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GENETICS
AND SOCIETY

BioPolitical

News&Views

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SPOTLIGHT



GATTACA on Screen in San Rafael with Katie Hasson

Pete Shanks, *Biopolitical Times* | 06.26.2024

GATTACA was released in 1997, but is even more relevant now than it was then, as the technologies whose social implications it explores have developed considerably. The sci-fi setup may have seemed far out when the film was released, but today companies are selling Gattaca-like claims about selecting the healthiest and smartest embryos.

ANNOUNCEMENTS



The Promise and Peril of CRISPR: Out July 2nd!

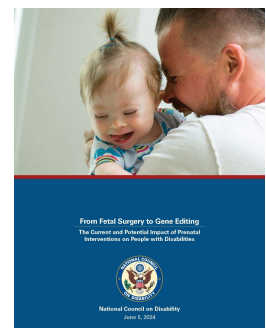
CGS' Marcy Darnovsky and Katie Hasson have an essay in an exciting new edited volume on the potential impacts of gene editing technology, due out July 2 from Johns Hopkins University Press. Edited by Neal Baer, the collection brings together essays by influential bioethicists, philosophers, and geneticists to explore the moral, ethical, and policy challenges posed by CRISPR technology. Look for Marcy and Katie's essay "Untangling CRISPR's Twisted Tales."

Now Available: Spanish and German translations of groundbreaking social justice principles on heritable genome editing

Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing, a groundbreaking document authored by an international coalition of scholars and advocates and endorsed by 70+ individuals and organizations, is now available in Spanish and German. The 11 principles point to the conclusion that no argument for pursuing heritable genome editing aligns with feminist, anti-eugenic, and

Principios de justicia social y derechos humanos para el debate mundial sobre la edición del genoma humano heredable: Resumen

01. **Principio 1:** Garantizar la salud reproductiva y la seguridad de las mujeres y las personas embarazadas y evitar los daños genéticos derivados de la experimentación en humanos.
02. **Principio 2:** Salvaguardar la justicia de género y la justicia reproductiva de todas las personas.
03. **Principio 3:** Valorar todas las vidas y la diversidad corporal, intelectual y de capacidades.
04. **Principio 4:** Desmantelar los legados eugenésicos y hacer frente a la tentación eugenésica.
05. **Principio 5:** Promover una comprensión integral de la salud, garantizar el acceso a la salud y a los recursos relacionados y asegurar la no discriminación de las personas con discapacidad.
06. **Principio 6:** Dar prioridad a los cambios sociales y políticos para eliminar la inequidad en materia de salud, poner fin a la discriminación y fomentar la prosperidad de todas las personas.
07. **Principio 7:** Salvaguardar los derechos, los intereses y el bienestar de las generaciones futuras y de las personas nacidas gracias a la edición genómica heredable en los dispositivos públicos respecto a esta tecnología.
08. **Principio 8:** Garantizar el derecho a la autogestión del material genético y los datos biológicos.
09. **Principio 9:** Adoptar un enfoque preventivo en la elaboración de políticas.
10. **Principio 10:** Dar prioridad a las personas sobre los beneficios.
11. **Principio 11:** Implementar programas de empoderamiento público para garantizar una toma de decisiones incluyente en aras del bien común.



human rights commitments. Many thanks to [Gender Justice and Disability Rights Coalition](#) members Gen-Esthisches Netzwerk and biorespect for producing the [German translation](#). Learn more about the principles in this [February 2024 blog post](#).

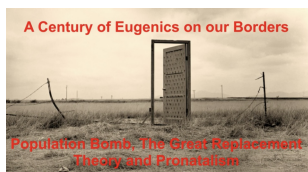
National Council on Disability releases report: From Fetal Surgery to Gene Editing

A new report outlining a disability rights critique of heritable gene editing and other "prenatal interventions" has been released by the National Council on Disability, an independent US federal agency. The report explores the current and future impact of new and emerging reprogenetic technologies on people with disabilities. CGS executive director Marcy Darnovsky was a key informant and is quoted extensively throughout the report, along with several CGS allies.

Welcome, Kyla!

Kyla Rosin has joined CGS this summer as an intern through the [Collective Rising internship program](#). Kyla is a rising sophomore at Emory University pursuing a Neuroscience and Behavioral Biology degree. She hopes to deepen her knowledge of the intersections between science and politics while working toward a more equitable and inclusive future in both. In particular, she is curious about how mental illness is included in discussions of genetic selection and modification. She strives to eventually become a practicing therapist, founding her work on social justice.

COMMENTARY



Population Bomb, Great Replacement Theory, and Pronatalism

[Kyla Rosin](#), *Biopolitical Times* | 06.27.2024

Panelists including CGS Executive Director Marcy Darnovsky discussed the history of eugenics and population control and its legacies, which are visible today in right-wing politics, anti-immigrant bias, and the selection of embryos based on polygenic risk scores. The conversation was part of the symposium "A Century of Eugenics on our Borders."



CALIFORNIA INSTITUTE FOR REGENERATIVE MEDICINE
The State Stem Cell Agency

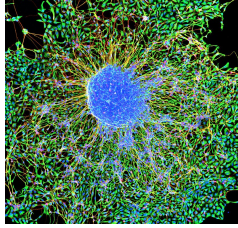
How Long Will the California Institute for Regenerative Medicine Survive?

[Pete Shanks](#), *Biopolitical Times* | 06.17.2024

California's state-funded stem cell agency is at a "watershed moment" in its 20-year history. With few successes to show for its investments thus far and a changing landscape of gene therapies and stem cell innovations, CIRM faces questions about its leadership, funding priorities, and long-term sustainability.

CGS IN THE NEWS

[Biopolitical Times](#) on CIRM's 'Depressingly Small



Number of Effective Treatments or Cures'

David Jensen, *The California Stem Cell Report* | 06.24.2024

An article in CGS' *Biopolitical Times* comments on the state of California's stem cell agency—finding that the program is in “serious trouble” with few successes to show after 20 years of significant financial investment in stem cell and gene therapy treatments.



The legacy of eugenics

Sheila Kaplan, *UC Berkeley School of Public Health* | 06.20.2024

With support from CGS and other organizations, UC Berkeley professor of law and bioethics and CGS Senior Fellow Osagie Obasogie has launched “Legacies of Eugenics,” a series of essays on eugenics in science, medicine, and technology, published in the *Los Angeles Review of Books*.

WHAT WE'RE READING

GENE EDITING | GENOMICS | GENE THERAPY | EUGENICS
ASSISTED REPRODUCTION | SURROGACY360 | STEM CELLS

GENE EDITING

Come Together: Bridge RNAs Close the Gap to Genome Design

Jonathan D. Grinstein, *Genetic Engineering & Biotechnology News* | 06.26.2024

A new study proposes a more flexible gene editing technique, an RNA-guided system that enables modular and programmable DNA insertions, excisions, and inversions. The approach avoids making permanent, and sometimes unintended, changes to genetic code.

AI plus gene editing promises to shift biotech into high gear

Marc Zimmer, *The Conversation* | 06.06.2024

Researchers are attempting to pair CRISPR techniques with AI to design and produce “bespoke proteins,” but could the AI-CRISPR combo compound the risks posed by each technology?

Gene editing's next big targets

Alison Snyder, *Axios* | 06.06.2024

Following FDA approval of a gene therapy for sickle cell disease, researchers are exploring new techniques and turning their attention to developing gene therapies for cancers, common diseases, and ageing.

Expert: Blaming Greenpeace for blocking Golden Rice is “sleazy sleight of hand”

Claire Robinson and Jonathan Matthews, *GMWatch* | 06.02.2024

Pro-GMO groups are blaming Greenpeace for blocking the GM crop Golden Rice in the Philippines, but the move is merely a “a sleazy sleight of hand to hide the fact that after 30 years of development, Golden Rice is still not ready.”

GENOMICS

Patents based on traditional knowledge are often ‘biopiracy’. A new international treaty will finally combat this

Miri (Margaret) Raven, Alana Gall, Bibi Barba, and Daniel Robinson, *The Conversation* | 06.02.2024

At a recent conference, member states of the World Intellectual Property Organisation agreed on a new treaty aimed to prevent for-profit “biopiracy,” in which companies steal ideas from indigenous communities and patent them.

Scientists Find the Largest Known Genome Inside a Small Plant

[Carl Zimmer](#), *The New York Times* | 05.31.2024

A combination of virus-like DNA and duplicated genomes may be responsible for the record-setting genome of the fern plant *Tmesipteris oblancoolata*, but it's a mystery why some species — like humans — have so much less DNA than other plants and animals.

For Some Families of Color, a Painful Fight for a Cystic Fibrosis Diagnosis

[Liz Szabo](#), *The New York Times* | 05.29.2024

People of color have struggled to get a diagnosis for cystic fibrosis because many doctors believe that the disease only affects white people and genetic tests primarily screen for variants found in people of European ancestry.

GENE THERAPY

When there's no commercial incentive to develop gene therapy – hospitals will try to fill the gap

[Claire Booth](#), *The Conversation* | 06.12.2024

To improve accessibility of costly gene therapies for rare diseases, Great Ormond Street Hospital is exploring whether it's possible to apply for and take on the licenses for gene therapies, beginning with a therapy for ADA-SCID, a form of severe combined immune deficiency.

Who's Paying for Million-Dollar Gene Therapies?

[Karen Fischer](#), *BioSpace* | 06.12.2024

Private insurers in the U.S. seem to be covering costly gene therapies for sickle cell disease and a type of hemophilia. Public payers are negotiating lower price tags for gene therapies and are developing rebate options in case the treatments don't work.

CAR-T therapy is considered a cure for some types of cancer. Penn researchers found significant racial disparities in who has access

[Sarah Gantz](#), *The Philadelphia Inquirer* | 06.10.2024

Researchers found significant racial disparities in who gets treated with CAR-T gene therapy for lymphoma. Penn Medicine patients from racial and ethnic minority groups were less likely to receive the treatment involving genetically modified white blood cells that attack the cancer.

Innovative Thinking Could Make New Sickle Cell Treatments More Accessible

[Shobita Parthasarathy](#), *Scientific American* | 05.22.2024

The cost of new gene-based sickle cell treatments isn't the only barrier to access. If we want technology to serve society, and particularly to advance equity, governments and innovators can't only focus on creating potentially lifesaving treatments.

EUGENICS

Supreme Court outlawed segregation of disabled people 25 years ago. But change has come slowly

[Timmy Broderick](#), *STAT* | 06.21.2024

25 years after the Supreme Court ruled that isolating people with disabilities violated the ADA, community-based services are the norm. But gains remain unevenly distributed and incomplete.

Journals that published Richard Lynn's racist 'research' articles should retract them

[Dan Samorodnitsky et al.](#), *STAT* | 06.20.2024

Richard Lynn used glaringly bad scientific practices to advance a racist agenda under the guise of science. Why aren't more scientific journals retracting his publications?

Sam Bankman-Fried funded a group with racist ties. FTX wants its \$5m back

Jason Wilson and Ali Winston, *The Guardian* | 06.16.2024

With funds from Sam Bankman-Fried, a hotel in Berkeley, CA has been repurposed as a compound to host events and speakers who promote longtermism, transhumanism, and eugenics.

Cleaning the ‘Bangladeshi’: DNA and citizenship in contemporary India

Suraj Gogoi, *News Laundry* | 05.28.2024

Far-right ideologies in India that envision a Hindu utopia without Muslims, anti-immigrant sentiments that demonize Bengali people, and discriminatory genetic testing and sterilization policies all echo the racism of the 20th-century eugenics movement in Europe and the U.S.

Today, ‘disability justice is reproductive justice’ — but that hasn’t always been the case

Sara Luterman, *The 19th News* | 05.23.2024

A remarkable coalition of disability and reproductive rights and justice groups came together to advocate for establishing an annual Disability Reproductive Equity Day. The efforts can be traced back to conversations in disability rights groups instigated by Rebecca Cokley, Judy Heumann, and other key figures.

It’s Time to End Forced Sterilization—And Write a New Reproductive Equity Story by and for Disabled People

Ma’ayan Anafi, *National Women’s Law Center* | 05.22.2024

The story that we’re told about forced sterilization is that it began and ended with the eugenics movement in the early 20th century. But the truth is that forced sterilization of disabled people is legal in the majority of US states today.

How doctors are pressuring sickle cell patients into unwanted sterilizations

Eric Boodman, *STAT* | 05.21.2024

For decades, women with sickle cell disease have been pressured into sterilization procedures without being offered accurate information or less invasive options, a disturbing continuation of patterns of forced sterilization for women of color and women with disabilities.

ASSISTED REPRODUCTION

Senate Republicans block bill on women’s right to IVF as Democrats make push on reproductive care

Stephen Groves, *Associated Press* | 06.13.2024

Senate Republicans blocked legislation that would make it a right nationwide for women to access in vitro fertilization and other fertility treatments and proposed their own legislation, which Democrats blocked.

Southern Baptists Vote to Oppose Use of I.V.F.

Ruth Graham, *The New York Times* | 06.12.2024

Southern Baptists, the country’s largest Protestant denomination, voted to oppose IVF, suggesting that the powerful conservative voting bloc may support fetal personhood laws that limit access to IVF.

The push for embryo rights in state legislatures worries IVF patients and doctors

Natalie Krebs, *NPR* | 06.04.2024

State lawmakers are attempting to pass fetal personhood bills across the country, raising concerns among IVF patients and doctors over whether they will be allowed to create, store, and discard embryos in the IVF process.

It Is Too Soon for Clinical Trials on Artificial Wombs

Vardit Ravitsky and Louise King, *Scientific American* | 06.01.2024

Without clear evidence of potential benefits, first in-human trials of artificial wombs would head down

SURROGACY 360



‘We traveled thousands of miles for a child’ – is Taiwan ready for surrogacy?

Evelyn Yang, *Focus Taiwan* | 06.15.2024

Taiwan’s Ministry of Health and Welfare plans to amend the Assisted Reproduction Act to legalize surrogacy, a move supported by many LGBTQ families who sought surrogacy arrangements abroad. Some women’s groups and scholars want to see surrogacy addressed in separate law amendments.

STEM CELLS

Nature retracts highly cited 2002 paper that claimed adult stem cells could become any type of cell

Ellie Kincaid, *Retraction Watch* | 06.18.2024

Nature has retracted a 2002 paper from the lab of Catherine Verfaillie, whose stem cell research has already been scrutinized—and in some cases retracted. This paper claimed to show that a type of adult stem cell could contribute to most, if not all, somatic cell types.

Some hawking stem cells say they can treat almost anything. They can’t

Heather Hollingsworth, *Associated Press* | 06.15.2024

Iowa’s attorney general joined other states in suing businesses that have fraudulently promoted unproven and costly stem cell treatments that have caused blindness, bacterial infections, and tumors.

Can money conquer death? How wealthy people are trying to live forever

Andrea Chang, *Los Angeles Times* | 06.04.2024

Ultra-wealthy immortality “biohackers” are spending some of their riches on unproven treatments in the hopes of extending their lifespans.

Scientists Just Inched Closer to Lab-Made Human Eggs and Sperm

Shelly Fan, *Singularity Hub* | 05.31.2024

A team of researchers was able to chemically erase the epigenetic memories of germ cells that eventually develop into sperm or egg in an attempt to advance in vitro gametogenesis, despite the risks with the nascent technique.

If you’ve read this far, you clearly care about the fight to reclaim human biotechnologies for the common good. Thank you!

Will you support CGS by making a donation today?

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