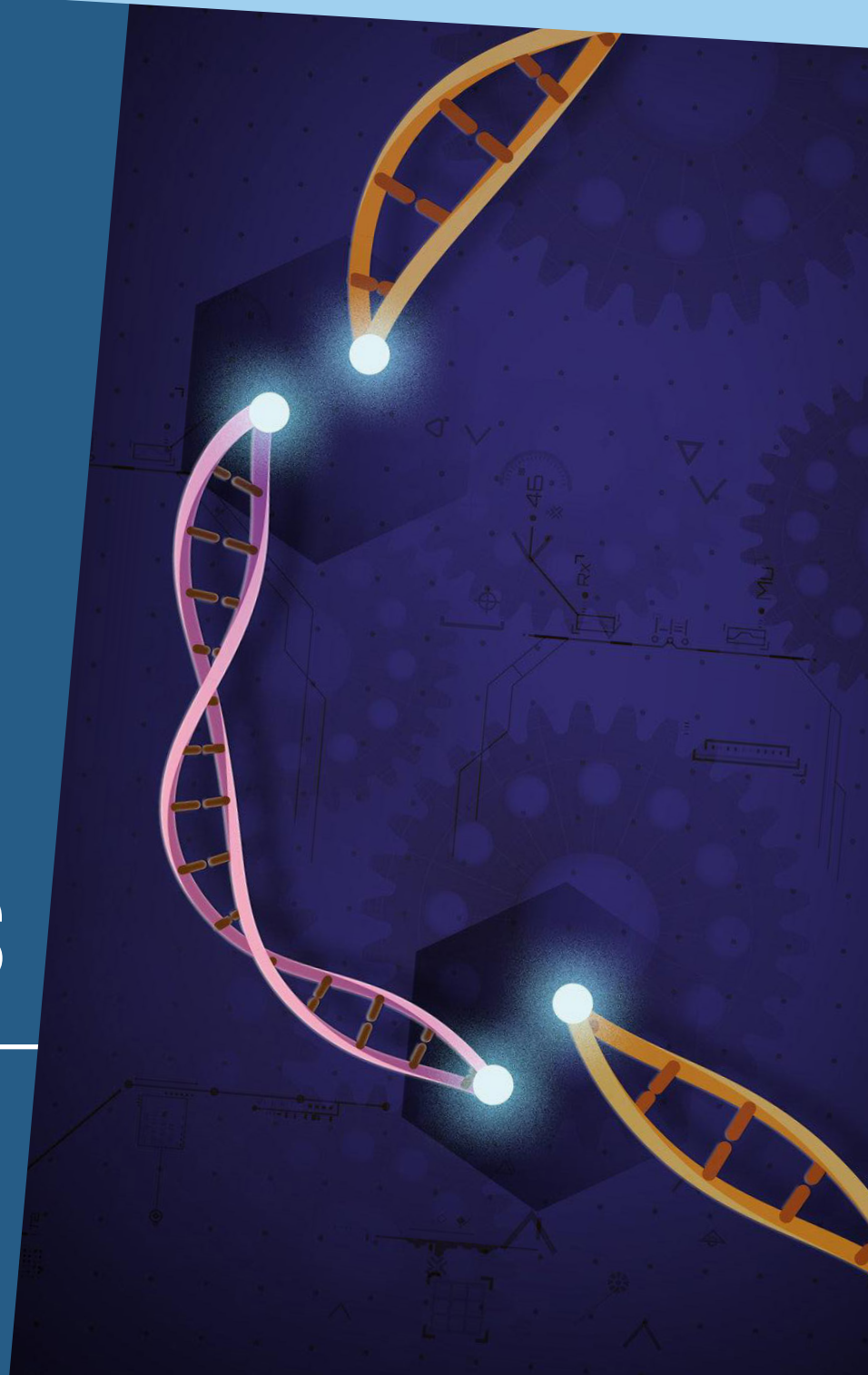


CENTER FOR
GENETICS
AND SOCIETY

2020-2021

REPORT ON ACTIVITIES

The social justice case for the responsible
use of human biotechnologies



CENTER FOR GENETICS AND SOCIETY IN 2020-2021

CGS is the only US non-profit organization committed to ensuring that social justice and human rights are at the center of ongoing debates about whether and how to use rapidly developing human biotechnologies.

The years 2020-2021 challenged, touched, and changed all of us at CGS. We learned to navigate pandemic conditions. We deepened our intersectional analysis of human genetics and assisted reproduction, learning from domestic and global racial justice uprisings. We gained traction in challenging resurgent eugenic beliefs and policies. Through it all, the CGS team worked to ensure a just, equitable, and sustainable future where human genetic and reproductive technologies benefit the common good.

HERITABLE GENOME EDITING

For more than two decades, the Center for Genetics and Society has sounded alarms about the grave social implications of heritable genome editing – altering the genes and traits of future children and generations. CGS collaborates with a network of scholars and advocates to make the case that heritable genome editing is unsafe and unneeded; would open the door to a new high-tech eugenics; and should remain off-limits, in keeping with established policies in more than 70 countries. In 2020-2021, we worked to bring social justice and human rights perspectives to the center of ongoing international debates and policy deliberations, challenging scientists’ and bioethicists’ narrow technical focus while emphasizing the need for broad public engagement.

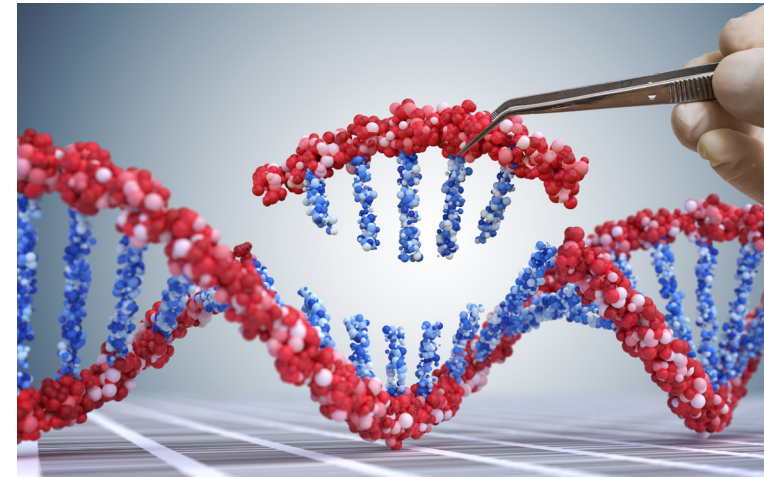
NEW INITIATIVES

Missing Voices Initiative: Centering Social Justice and Human Rights Voices

CGS created the [Missing Voices Initiative Working Group](#) in 2021 to amplify social justice and human rights perspectives in anticipation of the [Third International Summit on Human Gene Editing](#) (organized by the US and UK science academies; postponed from March 2022 to March 2023). The Working Group includes advocates and scholars in the fields of human rights, reproductive and disability rights and justice, racial and environmental justice, Indigenous sovereignty, and global health equity.

Generation Equality “Commitment Maker”

As a Commitment Maker with the [Generation Equality Forum](#), CGS launched a five-year plan to [lead a coalition](#) of international organizational and academic leaders to bring gender, reproductive, racial, disability, and LGBTQ justice to the forefront of debates about human biotechnologies. The coalition will develop principles and tools to ensure the inclusion of feminist and other civil society voices for gender equality in public discussions and regulatory deliberations on heritable human genome editing, and create model policies to prevent harms to women and girls stemming from attempts to alter the genes of future generations.



HERITABLE GENOME EDITING

EVENTS AND PRESENTATIONS

TEDx Talk: “Use Gene Editing to Treat Patients, Not Design Babies”

CGS Executive Director Marcy Darnovsky [spoke](#) to an audience of 600 in Santa Barbara, California at TEDxLagunaBlanca.

Doha Debates: “Future of Genetics—Should We Create Superhumans?”

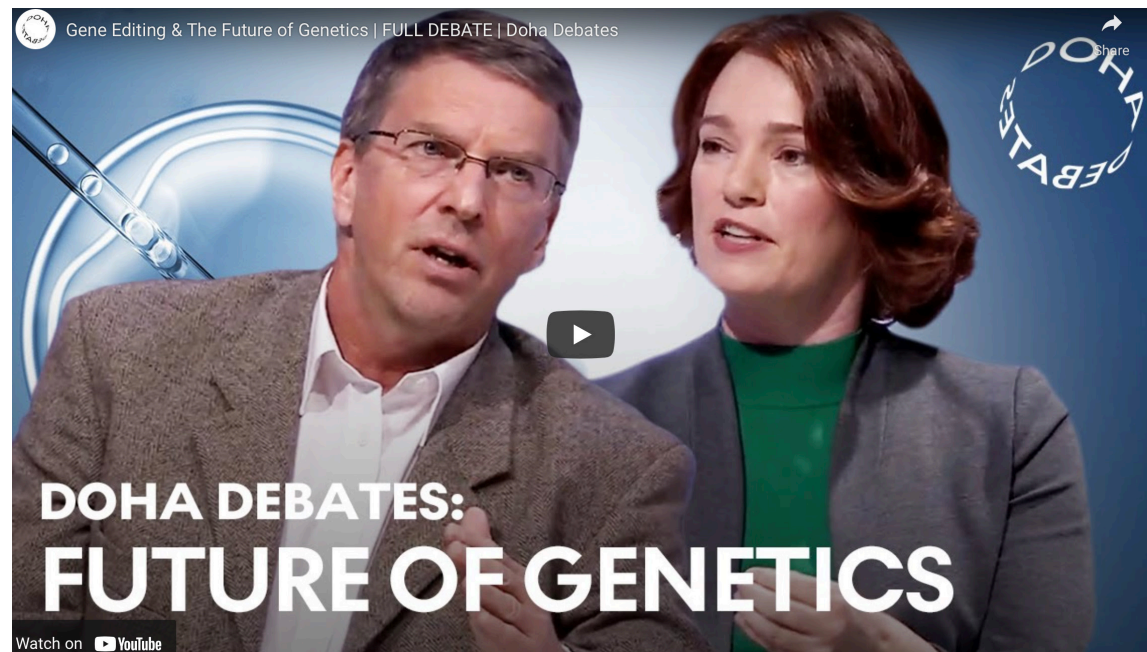
CGS Associate Director Katie Hasson [debated](#) Julian Savulescu and Jamie Metzl in Doha, Qatar, winning the debate and drawing 4.9 million Twitter viewers.

Webinar: “Climate Crisis, Designer Babies and Pandemics: Challenging the Techno-Utopianism of the Genetically Engineered Age”

This [webinar](#) featuring Bill McKibben, Marsha Darling, and Stuart Newman was co-sponsored by CGS, [Friends of the Earth](#), and [Alliance for Humane Biotechnology](#) and hosted by Organic Consumers Association.

Democratic Imaginations at the Frontiers of Science and Technology

Marcy joined co-panels to [discuss](#) democracy, technology, and the human future at this event hosted in April by the [Global Observatory for Genome Editing](#).



GM ‘Designer Babies’: Breakthrough or Nightmare?

At this online [event](#) hosted by the UK organization [Stop Designer Babies](#), Marcy spoke about what’s left out and what’s distorted in the “official” debate about heritable genome editing.

Should We Genetically Modify Our Children?

Katie and Marcy gave (virtual) classroom presentations at schools across the country, including American University, Case Western Reserve University, Castilleja High School, Columbia University School of Public Health, Georgia Institute of Technology, Pasadena City College, and Santa Clara University.

HERITABLE GENOME EDITING

PUBLICATIONS AND STATEMENTS

The Global Policy Landscape

This groundbreaking study documented the widespread global agreement to prohibit heritable genome editing – a key point previously under-recognized in ongoing debates. [Human Germline and Heritable Genome Editing: The Global Policy Landscape](#) was co-authored by Marcy Darnovsky, Katie Hasson, and Canadian scholars Françoise Baylis and Timothy Krahn

Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction

The [Geneva Statement](#) calls for meaningful democratic deliberation about altering the genes of future generations grew out of a CGS-organized workshop held at the [Brocher Foundation](#), which also supported its open-access status in *Trends in Biotechnology*. Its 21 co-authors include CGS' Katie Hasson, Marcy Darnovsky, and Osagie Obasogie.

CRISPR's Twisted Tales: Clarifying Misconceptions about Heritable Genome Editing

Marcy Darnovsky and Katie Hasson [explore](#) significant shortcomings in debates about heritable genome editing in a special issue of *Perspectives in Biology and Medicine*, which received the [2020 Best Public Intellectual Special Issue](#) award from the Council of Editors of Learned Journals.

Genetic Justice: Identity and Equality in the Biotech Age

In the journal *Development*, Katie Hasson and Marcy Darnovsky [argue](#) that genetic ancestry testing may pave the way for accepting heritable genome editing.

Memo for the incoming US presidential administration

CGS wrote and circulated [Heritable Human Genome Editing: Political Implications and Opportunities for Leadership](#), a memo for the Biden-Harris Administration that details the societal implications of heritable genome editing and the urgent need for prohibitions and global cooperation in governing this technology.

Responses to reports from World Health Organization and US / UK science academies

CGS released a [press statement](#) on a 2020 report on heritable genome editing by the US National Academy of Sciences and UK Royal Society, and [another](#) on the World Health Organization's 2021 reports. Media outlets citing CGS' reactions included [The Guardian](#), [Science News](#), [STAT](#), and [BioNews](#).



International policy

CGS contributed to international policy conversations through comments on the UK Parliamentary Office of Science and Technology's [Human germline genome editing](#); interviews for the UN Conference on Trade and Development's [Potential impacts of technologies on social inequalities and sustainable development](#); and a talk and written comments to the World Health Organization about their [Recommendations](#).

ASSISTED REPRODUCTION

CGS' work on assisted reproduction highlights inequities and power imbalances, profit motives, and health risks that receive little attention despite their high stakes for surrogates, egg providers, intended parents, and children. We highlight the prospect that reproductive genome editing – if allowed to proceed – will roll out in the notoriously under-regulated fertility industry. We bring these social justice concerns to advocates for reproductive health, rights, and justice advocates; and their voices and perspectives to policy and public deliberations.

REPRODUCTIVE RIGHTS AND JUSTICE

The **Assisted Reproductive Technologies Working Group**, co-hosted by CGS and sister organization [Pro-Choice Alliance for Responsible Research](#), is an invitational community of advocates and scholars who assess developments in assisted reproduction, share resources, and promote public policies consistent with social and reproductive justice. Established in 2013, the Working Group now includes 130 members from 12 countries who contribute to a members-only website, listserv, and webinars. In 2021, we launched monthly “Coffee Hours” where members engage with challenging topics related to reproductive and genetic technologies.

CGS works with a range of organizations focused on reproductive rights and justice.

- In partnership with [Black Women for Wellness](#), CGS produced a [fact sheet](#) and [infographic](#)

articulating a reproductive justice perspective against heritable genome editing.

- We co-authored “Assisted Reproductive Technologies, Gene Editing, and Reproductive Justice” in the new edition of the [Reproductive Justice Briefing Book](#).
- CGS consultant Emily Galpern spoke at the [2020 Advocacy and Research Forum](#) organized by [Men Having Babies](#), and on “Ethics of Surrogacy from a Reproductive Justice Perspective” at a [2021 conference](#) organized by the [Society for Ethics in Egg Donation and Surrogacy](#).
- In collaboration with reproductive and LGBTQ rights organizations, we educated legislators about health and rights concerns related to a New York state surrogacy bill.

A REPRODUCTIVE JUSTICE PERSPECTIVE THE CASE AGAINST GERMLINE MODIFICATION

GERMLINE MODIFICATION IS EXTREMELY CONTROVERSIAL



Puts women and people who would carry modified fetuses at risk

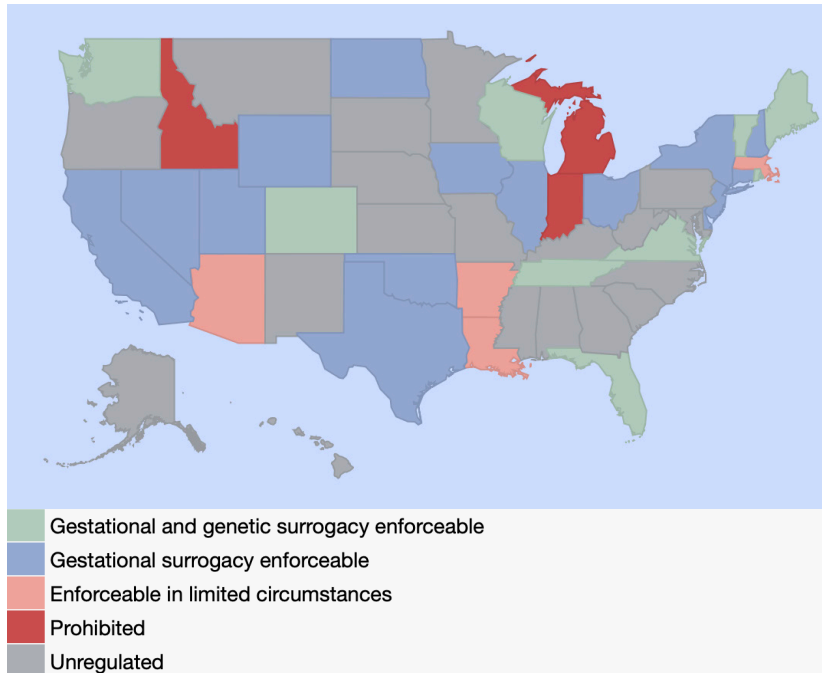


Poses harm to the resulting children and future generations



Has the potential to increase social inequality and usher in a new eugenics

ASSISTED REPRODUCTION



SURROGACY360

CGS continued to enrich, refine, and update our [Surrogacy360](#) website, a comprehensive and non-commercial resource about the complexities of cross-border surrogacy.

- We formed an [International Advisory Committee](#) and confirmed five new global collaborators: [We Are Egg Donors](#), [National Center for Lesbian Rights](#), [Grupo de Información en Reproducción Elegida/Information Group on Reproductive Choice-GIRE](#) (Mexico), and [National Alliance of Women Human Rights Defenders and Tarangini Foundation](#) (Nepal).
- We partnered with the National Center for Lesbian Rights to [update our US policy map](#), the most detailed and accurate representation of US surrogacy policy available online.
- With We Are Egg Donors, we curated [Video Stories: What Egg Donors Want Intended Parents to Know](#) to amplify egg providers' perspectives and offer advice to intended parents.
- Our [COVID-19 Advisory on International Surrogacy Arrangements](#) addressed the crisis of babies stranded by the pandemic, explored further in two blog posts ([1](#), [2](#)). Emily Galpern was featured in [Fertility Industry Growth Expected Despite COVID-19 Headwinds](#) in *Newsy*.
- In response to the nationwide uprisings after the murder of George Floyd, we wrote and promoted the statement [Racial Justice and International Surrogacy](#).

EUGENICS

CGS has always worked to highlight the relevance of eugenics, scientific racism, and disability discrimination in assessing the social implications of human biotechnologies. In 2020 and 2021, we sharpened this focus in response to the disturbing resurgence of eugenic ideas and practices, including pandemic-related protocols, reports of involuntary sterilization in ICE detention centers, Donald Trump's repeated claims that genes explain success, and other manifestations of white supremacy and anti-Semitism in the US and elsewhere. Fortunately, these developments were met with significant resistance. In collaboration with other civil society and social justice organizations and academics, CGS responded with a firm commitment to valuing the lives of all people, including in considerations about human biotechnologies.

EVENTS AND PRESENTATIONS

A Dangerous Idea: Eugenics in America

Following a screening of this [award-winning documentary](#), CGS' Marcy Darnovsky and Osagie Obasogie, with filmmaker Stephanie Welch, discussed eugenic legacies in genetics and US history. The virtual [event](#) was hosted by the San Francisco Asian Art Museum and moderated by CGS colleague Milton Reynolds.

California Eugenics Legacies symposium

This [virtual symposium](#) at UC Santa Barbara featured experts including CGS Executive Director Marcy Darnovsky, Senior Fellow Osagie Obasogie, Advisory Board member Alexandra Minna Stern, and colleague Milton Reynolds.

Dismantling Eugenics convening

The week-long [virtual convening](#) featured thought leaders, activists, artists, scholars, and philanthropists in more than 100 short presentations, conversations, and artistic interventions. Marcy Darnovsky moderated a panel titled "How We Reckon" that focused on recent policy and organizing efforts to counter eugenics.



Top to bottom, Osagie Obasogie, Milton Reynolds, Marcy Darnovsky

EUGENICS

PUBLICATIONS AND POSTS

Disability Rights, Triage and Countering Eugenics in a Time of Pandemic

Reactions to the COVID-19 pandemic demonstrate that activism can help counter eugenic thinking, and the importance of the disability rights community to this effort.

[Pete Shanks, *Biopolitical Times* | 04.18.2020](#)

Police Killing Black People is a Pandemic, Too

In the US, an underlying eugenic ideology lets disease and violence thin the herds of undesirable groups.

[Osagie Obasogie, *Washington Post* | 06.05.2020](#)

California Must Act Now to Redress Another Form of State Violence

The bill would compensate survivors of both California's eugenic sterilization law, on the books from 1909 to 1979, and involuntary sterilizations in women's prisons after 1979.

[Emily Galpern, *Biopolitical Times* | 06.13.2020](#)

Reckoning (or Not) with Racism and Eugenics in Genetics

Direct-to-consumer gene testing giants released solidarity statements last week – but failed to reflect on the centrality of genetics to scientific racism and eugenics.

[Katie Hasson, *Biopolitical Times* | 06.18.2020](#)

Forced sterilization policies in the US targeted minorities and those with disabilities – and lasted into the 21st century

All forced sterilization campaigns dehumanize a subset of the population deemed less worthy of reproduction, merging perceptions of disability with racism, xenophobia, and sexism.

[Alexandra Minna Stern, guest contributor, *Biopolitical Times* | 09.09.2020](#)

Trump's "Racehorse Theory" and Why it Matters

When Trump talks about his own good genes, he is encouraging his followers to see certain others as having bad genes, or perhaps as "polluting" our body politic.

[Jonathan Kahn, Marcy Darnovsky, and Jonathan Marks, *Biopolitical Times* | 10.05.2020](#)

ICE Sterilizations Should Be a Wake-Up Call to California and its Governor

Governor Newsom now has the opportunity to confront the state's shameful legacy once and for all.

[Emily Galpern, Alexandra Minna Stern, Laura Jiménez, Carly A. Myers, and Diana Block, *Biopolitical Times* | 10.26.2020](#)

Victory for Reproductive Justice in California: New Budget Includes Reparations for Survivors of Eugenic Sterilization

The effort to secure reparations was spearheaded by California Latinas for Reproductive Justice, Disability Rights Education and Defense Fund, and California Coalition for Women Prisoners, and was actively supported by many allies, including CGS' biopolitical network.

[Emily Galpern, *Biopolitical Times* | 07.13.2021](#)

MEDIA

CGS was cited in approximately 76 news articles during 2020-2021, on topics including heritable genome editing, direct-to-consumer DNA testing, the use of DNA databases in immigration policy and criminal investigations, the California ballot initiative on renewed funding for the state stem cell agency, rules on human embryo research, the fertility industry and surrogacy, and companies offering to rate IVF embryos. Among the media outlets in which CGS appeared are:

DAILY AND WEEKLY NEWSPAPERS

Associated Press, Capitol Weekly, Des Moines Register, The Guardian, Gulf Times, Los Angeles Times, Neue Zürcher Zeitung, San Diego Reader, San Francisco Business Times, USA Today, Wall Street Journal

SCIENCE MEDIA

BioEdge, BioNews, California Healthline, Health Day, OneZero - Medium, Science News, Smithsonian Magazine, STAT, Wired

RADIO

ABC News Channel 3, CapRadio, KALW, NBC Bay Area, NPR News

OTHER

Al Jazeera, ABA Journal, Bloomberg Government, Forbes, Newsy, n+1 Magazine, San Francisco Bay Guardian

ON HERITABLE GENOME EDITING

- *The Guardian*: Genome editing for heritable diseases not yet safe, report states
- *Science News*: Strict new guidelines lay out a path to heritable human gene editing
- *Wall Street Journal*: Crispr Gene Editing Can Lead to Big Mistakes in Human Embryos
- *Forbes*: Study: There Is No Country Where Heritable Human Genome Editing Is Permitted
- *STAT*: World Health Organization advisers urge global effort to regulate genome editing
- *Al Jazeera*: What is the future of CRISPR gene editing?

ON EMBRYO RANKING AND RESEARCH

- *The Guardian*: Polygenic screening of embryos is here, but is it ethical?
- *Associated Press*: Change may allow scientists to grow human embryos longer
- *USA Today*: Should scientists be allowed to grow human embryos in a dish beyond 14 days? Is it scientifically important or morally wrong?

ON DNA TESTING

- *Los Angeles Times*: Layoffs result as consumers think twice about DNA testing



- *Wired*: Your 'Ethnicity Estimate' Doesn't Mean What You Think It Does
- *OneZero - Medium*: The U.S. Government's Mass Collection of Immigrant DNA Hints at Surveillance Future

ON EUGENICS

Los Angeles Times: UC Berkeley is disavowing its eugenic research fund after bioethicist and other faculty call it out

CGS-AUTHORED ARTICLES

Heritable Human Genome Editing Is Not Inevitable

Before we start trying to set standards for how and when scientists may genetically engineer future children, we must ask whether they should do it at all.

Donna Dickenson, Katie Hasson, and Marcy Darnovsky, *Project Syndicate* | 03.17.2020

Forum: Risks and rewards of gene editing

Jennifer Doudna fails to mention the broader social justice alarms about heritable genome editing.

Marcy Darnovsky, *Issues in Science and Technology* | 07.31.2020

Are we mapping a path to CRISPR babies?

A new report minimizes the complex social realities in which technological developments unfold.

Katie Hasson and Marcy Darnovsky, *The Hill* | 09.13.2020

Billions more of public money for stem cell research?

Proposition 14 commits California to spending \$5 billion that we don't have, on a bureaucracy we don't need, in pursuit of cures no one can guarantee.

Pete Shanks, *Capitol Weekly* | 10.26.2020

Heritable Human Genome Editing? It May Never Be Safe

Safety is far from the only concern about heritable genome editing, but recent scientific findings confirm that the question of whether it will ever be safe is far from settled.

Katie Hasson, *Impact Ethics* | 12.04.2020

Hype over Cloned Ferret Rings Hollow

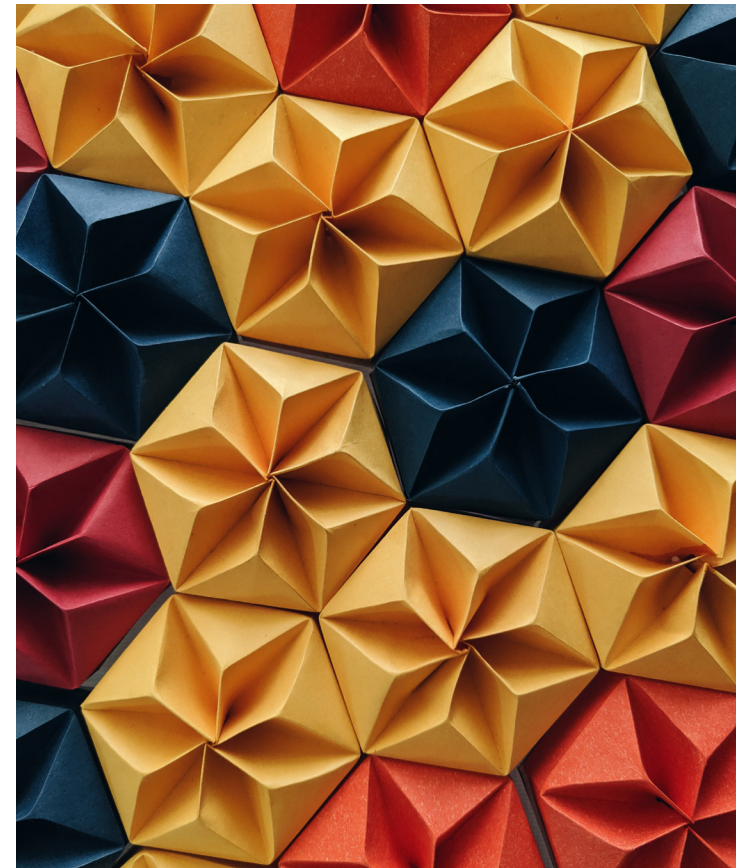
Grand claims for animal cloning go back to the birth of the first cloned sheep. Many believe that "de-extinction" efforts are counterproductive.

Pete Shanks, *GM Watch* | 02.26.2021

Ethics of Surrogacy During COVID-19 Pandemic

It is imperative that intended parents contemplating surrogacy during the pandemic consider how to do so ethically, given heightened health risks and the impacts of COVID precautions.

Cathy Sakimura and Emily Galpern, *Men Having Babies* blog | 05.12.2021



BIOPOLITICAL TIMES

The CGS blog, *Biopolitical Times*, published 97 posts in 2020-2021 on topics including human genome editing, eugenics, DNA forensics, direct-to-consumer genetic testing, assisted reproduction and surrogacy, and the pandemic.

SELECTED POSTS

Reactions to Jail Sentences for “CRISPR Babies” Scientists, and What Comes Next

Commenters from across the spectrum weighed in immediately after the news broke.

[Pete Shanks | 01.09.2020](#)

A Tipping Point for DNA Tests and Surveillance Technologies?

23andMe is laying off 100 of its 700 staff as concerns grow about privacy, corporate control, and the need for regulation of genetic technologies.

[Pete Shanks | 01.28.2020](#)

Gene-Edited ‘Haves’ and ‘Have-nots’ at Davos

The *Global Risks Report*, prepared for this year’s World Economic Forum at Davos, adds elite recognition to the alarms that have been sounding about human heritable genome editing.

[Pete Shanks | 02.10.2020](#)

The Scandal-Plagued Company Behind Stranded Surrogacy Babies is Also Promoting a Controversial IVF Technique

A clinic in Ukraine exemplifies many longstanding concerns about the international fertility industry and cross-border surrogacy.

[Katie Hasson | 06.5.2020](#)

“Disastrous” Embryo Editing Results Deliver “Restraining Order” for Heritable Genome Editing

Researchers find disturbing results for anyone intent on pursuing heritable human genome editing.

[Katie Hasson | 06.18.2020](#)

Book Review: *Let There Be Life: An Intimate Portrait of Robert Edwards and His IVF Revolution*

This self-published portrait of Robert Edwards — IVF pioneer, Nobel prize-winner, and eugenicist — is an unfortunate hagiography.

[Gina Maranto, guest contributor | 07.20.2020](#)

Private Equity Mega-Firm Founded by Trump Buddy Buys World’s Largest DNA Database

Why is a private equity firm with ties to Donald Trump paying \$4.7 billion for Ancestry, the consumer genetic testing company with more than 18 million people’s DNA?

[Katie Hasson | 08.13.2020](#)

Surrogacy: New Challenges to Law and Ethics

A special issue of *The New Bioethics* explores the political and social pressures giving rise to new surrogacy-related legal initiatives and controversies around the world.

[Donna Dickenson, guest contributor | 12.08.2020](#)

Dropping Limits, Pushing Envelopes: Stem cell research organization wants fewer rules

Recommendations by scientists to roll back limits on research run counter to laws or regulations in numerous countries and erase widely observed boundaries.

[Marcy Darnovsky and Katie Hasson | 05.28.2021](#)

Planning to Profit from Designer Babies. Now.

Two prominent groups of scientists at US universities are trying to patent methods for editing human embryos, with reproductive use clearly intended.

[Pete Shanks | 05.25.2021](#)

The First Polygenic Risk Score Baby

Her parents, at least one of whom is a transhumanist, chose from among IVF embryos scored by Genomic Prediction on their risk of developing heart disease, diabetes, and cancer as an adult.

[Pete Shanks | 09.30.2021](#)

Translating Genes into Health® — Or Dollars?

The new carrier screening guidelines are riddled with problems, including potential conflicts of interest.

[Pete Shanks and Emily Galpern | 10.15.2021](#)

Will Biden’s FDA Chief be Tied to Biotech and Big Pharma?

President Biden has not yet nominated a permanent FDA head. Several candidates have close ties to the pharmaceutical and biotechnology industries.

[Marcy Darnovsky | 10.14.2021](#)



CENTER FOR GENETICS AND SOCIETY

WHO WE ARE

FULL-TIME STAFF

Marcy Darnovsky, PhD, *Executive Director*

Katie Hasson, PhD, *Associate Director*¹

Adrienne van der Valk, *Communications
Director*²

Charles Garzón, MA, *Director of Finance and
Administration*³

KEY CONSULTANTS

Jonathan Chernoguz⁴

Emily Galpern, MPH

Pete Shanks, MA

PART-TIME TEMPORARY STAFF

Quinn Brashares⁵

Anna Fang⁶

Connor McAlister⁷

1. Program Director on Genetic Justice 2020

2. through March 2020

3. through April 2020

4. through July 2021

5. March 2020-February 2021

6. beginning February 2021

7. beginning June 2021

FELLOWS

Osagie Obasogie, JD, PhD (*Senior Fellow*)

Lisa Ikemoto, JD, LL.M

Gina Maranto, MA

Brendan Parent, JD

ADVISORY BOARD

Francine Coeytaux, MPH (*Chair*)

Dorothy Roberts, JD

Alexandra Minna Stern, PhD

FINANCIALS

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CENTER FOR GENETICS AND SOCIETY

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+1 (510) 665.7760

2900 Lakeshore Avenue
Oakland, CA 94610 USA

cgs@geneticsandsociety.org