

February 24, 2023

SPOTLIGHT ///



Next week, on February 27 and 28, CGS'two-part online symposium will challenge the Third International Summit on Human Genome Editing (March 6-8 in London and online). In this special issue, we share the latest on Genetic Justice from Start to Summit, on a new international declaration, and on other counter-events focused on the summit, as well as all the background info you need to get up to speed.

ANNOUNCEMENTS



Genetic Justice from Start to Summit

Register today to join CGS for a two-part virtual symposium that will challenge the failure to center social justice and human rights voices and perspectives at the Third International Summit on Human Genome Editing. We'll bring together feminist, disability rights, reproductive rights and justice, racial justice, environmental, and human rights advocates and scholars for a discussion of heritable genome editing. Feb 27 (9-10:30am PST) and Feb 28 (9-11am PST).

International Declaration

Now open for signatures by organizations and individuals: **Declaration Against Legalisation of Human Genetic Modification**, organized by the newly formed International Coalition to Stop Designer Babies, of which CGS is a part.

International Declaration Against Legalisation of Human Genetic Modification

The undersigned organisations and individuals support the existing strong international consensus against genetic modification of human beings (HGM*). We wish to express our great concern about and opposition to those scientific academies and others presently seeking to legalise HGM. HGM is medically unnecessary. Pursuing it is an act of extreme scientific irresponsibility, likely to result in enormously harmful consequences for individuals and for global society as a whole.



Summit Counter-events in London

Two additional public events are working to broaden the perspectives on gene editing beyond those featured at the Summit. "Designer baby eugenics and how to stop it" (March 4, in person and online) will feature perspectives from black/antiracist, disability rights, working class, feminist, parents and human rights movements. It is co-sponsored by Stop Designer Babies (UK), Alliance for Humane Biotechnology (USA), Genethisches Netzwerk (Germany), and GeneEthics (Australia).

The international conference "Heritable Genome Editing and Equality" will take place March 3–4 at the Centre of Bioethics and Emerging Technologies at St. Mary's University, Twickenham, co-hosted by the Scottish Council for Human Bioethics.

COMMENTARY



A Sandbox for Designer Babies?

Pete Shanks, *Biopolitical Times* | 02.23.2023 Advocates of legalizing heritable human genome editing in the U.K. are skipping right over the relevant questions—whether it should go forward (and why on earth that would be justifiable)—and focusing instead on how they can make it happen.



End of an Error? The He Jiankui Show Folds Its Tent

Pete Shanks, Biopolitical Times | 02.23.2023 Having completed a prison sentence for his reckless gene editing experiment, He Jiankui appeared to attempt a publicity campaign but backed off, perhaps under pressure. He has forfeited his credibility, but the attention to his every move may distract from needed conversations about why heritable genome editing is unsafe, unneeded, and perilous for societal reasons.

CGS IN THE NEWS



Disgraced CRISPR-baby scientist's 'publicity stunt' frustrates researchers

Smriti Mallapaty, Nature | 02.12.2023

He Jiankui, who notoriously altered genes in embryos and used them to initiate pregnancies, is again in the news. Instead of asking whether he will apologize, the focus should be on the

FROM THE CGS ARCHIVES

Below, find resources regarding the upcoming gene editing summit, past summits, and societal implications of heritable genome editing.

2023 SUMMIT | 2018 SUMMIT & 2020 REPORT | HERITABLE GENOME EDITING | MISSING VOICES ON HERITABLE GENOME EDITING

2023 SUMMIT

The Next Gene Editing Summit Begins to Come into Focus

Pete Shanks, Biopolitical Times | 10.07.2022

With almost no time for human rights and social justice perspectives to weigh in on human heritable genome editing, will the March 2023 gene editing summit wind up being an opportunity for advocacy in favor of adopting heritable genome editing, disguised as dialogue?

Virtual Conference Wrapup: Looking Ahead to the Third Human Genome Editing Summit

Pete Shanks, Biopolitical Times | 03.15.2022

An overview of the three-day event in March 2022 that substituted for the Third International Summit on Human Genome Editing, which demonstrated a somewhat broader approach than did the first two Summits but still suffered from limited public engagement and a tendency to consider separately topics that are intrinsically intertwined.

The Planning Committee for the Third Summit: Now Who Decides?

Pete Shanks, Biopolitical Times | 11.18.2021

The planning committee for the third summit has been announced. It is a little larger than its predecessors, and the members are somewhat more geographically diverse, though several have been prominently involved in both previous summits. The broad agenda seems to be set already, so how much influence the new members will have is unclear.

2018 SUMMIT & 2020 REPORT

Are we mapping a path to CRISPR babies?

Katie Hasson and Marcy Darnovsky, The Hill | 09.13.2020

Amid our multiple ongoing crises, it would be easy to overlook another report on still speculative biotechnology. But this one represents a profoundly consequential step.

The Year After the "CRISPR Babies" Bombshell

Pete Shanks, Biopolitical Times | 11.22.2019

The "CRISPR babies" announcement made headlines around the world, and the response is still developing. Looking back at key events surrounding the human germline editing debate, it's clear we need better and more concrete proposals for regulation if we are to head off more bombshells.

The Scandal and the Summit: Reactions to the Announcement of Gene-Edited Babies

Pete Shanks, Biopolitical Times | 12.07.2018

The CRISPR era's biggest gene editing story dominated the conversation around the Summit. It's time for action toward an enforceable global agreement.

Gene-edited babies: no one has the moral warrant to go it alone

Katie Hasson and Marcy Darnovsky, The Guardian | 11.27.2018

The reckless actions of one scientist cannot and should not pre-empt the global public conversation over whether to proceed with reproductive germline editing. In fact, the conversation is now more urgent and necessary than ever.

HERITABLE GENOME EDITING

Assessing the Global Policy Landscape for Human Germline and Heritable Genome Editing

Katie Hasson, Biopolitical Times | 11.02.2020

Approaching global governance with the assumption that there is a policy vacuum ignores the large number of countries that already have policies and the near-consensus among them.

The "Geneva Statement" Calls for Course Correction on Heritable Genome Editing

CGS Staff, Biopolitical Times | 01.31.2020

Trends in Biotechnology published this important statement authored by a group of 21 influential social scientists, ethicists, life scientists, policy experts, and public interest advocates from around the world, including CGS' Katie Hasson, Marcy Darnovsky, and Osagie K. Obasogie.

5 Reasons to Say No to Genetically Modified Humans

Reasons to ban germline gene editing include the profound risks to future children, thin medical justifications, reinforcing existing inequalities and creating new forms of discrimination, eroding public trust in responsible science, and undermining global agreements.

MISSING VOICES ON HERITABLE GENOME EDITING













Heritable Genome Editing

In this roundtable conversation, Silvia Yee, Larkin Taylor-Parker, Teresa Blankmeyer Burke, and Rebecca Cokley explored how new narratives can challenge uses of genetic and reproductive technologies based on ingrained ableism, and promote futures in which disabled people flourish.

Forging New Disability Rights Narratives about

Equity, Sovereignty, and Racial Justice BEYOND ACCESS IN DEBATES ON HUMAN GENOME EDITING September 14, 2022 10 am FT/1 pm ET

Equity, Sovereignty, and Racial Justice: Beyond Access in Debates on Human Genome Editing CGS Webinar | 09.14.2022

What gets missed in conversations about heritable genome editing when "equity" is flattened to issues of "access?" That question was tackled at a CGS-hosted roundtable conversation, featuring Indigenous geneticist-bioethicist Krystal Tsosie, reproductive justice scholar and advocate Dorothy Roberts, and educator and activist Milton Reynolds.

The Dark Side of CRISPR

Sandy Sufian and Rosemarie Garland-Thomson, Scientific American | 02.16.2021 Many in our society continue to believe that ridding society of genetic differences that count as disease or defect is an undeniable "good." But our genetic conditions are not simply entities that can be clipped away from us as if they were some kind of a misspelled word or an awkward sentence in a document.

An Indigenous bioethicist on CRISPR and decolonizing DNA

Alissa Greenberg, NOVA | 09.11.2020

An interview with geneticist-bioethicist Krystal Tsosie, who is an enrolled member of the Navajo Nation, about how Indigenous culture, gene editing, and bioethics converge, and what it might take to #DecolonizeDNA.

Germline Modification Could Be New Frontier of Reproductive and Disability Oppression

Emily Galpern, Biopolitical Times | 01.30.2020

CGS and Black Women for Wellness have released an infographic and fact sheet articulating a reproductive justice perspective against human germline modification. Reproductive justice advocates are uniquely positioned to change the conversation about germline editing in mainstream media, public conversation, and policymaking.

Please don't edit me out

Rebecca Cokley, The Washington Post | 08.10.2017

Proponents of genetic engineering deliberately use vague language, such as "prevention of serious diseases," leading many people with disabilities to ask what, in fact, is a serious disease. Where is the line between what society perceives to be a horrible genetic mutation and someone's culture?

If you've read this far, you clearly care about the fight to reclaim human biotechnologies for the common good. Thank you!

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