

To ensure delivery, please add info@geneticsandsociety.org to your address book or contacts.



CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

December 7, 2018

WEBSITE

BLOG

ABOUT US

PRESS ROOM

DONATE

SUBSCRIBE

Please also follow us on [Twitter](#), [Facebook](#), [YouTube](#), [Google+](#), [RSS](#) and on our [website](#) and [blog](#).

[Announcements](#)

[Commentary](#)

[CGS in the News](#)

[News](#)

Dear friends,

By now you've likely heard the alarming news: last week, on the eve of the 2nd International Summit on Human Genome Editing in Hong Kong, scientist He Jiankui announced his creation of the first genetically modified babies: twin girls born a few weeks ago.

As nearly all observers agree, if He's claims are true, this was an act of reckless human experimentation. We believe it is also an egregious human rights abuse that marks the failure of scientific self-regulation. Regrettably, some scientists continue to reject the need for enforceable public policy, and to argue that one rogue researcher should not deter or delay moving toward reproductive uses of human germline modification.

Given their immense importance, we've devoted December's Biopolitical Views & News to these developments. Here you'll find the Center for Genetics and Society's responses in press statements, on our blog, and in the media; a statement organized by CGS and Human Genetics Alert, with more than 100 individual and organization signatures; and a curated collection of news and commentary, as well as resources from the CGS archive, to help make sense of what happened and what comes next.

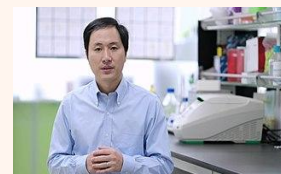
Please read on – and forward widely! You can also follow CGS on [Twitter](#) and [Facebook](#) for up-to-the-minute news, analysis, and opportunities for action. Thank you for your continued support of CGS.

Sincerely,
Marcy Darnovsky and Katie Hasson

ANNOUNCEMENTS

[CGS Responds to Claims of Gene-Edited Twins](#)

In response to the news that a scientist claimed to have created heritable genetic modifications in newborn twins, a [CGS press statement](#) called the actions “a grave abuse of human rights.” Executive Director Marcy Darnovsky noted, “We wish the best for the health of these babies, but strongly condemn the stunt that threatens their safety, and puts the rest of us at risk.” She was widely quoted as saying, “In a time of resurgent racism and socio-economic disparity, the last thing we need is for some people and groups to consider themselves biologically superior to others.”



[Civil Society Calls for Decisive Action from Summit Organizers](#)

On the heels of this breaking news, CGS and Human Genetics Alert organized a [sign-on statement](#) urging the organizers of the Hong Kong Summit to clearly condemn He's actions and support enforceable regulation. The statement, circulated via listservs, was [signed by more than 100](#) civil society organizations, public interest advocates, scientists, and scholars in a 24-hour period. In the wake of the tepid response from Summit organizers, the number of signers continues to grow. The civil society statement documents widespread "outrage and dismay" at the dangers posed by attempts to alter the genes of future generations, and the failure of scientific self-regulation.



[Support Our Work](#)

Thank you for your generosity on Giving Tuesday, November, 27, 2018! Especially at this crucial moment, CGS relies on your support to make sure that social justice is a key element of any discussion of human gene editing and related reproductive technologies. If you missed your chance to donate on Giving Tuesday, it's not too late (or too early!) to make a year-end contribution [here](#). Your support makes our multi-prong communications, campaign, and policy work possible. You can also help our work by spreading the word about our search for a [new Communications Manager](#). With your help, we can head into 2019 with the resources and resolve to push back against harmful and divisive uses of human genetic and reproductive technologies.



CGS COMMENTARY

[Gene-edited babies: no one has the moral warrant to go it alone](#)

By Katie Hasson and Marcy Darnovsky, *The Guardian* | 11.27.2018

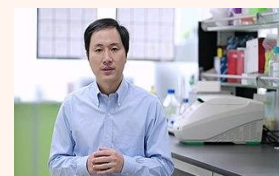
The reckless actions of one scientist cannot and should not pre-empt the global public conversation over whether to proceed with reproductive germline editing. In fact, the conversation is now more urgent and necessary than ever.



[The Scandal and the Summit: Reactions to the Announcement of Gene-Edited Babies](#)

By Pete Shanks, *Biopolitical Times* | 12.06.2018

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



[Be Wary of the Techno-Fix](#)

By Marcy Darnovsky, *Boston Review* | 11.19.2018

In Merve Emre's essay "All Reproduction is Assisted," her commitment to the emancipatory power of reproductive technologies is untroubled by her own accounts of unsatisfactory endings. Perhaps she assumes that one day soon, when the technologies improve, they will set us free.

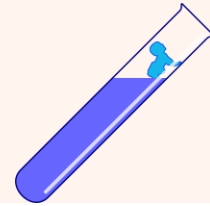


[A Public View Into "A Private Life"](#)

By Ayesha Chatterjee, Pop A.R.T. Guest Columnist, *Biopolitical Times* | 12.05.2018

Private Life, the latest offering from Netflix, peels back the layers on the human

quest for genetically related children.



[Risks Versus Ratings: How Will Michelle's Memoir Reframe Conversations Around Infertility?](#)

By Ayesha Chatterjee, Pop A.R.T. Guest Columnist, *Biopolitical Times*
| 12.05.2018

Michelle Obama is more than her fertility, and there is more to treating infertility than meets the eye. I agree with her fundamental assertion: that the worst thing we do to each other as women is not share the truth about our bodies.



- TOP -

CGS in the NEWS

[Scientist's Claim of Genetically-Edited Babies Renews Ethics](#)

► [Concerns](#)

[with CGS' Marcy Darnovsky]

by Michael Krasny, *KQED Forum* | 11.28.2018

Forum talks about the future and ethics of using new gene editing tools like CRISPR to create genetically-altered humans with Marcy Darnovsky, PhD, Dr. Fyodor Urnov, and Dr. Alex Marson.



[Science Summit Denounces Gene-Edited Babies Claim, But Rejects](#)

► [Moratorium](#)

[cites CGS, with Marcy Darnovsky]

by Rob Stein, *National Public Radio* | 11.29.2018

Despite the controversial breaking news of twins born with gene-edited cells, the organizers of the Second International Summit on Human Genome Editing rejected calls for a blanket moratorium on such research.

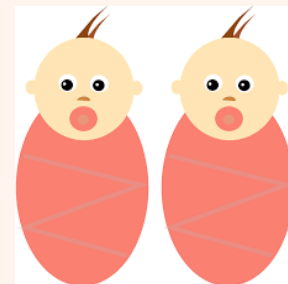


[Claim of CRISPR'd baby girls stuns genome editing summit](#)

[cites CGS]

by Sharon Begley, *STAT* | 11.26.2018

"Throwing open the door to a society of genetic haves and have-nots undermines our chances for a fair and just future."



[The CRISPR Baby Scandal Gets Worse by the Day](#)

[cites CGS]

by Ed Yong, *The Atlantic* | 12.03.2018

The alleged creation of the world's first gene-edited infants was full of technical errors and ethical blunders. Here are the 15 most damning details.



[Organizers of gene-editing meeting blast Chinese study but call for 'pathway' to human trials](#)

[cites CGS]

by Dennis Normile, *Science* | 11.29.2018

A petition circulated online and emailed to the committee and journalists urged the group to "call on governments and the United Nations (UN) to establish enforceable moratoria prohibiting reproductive experiments with human genetic engineering."



[Q&A on scientist's bombshell claim of gene-edited babies](#)

[cites CGS' Marcy Darnovsky]

by Luran Neergaard & Malcolm Ritter, *Associated Press* | 11.26.2018

"If this goes unchallenged, other rogue actors will soon offer wealthy parents purported genetic enhancements for their children," said Marcy Darnovsky of the Center for Genetics and Society.



[Ethics Questions Swirl Around Human Gene-Editing](#)

[with CGS' Marcy Darnovsky]

CNN Today | 11.28.2018

"Gene editing to help people who are sick is widely supported. Heritable gene editing to alter the traits of future children is medically unnecessary. When you alter one gene, you're altering potentially many, many things other than what you think that gene, or know that gene controls. We hope the best for the health of these children, but we can't know for sure."



[Why 2 key gene-editing voices in Berkeley condemn Chinese scientist's designer babies 'stunt'](#)

[cites CGS' Marcy Darnovsky]

by Ron Leuty, *San Francisco Business Times* | 11.26.2018

Both Jennifer Doudna, co-discoverer of CRISPR-Cas9, and Marcy Darnovsky, executive director of the Center for Genetics and Society, condemned the work of He Jiankui.



[Marcy Darnovsky, PhD on ethics of human genetic modification](#)

[with CGS' Marcy Darnovsky]

CGTN America | 11.26.2018

A Chinese scientist claims to have genetically edited twin babies. What is the code of conduct for human genetic modification?



[Controversial Gene Editing Physicist Missing](#)

[with CGS' Marcy Darnovsk]

KPIX 5/CBS | 12.04.2018

"As we think about what has happened here, it's important not to scapegoat this one scientist, even though what he did was wrong and unconscionable and reckless," Darnovsky said. "I think we also have to look in the mirror at ourselves and our country and our scientists."



NEWS

[First Gene-Edited Babies?](#)

[Reactions and Perspectives](#)

[On the Horizon](#)

[Ethics and Self-Regulation](#)

[In Other News](#)

FIRST GENE-EDITED BABIES?

[Chinese scientists are creating CRISPR babies](#)

by Antonio Regalado, *MIT Technology Review* | 11.25.2018

A daring effort is under way to create the first children whose DNA has been tailored using gene editing.

[Chinese researcher claims first gene-edited babies](#)

by Marilyn Marchione, *AP News* | 11.26.2018

A Chinese researcher claims that he helped make the world's first genetically edited babies — twin girls born this month whose DNA he said he altered with the powerful new tool, CRISPR-Cas9.

[China Halts Work by Scientist Who Says He Edited Babies' Genes](#)

by Sui-Lee Wee, *The New York Times* | 11.29.2018

Xu Nanping, China's vice minister of science and technology, said Dr. He's work was still being investigated. His suspension follows international condemnation from scientists who maintain that Dr. He's conduct was unethical.

[HIV Researchers Slam the Scientist Who Made Genetically Engineered Babies](#)

by Nidhi Subbaraman, *BuzzFeed* | 12.03.2018

Researchers point out that existing methods already offer parents simple ways to have children without transmitting the disease. "I'm angry on behalf of the genetic engineering community. I'm angry on behalf of the HIV community," one expert said.

[Screening the human future: YouTube, persuasion and genetically engineered children](#)

by George Estreich, *The Conversation* | 12.03.2018

Scientist He Jiankui did what movie directors do: release a trailer on YouTube. In a masterfully manipulative video posted before publishing in scientific peer-reviewed journals, He tells the world about the first genetically edited babies.

From the CGS Archive

[What Just Happened? Looking Back at 2017's Human Germline Editing Developments](#)

by Leah Lowthorp and Katie Hasson, *Biopolitical Times* | 01.10.2018

The events of 2017 and prospective developments of 2018 underscore the

urgent need for broad public and civil society engagement. The stakes are too high and the potential risks too far-reaching for decisions about germline gene editing to be made by a few scientists or small panels of experts.

▶ [Human gene editing is a social and political matter, not just a scientific one](#)

by Marcy Darnovsky, *The Guardian* | 12.04.2015

The statement issued at the conclusion of the First International Summit on Human Gene Editing amounted to kicking the can down the road, leaving the door open for those who want to use gene editing for human reproduction

▶ [Human Gene Editing Frequently Asked Questions](#)

Center for Genetics and Society | 2016

Is human germline genetic modification medically necessary? Are there alternatives? What are the social consequences? We answer the most frequently asked questions on CRISPR-Cas9 and human germline modification.

REACTIONS AND PERSPECTIVES

- News TOP -

▶ [CRISPR inventor Feng Zhang calls for moratorium on gene-edited babies](#)

by Antonio Regalado, *MIT Technology Review* | 11.16.2018

Feng Zhang, one of the inventors of CRISPR, has called for a global moratorium on using the technology to create gene-edited babies.

▶ [An 'epic scientific misadventure': NIH head Francis Collins ponders fallout from CRISPR baby study](#)

by Jon Cohen, *Science* | 11.30.2018

"Should such epic scientific misadventures proceed, a technology with enormous promise for prevention and treatment of disease will be overshadowed by justifiable public outrage, fear, and disgust. NIH does not support the use of gene-editing technologies in human embryos."

▶ [We need a temporary moratorium on using gene editing to create babies](#)

by Paul Knoepfler, *STAT* | 12.03.2018

"The rationales for human germline editing don't make much sense to me. They consist of invoking rare or even hypothetical scenarios where CRISPR might serve some purpose that cannot be achieved by already proven and safe embryo screening methods such as pre-implantation genetic diagnosis."

▶ [Editing Babies? We Need to Learn a Lot More First](#)

by Eric J. Topol, *The New York Times* [[links to CGS](#)] | 11.27.2018

This is not to say that medicine won't someday employ gene-editing technologies in similar ways. But that time has not arrived. There are still too many risks, too many unknowns, about tinkering with our heritable genetic blueprints.

▶ [How to Respond to Crispr Babies](#)

Editorial, *Nature* | 12.05.2018

[We] "should not start with the assumption that future germline editing is a foregone conclusion — that is a question for society, not scientists, and one that demands the input of different stakeholders from across the world. Researchers and physicians must ask permission rather than beg for forgiveness."

▶ [Reproductive gene editing imperils universal human rights](#)

by Marcy Darnovsky, Leah Lowthorp, and Katie Hasson, *OpenGlobalRights* | 02.15.2018

The rapid pace of developments creates an urgent need for the global community—perhaps gathering under UN auspices—to reaffirm existing agreements and clearly prohibit the dangerous and unethical use of reproductive gene-editing.

▶ [Gene Editing and Human Rights \(video\)](#)

CGS webinar | 10.24.2018

With Alicia Ely Yamin, Roberto Andorno, David Petrasek, and Katie Hasson
Exploring the links between human rights and human gene editing technologies.

▶ [An open letter & report: Calling for prohibitions on human germline engineering](#)

Center for Genetics and Society | 11.29.2015

Over 150 scholars, health practitioners, scientists, public interest advocates, and others signed this CGS-organized open letter. “There is no justification for, and many arguments against, human germline modification for reproductive purposes.”

ON THE HORIZON

- News TOP -

▶ [Another gene-edited baby may be on the way, scientist says](#)

by Marilyn Marchione, *Associated Press* | 11.28.2018

Researcher He Jiankui, who claims to have helped make the world's first genetically edited babies, told those gathered in Hong Kong for a gene editing “summit” that a second pregnancy may be underway.

▶ [Despite CRISPR baby controversy, Harvard University will begin gene-editing sperm](#)

by Antonio Regalado, *MIT Technology Review* | 11.26.2018

Even as a furious debate broke out in China over gene-edited babies, some scientists in the US are also hoping to improve tomorrow’s children.

▶ [Designer Babies Are Here. What’s the Next Edit?](#)

by Emily Mullin, *Neo.Life (Medium)* | 11.29.2018

A Chinese scientist engineered kids to resist HIV. Here are other changes that could be on the feature list for Humanity 2.0.

From the CGS Archive

▶ [Five Reasons to Say No to Genetically Modified Humans](#)

CGS Infographic

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.

▶ [Designer DNA Isn’t Just for ‘Designer Babies’](#)

by Katie Hasson, *Zócalo Public Square* | 01.17.2018

“Designer babies” capture headlines but often limit discussion of serious concerns in debates about human gene editing. Here's why we need to talk about that.

► [Gene Editing and the Future of Reproductive Justice \(video\)](#)

CGS webinar | 06.13.2017

Lisa Ikemoto, Ruha Benjamin, and Dorothy Roberts discuss how reproductive health, rights, and justice advocates can play key roles in preventing a high-tech eugenic future where some people's genes are deemed more valuable for reproducing than others

► [Disability Justice & Gene Editing: Exploring Multiple Perspectives \(video\)](#)

CGS webinar | 04.24.2017

Anita Cameron, Mia Mingus, Tom Shakespeare, and Rosemarie Garland-Thomson explore how emerging biotechnologies like gene editing impact and shape our ideas about disability rights and justice today.

ETHICS AND SELF-REGULATION

- News TOP -

► [Rogue Chinese CRISPR scientist cited US report as his green light](#)

by Antonio Regalado, *MIT Technology Review* | 11.27.2018

Who has the authority to say yes or no to gene-modified babies? In the mind of He Jiankui, the answer was simple: the US National Academies of Sciences, Engineering, and Medicine. He assured hospital ethics reviewers everything would be fine, telling them that the US Academies had recently approved “for the first time” the idea of editing human embryos in order to treat serious disease.

► [Scientist Who CRISPR'd Babies Bucked His Own Ethics Policy](#)

by Megan Molteni, *Wired* | 11.27.2018

We said “don't freak out,” when scientists first used Crispr to edit DNA in non-viable human embryos. When they tried it in embryos that could theoretically produce babies, we said “don't panic.” Well, we might have been wrong. Permission to push the panic button granted.

► [The Chinese gene-editing experiment was an outrage. The scientific community shares blame.](#)

by J. Benjamin Hurlbut, Sheila Jasanoff and Krishanu Saha, *The Washington Post* | 11.29.2018

The seductive promise of engineering better genes for one's children — as if we were downloading wellness apps to a smartphone — denigrates that child and devalues the richness of humanity itself.

From the CGS Archive

► [Opening the Door to Genetically Engineered Future Generations: How the NAS Report Ignores Widespread International Agreement](#)

by Leah Lowthorp, *Biopolitical Times* | 2.22.2017

The report represented a radical departure from a long-standing international consensus that interventions in the human germline should remain off limits.

► [Reproductive genome editing and the U.S. National Academies Report: knocking on a closed door or throwing it wide open?](#)

by Leah Lowthorp & Marcy Darnovsky, *Bioethics Forum* | 09.2017

The report repeatedly raises but then dismisses serious concerns about the dubious nature of medical claims for the utility of germline gene editing, and the inadequacy of biomedical ethics frameworks for assessing its likely social consequences.

► [Genetically modifying future children isn't just wrong. It would harm all of us](#)

by Marcy Darnovsky, *The Guardian* | 07.17.2018

Sadly, the Nuffield Council on Bioethics has given its blessing to an unneeded and societally dangerous biotechnology, one that could be leveraged by privileged elites seeking purported genetic improvements to ensure that their children are treated as superior to the rest of us.

▶ [UK's Nuffield Council Releases Report on Human Genome Editing](#)

by Katie Hasson, *Biopolitical Times* | 08.02.2018

The report's implicit endorsement for human germline modification contradicts the longstanding international consensus that this should not be permitted, although it does seem in line with a recent drift towards greater acceptance of germline editing among some scientists and ethics professionals.

IN OTHER NEWS

- News TOP -

▶ [The DNA Industry's Role in the Erosion of Native Rights](#)

by Aviva Chomsky, *TruthDig* | 12.2.2018

Today's policy attacks on Native rights reproduce the same misunderstandings of race that the DNA industry is now so assiduously promoting.

▶ [Who can afford to get pregnant? IVF 'baby scholarships' raise a class issue](#)

by Anna Louie Sussman, *The Guardian* | 11.28.2018

Private foundations are now helping couples and individuals seeking fertility treatments in a country where IVF costs more than anywhere else on earth.

▶ [The 'Geno-Economists' Say DNA Can Predict Our Chances of Success](#)

by Jacob Ward, *The New York Times Magazine* | 11.16.2018

By measuring these social gaps, well-intentioned academics have in the past inadvertently pointed them out to those who want to exploit the gaps, or even make them wider.

▶ [Private IVF clinics urged to stop charging for expensive add-ons](#)

by Matthew Weaver, *The Guardian* | 11.12.2018

HFEA, the UK fertility authority, has published a draft consensus statement arguing that IVF clinics have been putting profits before patient care and that "there is currently no conclusive evidence that any of the add-ons offered in fertility treatment increase the chance of a pregnancy or live birth."

▶ [The promise and peril of gene drives](#)

Briefing, *The Economist* | 11.08.2018

If drives are engineered into species that play a pivotal but previously unappreciated ecological role, or if they spread from a species of little ecological consequence to a close relative that matters more, they could have damaging and perhaps irreversible effects on ecosystems.

DONATE NOW
SECURE DONATIONS
BY GROUNDSPRING.org