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.
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.

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-Flom 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.
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.
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**
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.”
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
SELECTED MEDIA CITATIONS

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

- 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.”
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.”
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* | 03.15.2019

**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
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

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

Three-Person IVF
From genetic disease to genetic design?
Ayesha Chatterjee, Guest Contributor | 03.26.2019

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

Genetics and Privacy: Part 1, Part 2
DNA ancestry testing, criminal justice, genetic databases & privacy.
Pete Shanks | 04.04.2019

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

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

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

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

Shaq’s New Ad Campaign
The dangerous push for race-specific medicine.
Jonathan Kahn, Guest Contributor | 04.26.2019

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

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
STAFF
Marcy Darnovsky, PhD, Executive Director
Charles Garzón, MA, Director of Finance and Administration
Katie Hasson, PhD, Program Director on Genetic Justice
Adrienne van der Valk, Communications Director

KEY CONSULTANTS
Jonathan Chernoguz
Emily Galpern, MPH
Pete Shanks, MA

FELLOWS
Osagie Obasogie, JD, PhD (Senior Fellow)
Lisa Ikemoto, JD, LLM
Gina Maranto, MA
Brendan Parent, JD

INTERNS
Kayla Hinkson-Grant
Kathrin Martin
Shrey Saretha

ADVISORY BOARD
Francine Coeytaux, MPH (Chair)
Dorothy Roberts, JD
Alexandra Minna Stern, PhD

FINANCIALS
The Center for Genetics and Society operates as a 501(c)3 organization under the fiscal sponsorship of the Tides Center. CGS’s adjusted expenses for 2019 were $687,780. 2019 funding for CGS was provided by the Appleton Foundation, the Open Society Foundations, and individual donors. Complete financial reports are available on request.
STAY CONNECTED

Check out our website
The CGS website features commentary, events, resource pages, infographics, videos, and more.

Join us on social media
Follow us on Twitter @C_G_S and Facebook for up-to-the-minute news and commentary, and on YouTube for a variety of videos.

Receive in your inbox
Stay tuned to news developments and analysis by signing up for our twice-monthly newsletter Biopolitical News & Views.

Donate to a biopolitical future grounded in social justice.