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To the Planning Committee of the Third International Summit on Human Genome Editing,

As preparations for the upcoming Summit get underway, **we are reaching out to urge that you prioritize the inclusion of civil society voices and perspectives grounded in human rights and social justice.** We appreciate the invitation for Katie Hasson to speak at the upcoming Summit and hope that the Center for Genetics and Society will be one among many civil society voices involved in the event. **It is critical that these voices and perspectives be meaningfully included in the event planning, agenda, and follow-up.**

The imperative for public engagement in deliberations about heritable human genome editing, and for broad societal consensus before any decision about it is reached, has been widely recognized. Numerous national scientific academies and international organizations have affirmed these commitments at meetings and in high-profile publications, as documented in the attached compilation of statements from recent major reports.

However, we have been dismayed that scientists dominated the organizing committees and presenter panels at the previous two Summits, and were the primary authors and reviewers of the science academies' published reports. As a result, technical issues related to heritable genetic modification have received far greater emphasis than social matters. Because neither civil society advocates nor scholars from the humanities and social sciences were adequately included, considerations of heritable genome editing's enormous societal implications have been superficial at best.

Meanwhile, advocates and scholars committed to human rights, reproductive and disability rights and justice, racial and environmental justice, and global health equity have repeatedly raised ethical and justice concerns about heritable genome editing. Examples of these concerns are offered in this letter.

The imbalances and omissions identified here have impoverished, and sometimes distorted, the ongoing debate about heritable genome editing. They further threaten to undermine the legitimacy of the debate and erode public support for genetic research and technologies overall. It is imperative to bring forward more voices focused on human rights, equity, and social justice.

How will the upcoming Summit include civil society voices and human rights and social justice concerns?

As the organizers of the upcoming Summit, we ask that you consider the following critical questions:

- What efforts or structures will you put in place to fulfill your commitments to meaningfully engage broadly inclusive publics and advance the goal set at the first Summit of building “broad societal consensus?”
- How will you ensure that civil society voices and perspectives grounded in human rights and social justice are fully included in the 2022 Summit?

We offer these recommendations for adequately addressing these questions:

- Include representatives of civil society organizations, specifically those grounded in social justice and human rights, on the Summit Planning Committee;
- Expand the proposed agenda to include discussion of historical and social contexts, and the ethical and justice consequences of heritable genome editing;
- Invite speakers with specific expertise in these areas, including civil society advocates and scholars in the humanities and social sciences working from human rights and social justice frameworks; and
- Address the human rights and social justice concerns of civil society advocates and include their recommendations in any concluding statement.

Social justice and human rights concerns

The paucity of civil society and human rights and social justice voices in previous convenings and publications on heritable genome editing has resulted in inadequate attention to societal concerns. These concerns are as essential to the conversation as technical issues, and will therefore require just as much time, care, and resourced support. Here we offer examples of these concerns:

- Without international cooperation in governance of heritable genome editing, there will be no way to prevent researchers, clinics, or consumers traveling to countries with minimal regulation or lax enforcement in order to evade regulations in their home country. Reports and discussions discount and undermine the potential for large-scale international cooperation when they fail to note that 75 nations already prohibit heritable genome editing.
- Limiting the use of heritable genome editing to specified conditions will not be possible in the numerous jurisdictions, including the United States, that lack policy mechanisms for regulating the fertility industry and controlling “off-label” uses of approved procedures.
- Commercial dynamics and profit motives will encourage the emergence of a market-based, high-tech form of eugenics that exacerbates our already shameful levels of inequality and discrimination, both within and among nations.
- Heritable genome editing will stoke assumptions – based on existing biases and patterns of discrimination – that some people’s genes are more valuable than others’. It could recapitulate and revive legacies of eugenic sterilization, population control, and unethical experimentation.
- Heritable genome editing would increase stigmatization of and diminish social support for people with disabilities; calls to prevent the births of people with particular genes or traits could harm disabled individuals and communities.

- In competitive societies, the availability of heritable genome editing may lead to social pressures on prospective parents to produce “better children” by modifying embryos to avoid or select for particular genetic configurations.
- Heritable genome editing could diminish the rights and interests of individuals and future generations who could be considered designed by others without their consent.
- The development, marketing, and use of heritable genome editing would be shaped by existing racism, sexism, and ableism, and could give rise to new forms of these oppressions.
- A focus on fixing “defective” genes (and individuals or communities who carry them) deflects attention from systemic and environmental problems and solutions.
- Given the extremity of existing health inequities domestically and globally, it is difficult to justify the significant investments of talent and funding that the pursuit of heritable genome editing would consume, especially given the availability of existing alternatives.

In this time of reckoning over eugenic abuses, the persistence of racism, and stark health inequities brought to light by a global pandemic, it has become clear that human rights and social justice concerns must be at the forefront of all policy discussions – especially those pertaining to powerful new technologies with effects on all humanity. **There is still time to meaningfully include these essential but neglected voices and concerns in the upcoming Summit.** We would be happy to discuss further, including putting forward specific names. **The suggestions in this letter outline a path of action that would make tremendous strides in meeting your obligations to the public and the scientific community as facilitators of this global dialogue.**

Sincerely,

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Katie Hasson, PhD, Associate Director

Center for Genetics and Society Advisory Board (*institutional affiliations listed for identification purposes only*)

Francine Coeytaux, MPH, Chair; Co-Founder, Pro-Choice Alliance for Responsible Research; Co-Founder and Co-Director, Plan C

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Attachment: Commitments to public engagement on heritable genome editing

Every major report addressing human genome editing since 2015 has recommended globally inclusive dialogue and meaningful public engagement on the challenging issues raised by the technology. Here are brief comments from recent reports published by international organizations.

- **World Health Organization (2021):** The Director General should “call for an inclusive dialogue on the future of human genome editing, including scientific, ethical and societal aspects.” WHO should “develop models of best practice of inclusive multidirectional, multistakeholder dialogue...” and “explore how best to include in decision-making under-represented groups that are interested in human genome editing.”¹
- **United Nations Conference on Trade and Development (2021):** “Keeping the SDGs [Sustainable Development Goals] as central guiding principles requires proactive participation of all stakeholders including civil society organizations. It will take time, but the combined efforts of civil society groups can lead to changes in regulations and laws and eventually trigger changes in user and consumer behaviour so as to align frontier technologies with societal goals.”²
- **European Commission, European Group on Ethics in Science and New Technologies (2021):** “Public engagement should involve a range of publics, scientists, scholars in the social sciences and humanities, ethicists, legal and policy specialists, and other experts, organised civil society, with special attention to representatives of women’s rights, rights of the child, gender equality, social equality, reproductive rights and justice, disability rights, and human rights in general.”³
- **Council of Europe Committee on Bioethics (2019):** “There is good reason to involve the public in debate about biomedical developments that may lead to changes in social norms and where there are risks of increasing inequalities and marginalisation of certain groups. Public debate can help to find appropriate and acceptable mechanisms to protect minorities and ensure equality of access to developments in biomedicine.”⁴

The “summits” and reports co-organized by national science academies have included similar pledges.

- The Organizing Committee of the first International Summit on Human Gene Editing (2015) stated, “It would be irresponsible to proceed with any clinical use of germline editing unless and until...there is broad societal consensus about the appropriateness of the proposed application.”⁵

1 World Health Organization Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. 2021. *Human Genome Editing: Recommendations*, p. 18. <https://www.who.int/publications/i/item/9789240030381>

2 United Nations Conference on Trade and Development. 2021. *Technology and Innovation Report 2021*, p. 123. <https://unctad.org/page/technology-and-innovation-report-2021>

3 European Group on Ethics in Science and New Technologies. 2021. *Ethics of Genome Editing*, p. 36. <https://op.europa.eu/en/web/eu-law-and-publications/publication-detail/-/publication/6d9879f7-8c55-11eb-b85c-01aa75ed71a1>

4 Council of Europe Committee on Bioethics (DH-BIO). 2019. *Guide to Public Debate on Human Rights and Biomedicine*, p. 9. <https://www.coe.int/en/web/bioethics/guide-on-public-debate>

5 Organizing Committee for the International Summit on Human Gene Editing. December 3, 2015. "On Human Gene Editing: International Summit Statement." <https://www.nationalacademies.org/news/2015/12/on-human-gene-editing-international-summit-statement>

- The National Academies of Sciences, Engineering and Medicine 2017 report on human genome editing recommended “extensive and inclusive public participation.”⁶
- The 2020 National Academies/Royal Society report recognized “[a] need to include an expansive array of topics in societal discussions of HHGE [human heritable genome editing]” and commented, “The focus of public engagement and civil society discussions will need to be on more than scientific and clinical dimensions and will need to include diverse voices as well as expert input from the humanities, social sciences, ethics, and faith communities.”⁷

Notwithstanding these repeated calls for robust public engagement and civil society participation, none of the organizations that have sponsored high-profile convenings or reports has made any attempt to enable them. In fact, recent years have seen moves to limit the extent, inclusiveness, and influence of public participation in deliberations about heritable human genome editing.

6 National Academies of Sciences, Engineering, and Medicine; Committee on Human Gene Editing. 2017. *Human Genome Editing: Science, Ethics, and Governance*, p. 178. <https://www.nap.edu/catalog/24623/human-genome-editing-science-ethics-and-governance>

7 National Academy of Medicine; National Academy of Sciences; The Royal Society; International Commission on the Clinical Use of Human Germline Genome Editing. 2020. *Heritable Human Genome Editing*, p. 150. <https://pubmed.ncbi.nlm.nih.gov/32897669/>