenda

Role of patient organisations:

- Mathieu Boudes, Montsouris Consilium
- Bettina Ryll, Melanoma Patient Network Europe & European Commission

Role of activists and DIY community:

- Alex Pearlman, Bioethicist & journalist

Role of cultural beliefs:

- Māui Hudson, University of Waikato

Moderators: Ewan Birney, The European Bioinformatics Institute & Elisa Reis, Federal University of Rio de Janeiro

15:30 – 16:00 *Afternoon break*

16:00 – 17:30 Regulation and Policy Approaches to Increase Accessibility for Somatic Editing

Range of governance mechanisms:

- Hervé Chneweiss, CNRS & Inserm Ethics Committee

Current known work on somatic editing globally and the relevant regulatory systems in place:

- Piers Millett, iGEM Foundation, Biosecure Ltd & University of Oxford

Ethical considerations for regulation and policy approaches:

- Alondra Nelson, Institute for Advanced Study
- TBC

Moderators: Alta Charo, University of Wisconsin-Madison & Cor Oosterwijk

## **Wednesday 9 March 2022**

08:30 – 10:10 Update on Science and Techniques for Heritable Editing of Embryos

Update of core technologies:

- Dieter Egli, Columbia University Irving Medical Center
- Shoukhrat Mitalipov, Oregon Health & Science University
- Kathy Niakan, Francis Crick Institute & University of Cambridge
- Yuyu Niu, State Key Laboratory of Primate Biomedical Research & Kunming University of Science and Technology

Update of diagnostics:

- Sunney Xie, Peking University

Translational pathway from the International Commission for the Clinical Use of Human Germline Genome Editing:

- Andy Greenfield, University of Oxford

Moderators: Michèle Ramsay, The University of the Witwatersrand & Haoyi Wang, Chinese Academy of Sciences

10:10 – 10:40 *Morning break*

10:40 – 12:20 Update on Science and Techniques of Heritable Editing of Gametes

Introduction and overview:

- Amander Clark, University of California, Los Angeles

Update of core technologies:

- Katsuhiko Hayashi, Kyushu University
- Kyle Orwig, University of Pittsburgh
- Mitinori Saitou, Kyoto University

Moderators: Robin Lovell-Badge & TBC

12:20 – 13:20 *Lunch*

13:20 – 15:30 Regulation and Policy Approaches for Heritable Editing

Overview of recent reports:

- Laurence Lwoff, Council of Europe

Enforcement of principles set out in reports panel:

- María de Jesús Medina Arellano, National Autonomous University of Mexico
- Katherine Littler, World Health Organisation
- Yaojin Peng, Chinese Academy of Sciences
- Leigh Turner, University of California, Irvine

Current known work on heritable editing globally and the relevant regulatory systems in place:

- Katie Hasson, Center for Genetics and Society

Reproductive options and genetic lineage viewed in different cultures:

- Ephrat Levy-Lahad, Shaare Zedek Medical Center
- César Palacios-González, University of Oxford
- Tina Rulli, University of California, Davis

Moderators: Françoise Baylis, Dalhousie University & Daria Julkowska, Thematic Institute of Genetics & European Joint Programme on Rare Disease

15:30 – 16:00 *Afternoon break*

16:00 – 17:30

A Better World for All: From Here to Where?

Increasing capacity for diagnosing, manufacturing treatments, and treating genetic diseases:

- TBC

Approaches within the current paradigm of researching, developing, and manufacturing novel treatments to lower cost and increase accessibility:

- Adrian Towse, UK Office of Health Economics

Approaches outside the current paradigm:

- Tania Bubela, Simon Fraser University

General Discussion

Moderators: Alta Charo & Javier Guzman, Center for Global Development

17:30 – 18:00

Concluding Remarks from Planning Committee

Presentation of statement:

- Robin Lovell-Badge

Q&A:

- Planning Committee