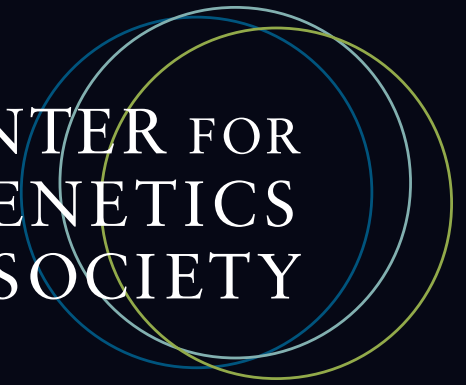


2017 ANNUAL REPORT



CENTER FOR
GENETICS
AND SOCIETY



The social justice case for the responsible use of human biotechnologies

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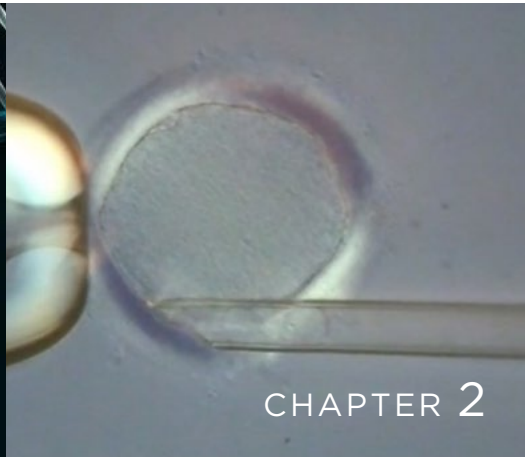


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1 | Introduction

*Explaining the social justice case
for responsible uses of human biotechnologies*

Letter from the Executive Director and Advisory Board Chair

THE CENTER FOR GENETICS AND SOCIETY HAS WORKED SINCE OUR founding in 2001 toward a world in which human biotechnologies promote social justice, the public interest, and the common good.

In recent years we've confronted the troubling prospect that powerful new gene editing tools could be misused in efforts to alter the traits of future children and generations. Notwithstanding the hoped-for benefits of other applications of gene editing, the risks of its use in human reproduction are widely recognized.

Given the history of eugenics in the US and around the world, reproductive gene editing could all too easily usher in a world of genetic “haves” and “have nots,” in which inequity and discrimination are intensified. In 2017, this prospect coincided with a revival of the discredited idea that race is a biological rather than a social category, and that racial differences in intelligence are based in genetics.

In other words, both technological and political events have heightened the urgency of the challenges we face. Yet they remain under the radar for most policy makers and public interest organizations, and for much of the public. Our work therefore aims to highlight the under-represented perspectives and voices that emphasize the social meanings and implications of human biotech developments.

To accomplish this, CGS collaborates with a growing network of advocates working on reproductive health, rights, and justice; racial justice; disability rights; environmentalism, and human rights. We also work with scholars across a range of disciplines, scientists, health professionals, legal experts, and policy analysts. We are widely recognized as a thought leader and a key voice in the media and in public settings. Highlights of our work in 2017 include:

Foregrounding the social justice implications of human biotech in the media and online. We were cited well over 100 times in media outlets from more than a dozen countries, and authored dozens of articles, op-eds, and commentaries.

Bringing together civil society advocates and engaged scholars. We partnered with disability and reproductive justice organizations on webinars on human gene editing and assisted reproductive technologies and practices.

Building public and policy-maker understanding of developments in human biotechnologies. We organized public events; spoke at international, national, and local meetings; and participated in policy processes in the US, Canada, the UK, and elsewhere.

As the development and marketing of powerful human biotechnologies proceed, the Center for Genetics and Society will continue informing the escalating controversies they engender with a unique, respected, and urgently needed perspective—one grounded in the values of social justice, human rights, the public interest, and democratic governance. There is no other organization like us in the United States. We invite you to join and support us as we carry this important work forward.



Marcy Darnovsky

Marcy Darnovsky
Executive Director



Francine Coeytaux

Francine Coeytaux,
Advisory Board Chair

The Center for Genetics and Society is a nonprofit organization working to encourage responsible uses and effective governance of human genetic and assisted reproductive technologies.

Encourage responsible uses of human genetic and reproductive technologies;

Promote effective societal governance of these technologies;

Collaborate with a growing network of scientists, health professionals, civil society leaders, and others;

Support equal access to benign and beneficial medical applications of these technologies both domestically and internationally;

Advocate for women's health and reproductive rights, for racial justice, for the rights of people with disabilities, and for the protection of our children;

Urge precaution in the use of technologies that could alter the fundamental processes of the natural world,
and

Oppose any applications that objectify and commodify human life and threaten to divide human society, such as inheritable genetic modification.

2 | In the Media/Online: Reclaiming Human Biotechnologies for the Common Good

“Once you approve any form of human germline modification you really open the door to all forms.”

—MARCY DARNOVSKY

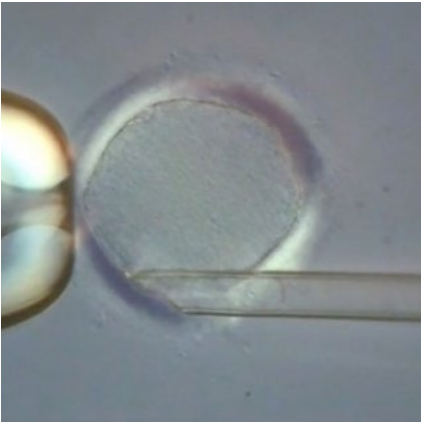
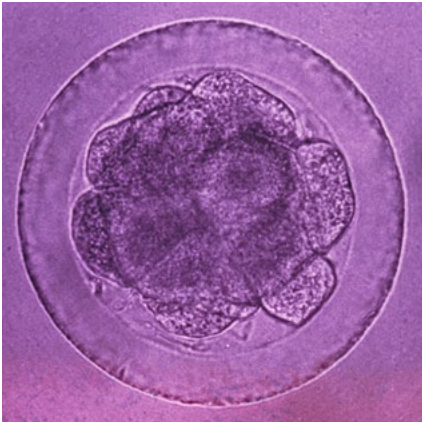
Media Citations

For more than a decade, CGS has consistently been a “go-to” source for media outlets around the world. In 2017 alone, we were cited well over 100 times in print, online, and broadcast media outlets in more than a dozen countries worldwide—an outsized media footprint far beyond other civil society organizations working on human biotech issues. Our comments appear in high-profile daily newspapers, news magazines, scientific and popular science publications, and on radio news and talk programs.

Our work with reporters, editors, and producers is an opportunity to foreground the social justice implications of human genetic and assisted reproductive technologies. In 2017, our comments were sought on topics including human germline modification, human gene editing, the history and legacy of eugenics, in vitro fertilization, and egg freezing.



Media Citations *continued*



[Scientific Panel Says Editing Heritable Human Genes Could Be OK In The Future](#)

Rob Stein,
NPR, February 14

“These kinds of scenarios used to be seen as far-off hypotheticals. “ But actually, right now, I think they’re urgent social justice questions.”

The New York Times

[Human Gene Editing Receives Science Panel’s Support](#)

Amy Harmon,
New York Times, February 14

“This opens the door to ads from fertility clinics about giving your child the best start in life with a gene-editing packet. Whether these are real advantages or perceived advantages, they would accrue disproportionately to people who are already advantaged.”

MIT Technology Review

[The Fertility Doctor Trying to Commercialize 3-Parent Babies](#)

Emily Mullin,
MIT Technology Review, June 13

“This is a biologically extreme and risky procedure. If you’re talking about using these techniques for age-related infertility, that’s really moving the human experimentation to a very large scale.”

Selected media outlets citing CGS in 2017

High-profile daily newspapers

- New York Times,*
- Washington Post,*
- New York Post, The Guardian,*
- Los Angeles Times,*
- Boston Globe, Deutsche Welle,*
- San Diego Union Tribune*

Magazines and news services

- Time, Newsweek,*
- New York Magazine,*
- Forward, Mother Jones,*
- LA Review of Books,*
- Buzzfeed, Glamour, Forbes,*
- Agence France Presse,*
- Smithsonian, Foreign Affairs,*
- Reuters*

Scientific and popular science publications

- Science, Nature, Gizmodo,*
- The Verge, Scientific American,*
- Ars Technica, STAT, The Scientist,*
- Seeker, MIT Technology Review,*
- Medscape, Healthline, Wired,*
- Nature Biotechnology, Smithsonian*

Radio

- NPR On Point, NPR All Things Considered, NPR Morning Edition,
- BBC The Enquiry, KPCC Air Talk

Media Citations *continued*



[Gene-edited embryo study: A 'milestone' — or a route toward 'genetic upgrades'?](#)

Mark Hallam,
Deutsche Welle, August 2

“There is no pretense to basic scientific discovery here. The goal is clearly to develop applications that could be marketed in fertility clinics.”

[Can 23andMe tell us if Jews are a race — And is that a good thing?](#)

Ari Feldman,
Forward, July 30

“It’s really important for all of us to resist the attempt to revive this discredited notion that race is a biological category rather than a political and social category.”

[Egg Freezing for Millennials: The Latest Start-up Trend](#)

Angelina Chapin,
New York Magazine, February 28

These companies “are selling you this carefree imagery and the idea that [egg freezing] is a piece of cake.”

[Fertility Futility: Procedures Claimed to Boost IVF Successes Lack Supporting Evidence](#)

Sandy Ong,
Newsweek, January 12

The CDC doesn’t collect information on whether babies were born healthy or if their mothers suffered from the long-term effects of egg harvesting — data that experts say is much-needed. “There’s not much of an appetite” for more regulation.

5 Reasons



REASONS TO SAY NO TO GENETICALLY MODIFIED HUMANS

REINFORCING INEQUALITIES

The social and commercial dynamics in which human germline modification would necessarily develop could easily exacerbate global disparities and take structural inequality to a new (molecular) level. Let's not open the door to an era of high-tech eugenics.



PROFOUND RISKS TO FUTURE CHILDREN

Altering the genomes of our offspring before they're born—alterations they would pass to their own children—means irreversibly changing the DNA of their bodies forever. We must preserve the human right to bodily integrity and an open future.



ERODING PUBLIC TRUST

Researchers working to develop gene therapies rightly worry that attempts to change the genetic inheritance of our species will provoke backlash. We can and should encourage beneficial applications of genetic technologies, and condemn pernicious ones.



THIN MEDICAL JUSTIFICATION

We already have methods to prevent transmission of inherited diseases without manipulating genes. Even with the latest gene editing tools, "off-target" and unintended effects are unsolved problems.

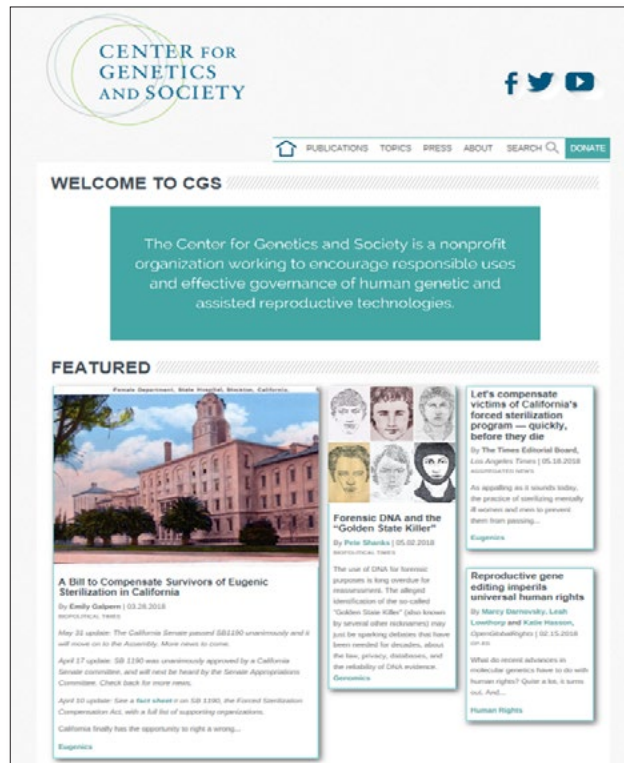
UNDERMINING GLOBAL AGREEMENTS

Our shared humanity is the starting point for every struggle for equality. Germline gene editing is prohibited by international human rights treaties and more than forty countries.



Our New Website

The Center for Genetics and Society’s website, completely redesigned and relaunched in 2017, offers a rich trove of up-to-date information and commentary on developments in human biotechnology worldwide. It features both CGS-produced content and links to hundreds of carefully selected articles, spanning more than a decade of monitoring the social implications of human biotechnologies.



Selections from *Biopolitical Times*

Our blog, *Biopolitical Times*, provides fresh and incisive commentary penned by CGS staff, fellows, consultants, and guest contributors. We circulate our social justice-based perspective on human biotechnologies via Twitter, YouTube, Facebook, and our monthly newsletter, *Biopolitical Views & News*.

[7 Questionable Claims in Reporting on Gene Editing Human Embryos](#)

– **Katie Hasson**

It’s worth taking a moment to evaluate oft-repeated questionable claims made by journalists when reporting on the latest gene editing “breakthrough.”

[Whatever Happened to #CRISPRfacts?](#)

– **Leah Lowthorp**

Using humor and a hashtag to put CRISPR hype in its place.

[Why reproductive justice is essential to understanding gene editing](#)

– **Victoria Massie**

Nourbese Flint of Black Women for Wellness discusses the need for RJ activists to have a seat at the table in discussions of gene editing.

[On Embryos and Spin](#)

– **George Estreich**, Guest Contributor

Media reports about CRISPR’d embryos too often mislead the public, and undermine our understandings of the implications of gene-editing technology.

[The Ongoing Tale About *The Handmaid’s Tale*](#)

– **Ayesha Chatterjee**, Guest Contributor
 Hulu’s adaptation of Margaret Atwood’s novel provides disturbing parallels to the realities of modern-day surrogacy.

[23andWho? Questions Cloud Partial Relaunch](#) – **Pete Shanks**

“Have the questions that previously plagued the company’s direct-to-consumer tests been resolved or repackaged?”

[Why I’m speaking about human genetic engineering as a Black woman with disabilities](#)

– **Anita Cameron**, Guest Contributor

“We need to incorporate discussions of reproductive germline editing into disability justice conversations.”

[Blinded by Bad Science and Bad Oversight](#) – **Pete Shanks**

“The cover-up of deaths and other serious injuries in medical experimentation has a long history.”

CGS-Authored Commentaries and Op-Eds

Center for Genetics and Society staff, fellows, and consultants explore the social justice case for responsible uses of human biotechnologies in articles, commentaries, and op-eds that appear in publications with a wide range of audiences—from scholars to scientists to public interest advocates to a mainstream audience.



[New assisted reproduction regulations require feminist voices](#)

An urgent call for the development of policy in this field to include the viewpoints of feminist scholars and advocates who have worked to safeguard women’s health and rights.

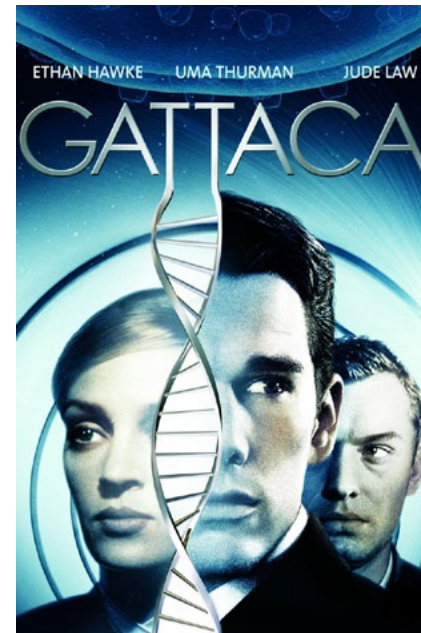
Francine Coeytaux, Marcy Darnovsky, Susan Berke Fogel, and Emily Galpern
| *International Journal of Feminist Approaches to Bioethics* | December 18, 2017



[FDA gives DTC genetic tests a partial restart](#)

Genetic analysis for medical reasons can be critical in some situations. But at least for now and probably for the long run, it needs careful regulation. Many believe the recent FDA ruling loosening its restrictions on direct-to-consumer genetic testing goes too far.

Pete Shanks | *Medical Laboratory Observer* | July 25, 2017



[Revisiting Gattaca in the Era of Trump](#)

What would it mean to embrace new gene-editing technologies such as CRISPR-Cas9 at the very moment white supremacy is, once again, on the rise?

Osagie K. Obasogie | *Scientific American* | November 1, 2017

Bioethica Forum

Schweizer Zeitschrift für Biomedizinische Ethik
Journal Suisse d’Ethique Biomédicale / Swiss Journal of Biomedical Ethics

[Reproductive Genome Editing and the U.S. National Academies Report: Knocking on a Closed Door or Throwing It Wide Open?](#)

Despite presenting its conclusions as cautious, the report in effect throws the door open for reproductive human gene editing, with serious implications.

Leah Lowthorp and Marcy Darnovsky
| *Bioethica Forum* | October 1, 2017



[Editing Humans](#)

Children whose families could afford “genetic upgrades” would likely be perceived by parents and teachers as superior, with all-too-predictable results.

Marcy Darnovsky | *Bioscience Technology* | February 27, 2017

3 | Collaboration | Engagement | Leadership: Building a New Biopolitics

Calls abound for “public engagement” and “democratic participation” in decisions about the trajectory of human technologies. The Center for Genetics and Society works to turn rhetoric into reality.

Bringing Together Civil Society Advocates and Engaged Scholars

Calls abound for “public engagement” and “democratic participation” in decisions about the trajectory of human biotechnologies. The Center for Genetics and Society works to turn this rhetoric into reality, bringing vitally needed civil society voices and social justice perspectives to deliberations about the social and ethical implications of human biotechnologies.

In 2017, we partnered with disability and reproductive justice organizations to launch a new series of webinars on human gene editing to stimulate conversation about the implications of this new technology for social justice movements. Each drew hundreds of participants.

We also launched a “Human Gene Editing and Social Justice” listserv to connect leading public interest advocates and scholars. And we hosted the invitational “Assisted Reproductive Technologies Working Group,” a community of advocates and scholars who share resources and promote public policies that are consistent with social and reproductive justice. Our ART Working Group webinars covered topics including “three-person IVF” and transnational commercial surrogacy.

Webinar Speakers and Co-Sponsors

April 14, 2017

Disability Justice & Gene Editing
EXPLORING MULTIPLE PERSPECTIVES

Mia Mingus
Tom Shakespeare
Anita Cameron
Rosemarie Garland-Thomson

June 13, 2017

Gene Editing and the Future of Reproductive Justice Webinar

Lisa Ikemoto
UC Davis
Ruha Benjamin
Princeton University
Dorothy Roberts
University of Pennsylvania



Public Events

The Center for Genetics and Society’s work builds public and policy-maker understanding of the social justice case for responsible use and governance

Talking Biopolitics Webinar Series

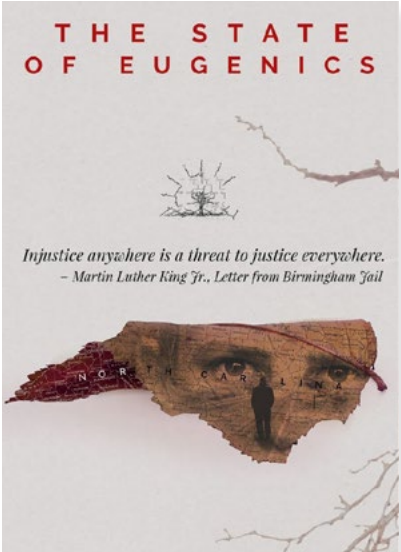
Talking Biopolitics features candid conversations with top biopolitical thinkers, and questions from participants.



of human biotechnologies. We foster the inclusion of voices seldom heard in these critical debates about the future of humanity in a genomic age.

Being Human in a Biotech Age Film Series

Our 2017 film series at the University of California, Berkeley consisted of three events. We screened two documentaries and one feature-length film; each screening was followed by a panel of prominent speakers and audience discussion.



CGS Policy Leadership

The Center for Genetics and Society brings social justice concerns and civil society voices to policy deliberations about the social implications of human biotechnologies. Examples from 2017 include written testimony on human gene editing submitted to a **US Senate HELP committee** hearing, participation in an event marking the 20th anniversary of the **Council of Europe’s Convention on Human Rights and Biomedicine**, and contributions to other policy conversations on human biotechnologies in the US and around the world.



Leah Lowthorp participated in the conference marking the 20th anniversary of the Council of Europe’s Convention on Human Rights and Biomedicine, Strasbourg, France, October 24-25

Invited Presentations

The Center for Genetics and Society’s unique perspective, rooted in a social understanding of human biotechnologies, is in ever-increasing demand at conferences, symposia, and other gatherings, both nationally and internationally. In 2017 we gave some two dozen invited presentations at international, national, and local events.



Katie Hasson debates Shoukhrat Mitalipov, Stanford University, November 3



Victoria Massie at “Power Manifesto,” Black Women for Wellness’ annual conference, Los Angeles, California, October 19

Invited Presentations *continued*



CRISPRcon 2017, Berkeley, California, August 16-17



Osagie Obasogie at CRISPRcon 2017, on the panel “Genome Surgery: CRISPR cures, community perceptions and questions of equity”



Marcy Darnovsky at CRISPRcon 2017, on the panel “Envisioning the Future: Where might CRISPR take us—and do we want to go there?”



Leah Lowthorp at the Takahashila Public Policy Institute, Bangalore, India, May 25



Marcy Darnovsky spoke about “Engineering Life” at South by Southwest in Austin, Texas, March 13



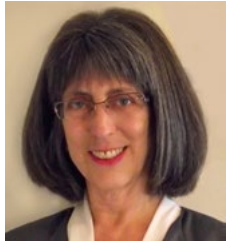
Leah Lowthorp spoke on “Gene Editing Ourselves” at the Genomics and Big Data Summit in San Diego, California, September 27

4 | CGS in 2017

With the guidance of our Advisory Board, and in collaboration with other colleagues and organizations, we work with a growing network of scholars across a range of disciplines; with scientists, health professionals, legal experts, and policy analysts; and with advocates across a range of civil society sectors.

Who We Are

2017 Staff



Marcy Darnovsky, PhD
Executive Director



Charles Garzón, MA
Director of Finance and Administration



Leah Lowthorp, PhD
Program Manager and Mellon/American Council of Learned Societies Public Fellow



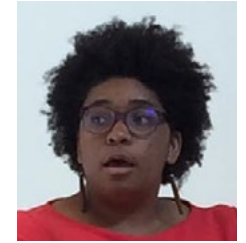
Katie Hasson, PhD
Program Director on Genetic Justice



Kayla Tolentino
Staff Associate



Jonathan Chernoguz
Intern



Victoria Massie, MA
PhD candidate, Communications Coordinator

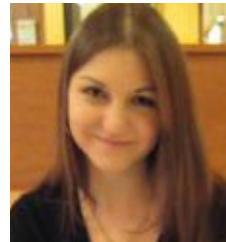
Key Consultants



Pete Shanks writes regularly for the CGS blog *Biopolitical Times* and other outlets.



Emily Galpern, former CGS staff member, coordinates the ART Working Group and collaborates on selected aspects of our work on human germline modification.



Jessica Cussins, former CGS staff member, works with us on selected articles and blog posts. She is now a Research Fellow at the Center for Long-Term Cybersecurity.

2017 Fellows



Osagie Obasogie, JD, PhD (Senior Fellow)
Haas Distinguished Chair and Professor of Bioethics in the Joint Medical Program and School of Public Health, University of California, Berkeley; Chair of the Haas Institute for a Fair and Inclusive Society's Diversity and Health Disparities Cluster



Lisa Ikemoto, JD, LLM
Martin Luther King, Jr. Professor of Law, University of California, Davis School of Law; Bioethics Associate, UC Davis Health System Bioethics Program; Faculty Associate, UC Davis Center for Science and Innovation Studies



Gina Maranto, MA
Director of the Ecosystem Science and Policy undergraduate program and coordinator of the graduate program in Environmental Science and Policy at the University of Miami's Leonard and Jayne Abess Center

Who We Are *continued*

Our esteemed Advisory Board plays essential roles in our fundraising, governance, and strategic planning work.



Francine Coeytaux, MPH (Advisory Board Chair), is a woman's health advocate and public health expert internationally known for her promotion of comprehensive reproductive health services, safe abortion services, and the development of new reproductive technologies. She is currently a Co-Director of [Plan C Pills](#), which provides reliable information for the safe, effective, and private method of medication abortion known as the abortion pill. She helped to found the Pacific Institute for Women's Health and the Reproductive Health Technologies Project, and is co-founder of the [Pro-Choice Alliance for Responsible Research](#). In 2011, she was awarded the Lifetime Achievement Award from the American Public Health Association.



Dorothy Roberts, JD, is Professor of Law and Sociology and of Civil Rights at the University of Pennsylvania Law School and Department of Sociology. An internationally recognized scholar, public intellectual, and social justice advocate, she studies the interplay of gender, race, and class in legal issues and has been a leader in transforming public thinking and policy on reproductive health, child welfare, and bioethics. Her books include [Killing the Black Body: Race, Reproduction, and the Meaning of Liberty](#) (Random House/Pantheon, 1997); [Shattered Bonds: The Color of Child Welfare](#) (Basic Books/Civitas, 2002); and [Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-First Century](#) (New Press, 2011).



Alexandra Minna Stern, PhD, is Professor and Chair of the Department of American Culture at the University of Michigan, where she directs the [Sterilization and Social Justice Lab](#). She also holds appointments in the Departments of History, Women's Studies, and Obstetrics and Gynecology. Her research focuses on the history of eugenics and the uses and misuses of genetics in the US and Latin America. Her books include the award-winning [Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America](#) (University of California Press, 2nd edition, 2015) and [Telling Genes: The Story of Genetic Counseling in America](#) (Johns Hopkins University Press, 2012). Her research and writings informed a 2018 California bill to provide monetary compensation to survivors of the state's 20th-century eugenic sterilization program.

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 2017 were \$746,926. 2017 funding for CGS was provided by the Appleton Foundation, the American Council of Learned Societies, the Winiarski Family Foundation, a matching grant from the John D. and Catherine T. MacArthur Foundation, and individual donors. Complete financial reports are available on request.

Stay Connected

Check out our website

The newly redesigned [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.

Updates in your inbox

Stay tuned to news developments and analysis by signing up for our monthly newsletter [Biopolitical Views & News](#).

Webinars with cutting-edge thinkers

Our [Talking Biopolitics](#) series and other free webinars bring you cutting-edge authors, filmmakers, and advocates exploring the social meanings and implications of human biotechnologies.

Make a donation

Donate to a biopolitical future grounded in social justice.



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