



CENTER FOR
GENETICS
AND SOCIETY

2019
ANNUAL
REPORT

The social justice case for the responsible
use of human biotechnologies

CENTER FOR GENETICS AND SOCIETY IN 2019

The Center for Genetics and Society (CGS) is a social justice organization working to ensure an equitable future in which human genetic and assisted reproductive technologies facilitate rather than undermine a just and sustainable future.

2019 was a year of both disturbing developments and glimmers of hope for advocates and scholars who monitor and challenge misuses of human biotechnologies. Working with our biopolitical network of colleagues and allies, CGS elevated and amplified voices grounded in social justice and human rights by using our media influence, leveraging our online presence, serving as a thought leader, and alerting and informing policy makers and the broader public.



Bill McKibben and John Powell discuss connections among the climate crisis, racial justice, and heritable genome editing.

PUBLIC ENGAGEMENT AND ADVOCACY

CGS-ORGANIZED EVENTS

Climate Crisis, Designer Babies, Our Common Future: A Conversation with Bill McKibben and John Powell

Inspired by Bill's recent *Falter: Has the Human Game Begun to Play Itself Out?* and by John's work on racial justice, [this event](#) was co-sponsored by CGS, Haas Institute for a Fair and Inclusive Society, and UC Berkeley School of Public Health. CGS Senior Fellow Osagie Obasogie moderated.

Engineering Future Generations? The New Debate about Societal Governance, Public Engagement, and Human Gene Editing for Reproduction
CGS organized this [workshop](#) of scholars and advocates from Europe, North America, and New Zealand, hosted at the Brocher Foundation near Geneva. The resulting [Geneva Statement on Heritable Genome Editing: The Need for Course Correction](#), was published in January 2020.

Fables and Futures

Award-winning author George Estreich [discussed](#) his new book, *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*, with disability rights scholar and activist Marsha Saxton. Co-hosted by CGS, Paul K. Longmore Institute on Disability, Health Equity Institute, and San Francisco Public Library.

Surrogacy360

In June, CGS relaunched this [unique resource](#) for those seeking news, recommendations, and other information on commercial surrogacy that is independent of industry influence. In July, CGS convened scholars and advocates for a day-long discussion on "Grappling with Surrogacy: Supporting LGBTQ Family Formation While Safeguarding the Rights and Health of Surrogates and Egg Providers."

Gene Editing, Ethics, Rights, and Health Equity

Katie Hasson and Marcy Darnovsky spoke at [this forum](#), co-organized by CGS and the Global Health and Rights Project at Harvard's Petrie-Floem Center.

Surge in Genetic Testing: Implications for Reproductive Health, Rights and Justice

A webinar in February featured Rosemarie Garland-Thomson, Katie Stoll, and Marsha Michie; co-sponsored by CGS and the Pro-Choice Alliance for Responsible Research.

PUBLIC ENGAGEMENT AND ADVOCACY

POLICY EDUCATION

US Congress

- CGS [brought public attention](#) to a [bipartisan Senate resolution on human gene editing](#) authored by Senator Dianne Feinstein.
- During the 2019 congressional budget process, [CGS alerted](#) policymakers and the public to a misguided effort to remove a provision that since 2016 has disallowed heritable genome editing.

New York State

CGS alerted legislative staff to a provision in a bill about surrogacy that would have implicitly authorized nuclear genome transfer (“3-person IVF”). The provision was changed to one that explicitly prohibits both that technique and heritable genome editing.

California

CGS, Equal Justice Society, and individual plaintiff Pete Shanks pursued a [lawsuit](#) arguing that the state must remove from its criminal database the DNA of hundreds of thousands of people who were never found guilty of the crimes of which they were suspected.



PUBLIC ENGAGEMENT AND ADVOCACY

SELECTED TALKS AND PRESENTATIONS

UC San Francisco Bioethics Group // February 19

Katie Hasson [spoke](#) on “The Dangers of Bracketing the Social in Ethical Considerations of Human Germline Editing” to an audience of scientists, bioethicists, and policy experts.

California Council for the Social Studies annual conference // March 15

Marcy Darnovsky, filmmaker Stephanie Welch (*A Dangerous Idea*), and educational consultant Milton Reynolds spoke about “[Reckoning with Race as a Technology](#).”

Film Screening: A Dangerous Idea // April 25

Marcy Darnovsky spoke about the history and persistence of eugenic ideas in the United States on a panel at the SF Delancey Street Theater following a screening of the documentary [A Dangerous Idea: Eugenics, Genetics and the American Dream](#).

Simons Institute for the Theory of Computing Conference // June 5

Marcy Darnovsky and Osagie Obasogie spoke on the panel “Policies, Politics, Publics” at the three-day workshop [Wrong at the Root: Racial Bias and The Tension Between Numbers and Words in Non-Internet Data](#).

Southeastern Association of Shared Resources annual conference // June 13

Marcy Darnovsky [keynoted](#) at the annual conference with “Human Gene Editing: What’s at Stake, Where Should We Draw the Lines?”

SIENNA workshop on the “Ethical, Legal, and Social Implications of Genomics” // June 15

Katie Hasson participated in this EU-funded workshop in Gothenburg, Sweden.

Black Women for Wellness conference // August 27

Emily Galpern spoke about “[Surrogacy: Bodies, Rights, and Reproductive Justice](#).”

Innovative Genomics Institute // October 26

Katie Hasson spoke on the panel “Bringing in the Public: Platforms and Pathways for Public Engagement and Debate,” part of the [CRISPR Consensus?](#) symposium.

Film Screening // October 29

[Any: What Does It Mean to Be Human?](#) Marcy Darnovsky spoke on a post-screening panel about this new “science + fiction” film.

American Society of Gene and Cell Therapy policy summit // November 6

Marcy Darnovsky spoke on [Ethical, Societal, and Policy Issues in Germline Gene Editing](#) in Washington, DC. Her talk was titled “Getting Serious about Social Implications.”



CENTER FOR
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MEDIA

BY THE NUMBERS

CGS is a leading source for media reports on human genetic and assisted reproductive technologies. In 2019, we were invited to comment on topics including heritable human genome editing, unethical practices in assisted reproduction, abuses of commercial and police DNA databases, and discredited but re-emerging ideas about “race” as a genetic rather than social category.

In the aftermath of the 2018 scandal about claims by a Chinese scientist that he had intentionally created gene-edited babies, numerous journalists explored its ethical, technical, and legal implications. This helped CGS in bringing social justice and human rights considerations to the forefront, and including perspectives rarely heard in the discussions about human biotechnologies. CGS writings were widely published, and CGS voices widely heard, across a range of traditional and social media outlets.

3,120

Facebook followers

52,000

Views on CGS' YouTube channel

8,900

Followers on Twitter

33,000

Monthly visitors to the
CGS website

80

Citations of CGS in print, online,
and broadcast media outlets

13

Op-eds and articles authored by
CGS staff and consultants

51

Commentaries at *Biopolitical
Times* by 14 CGS authors
and guest contributors

5,000

Newsletter subscribers

MEDIA

SELECTED MEDIA CITATIONS

CGS is a leading source for media outlets reporting on human biotechnologies. Among the outlets in which we appeared during 2019:

- Newspapers and news services: *Christian Science Monitor*, *Gay City News*, *New York Daily News*, *Los Angeles Times*, *Sacramento Bee*
- Television news, radio news, radio talk shows, podcasts: CBS Los Angeles, CNN International, NPR *All Things Considered*, NPR *Morning Edition*
- Scientific and popular science publications: *Discover*, *GM Watch*, *Health Law Journal*, *JAMA Pediatrics*, *OneZero*, *Science News*, *Scientific American*, *Smithsonian Magazine*, *STAT*
- Other magazines: *Counterpunch*, *Glamour*, *New York Review of Books*, *Salon*

ON HERITABLE GENOME EDITING

CNN International

“It’s important to recognize that even though a line has been crossed in an incredibly reckless way, that doesn’t mean we have to keep on crossing it. We can stop.”

National Public Radio

“This could open the door to a society of people who are considered to be genetic haves and genetic have-nots.”

Scientific American

Heritable gene editing is “not safe, it’s not needed and it’s way too dangerous from a social point of view.”



MEDIA

SELECTED MEDIA CITATIONS

ON ASSISTED REPRODUCTION

CBS Los Angeles

“This is a practice that’s growing up in the private sector, and there’s very little oversight of it, either by the state or by the federal government.”

Los Angeles Times

“It’s clear that money is the primary incentive. When anyone tries to recruit donors without payment, women won’t do it.”

ON DNA TESTING

Science News

“This kind of information is a little bit different than a phone number. People need to think about the ways making their genetic data public also makes their relatives’ DNA public.”

Christian Science Monitor

“When your personal information is monetized by private companies, it’s used for all kinds of things that you didn’t want. The effects can go beyond what you would imagine.”



MEDIA

CGS-AUTHORED ARTICLES



In 2019, CGS staff and consultants authored articles in publications focused on health and science, ethics, policy, and political news. In addition to those shown, others include: *Bill of Health*, *CQ Quarterly*, *Financial Times*, *GM Watch*, *Issues in Science and Technology*, *Journal of Assisted Reproduction and Genetics*, and *Southwestern Medical Perspectives*.

Scientists Disagree About the Ethics and Governance of Human Germline Editing

A small group of scientists is claiming authority over heritable genome editing – no matter that this technology could create new divides between genetic haves and have-nots.

Francoise Baylis and Marcy Darnovsky, *The Hastings Center Bioethics Forum* | 01.17.2019

Did a Permissive Scientific Culture Encourage the ‘CRISPR babies’ experiment?

Elite scientists are shaping a climate that may well have emboldened He Jiankui.

Donna Dickenson & Marcy Darnovsky, *Nature Biotechnology* | 3.15.2019

How Might we Approach Discussions on the Implications of Using Genetic Data from a Human Rights or Social Justice Perspective?

We have a significant historical record of the

use of genetics for human rights (as well as the specter of eugenics, of course).

Alicia Ely Yamin and Jonathan Chernoguz, *Bill of Health* | 05.20.2019

The wrong way to make policy about heritable genome modification

Why did a House Appropriations subcommittee remove a budget bill rider that prevents heritable genome editing?

Marcy Darnovsky, *The Hill* | 05.29.2019

A New Lens to International Commercial Surrogacy

Commercial bias and media over-simplification complicate decisions for families trying to weigh their options.

Emily Galpern, *Impact Ethics* | 06.05.2019

We Don’t Need More Reasons to Reject Heritable Genome Modification

No one alive today will ever truly know if using CRISPR technology in humans is safe.

Katie Hasson, *The Hill* | 06.10.2019

Scientists Can’t Be Trusted on Gene Editing

Scientific self-regulation is only as effective as the field’s ability to corral its strongest egos. In other words, it’s not.

Pete Shanks, *The Progressive* | 08.14.2019

MEDIA

BIOPOLITICAL TIMES

The CGS blog, *Biopolitical Times*, published 51 posts in 2019 on topics including human germline editing, stem cells, eugenics, DNA forensics, and new developments in assisted reproductive technologies.

SELECTED POSTS

Are CRISPR Babies Healthy? Enhanced? Speculation Takes a Disturbing Turn

Some scientists are speculating that the gene-edited twins born last year are fine—maybe even better than fine.

[Katie Hasson](#) | 03.08.2019

Three-Person IVF

From genetic disease to genetic design?

[Aysha Chatterjee, Guest Contributor](#) | 03.26.2019

Genetics and Privacy: Part 1, Part 2

DNA ancestry testing, criminal justice, genetic databases & privacy.

[Pete Shanks](#) | 04.04.2019

Shaq's New Ad Campaign

The dangerous push for race-specific medicine.

[Jonathan Kahn, Guest Contributor](#) | 04.26.2019

Talking Biopolitics: A Conversation with Tina Stevens and Stuart Newman

CGS spoke with the authors of *Biotech Juggernaut: Hope, Hype, and Hidden Agendas of Entrepreneurial BioScience*.

[Adrienne van der Valk](#) | 05.06.2019

Rigorous Pathway or Runaway Train?

The first meeting of the International Commission on the Clinical Use of Human Germline Genome Editing provided no clear signal about heritable genome editing.

[Katie Hasson](#) | 08.15.2019

It's Past Time to Compensate Survivors of Eugenic Sterilization

Each passing year, more people in California die who would be eligible for reparations.

[Emily Galpern](#) | 09.25.2019

We're a Disability Rights Organization, and We Oppose AB 922

Discussion of the California bill that expands the research market for women's eggs (which subsequently passed).

[Silvia Yee, Guest Contributor](#) | 10.04.2019

Why Has Abuse in the IVF Industry Gone Ignored?

Research reveals how unscrupulous clinics harm would-be parents.

[Pamela Mahoney Tsigdinos, Guest Contributor](#) | 10.15.2019

Another \$5.5 Billion for the California Stem Cell Agency?

Signatures are soon to be gathered for a new proposition on the November 2020 ballot.

[Pete Shanks](#) | 11.04.2019

Book Review: *Altered Inheritance—CRISPR and the Ethics of Human Genome Editing*

Françoise Baylis calls for decisions that are inclusive and consensual.

[Gina Maranto, Guest Contributor](#) | 11.15.2019

CRISPR Babies – One Year Later

We are at a tipping point with heritable genome editing and need to take decisive action—now.

[Katie Hasson & Adrienne van der Valk](#) | 12.02.2019

Polygenic Traits, Human Embryos, and Eugenic Dreams

A large genome-wide association study shows that attempts to predict the traits embryos may develop are much less likely to succeed than proponents claim.

[Pete Shanks](#) | 12.04.2019



CENTER FOR GENETICS AND SOCIETY

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FINANCIALS

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