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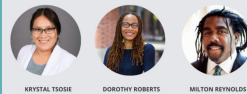
September 23, 2022

SPOTLIGHT

Equity, Sovereignty, and Racial Justice

BEYOND ACCESS IN DEBATES ON HUMAN GENOME EDITING

September 14, 2022
10 am PT / 1 pm ET



Equity, Sovereignty, and Racial Justice: Beyond Access in Debates on Human Genome Editing
Daisy Boyd, *Biopolitical Times* | 09.22.2022

What gets missed in conversations about heritable genome editing when “equity” is flattened to issues of “access?” That question was tackled at a CGS-hosted roundtable conversation last week, featuring Indigenous geneticist-bioethicist Krystal Tsosie, reproductive justice scholar and advocate Dorothy Roberts, and educator and activist Milton Reynolds. Watch the full video and read our recap of the event.

ANNOUNCEMENTS



On September 9, CGS Executive Director Marcy Darnovsky spoke at a [virtual conference on inclusive deliberation on heritable genome editing](#). She and four others discussed the social and ethical implications of heritable human genome editing and the urgent need for inclusive and broad public debate to inform democratic governance and regulation. Videos of their [presentations](#) and a summary of the [discussion](#) are now online.



On the latest episode of the podcast *Queer Diagnosis*, CGS intern Connor McAlister discusses the implications of emerging technologies, including CRISPR, on disabled communities. Listen [here](#).

COMMENTARY



Human
Fertilisation &
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Authority

A Campaign to Legalize Heritable Genome Editing in the UK?

Pete Shanks, *Biopolitical Times* | 09.21.2022

Greasing the skids for a formal approval of heritable human gene editing in the UK would be hugely controversial and hugely consequential. The agency charged with overseeing assisted reproduction should not be promoting speculative fantasies or engaging in inappropriate advocacy, tastelessly costumed as bureaucratic efficiency.

CGS IN THE NEWS

Dorothy Roberts Tried To Warn Us

Irin Carmon, *New York Magazine* | 09.06.2022

Clarence Thomas' linkage of abortion rights and racism is "a false retelling of history." If reproductive justice was at the forefront, Thomas' argument would be easily recognized as "blatantly ridiculous," says University of Pennsylvania professor and CGS advisory board member Dorothy Roberts.

Dorothy Roberts on reproductive justice: 'Abortion isn't the only focus'

Marian Jones, *The Guardian* | 08.28.2022

"Movements seeking to limit or abolish the power of the criminal legal system and the prison industrial complex are relevant to opposing Dobbs' assault on reproductive freedom. People are already being arrested and imprisoned for stillbirths and miscarriages; that standard will be applied to abortions as well. Recognizing the interconnected nature of these challenges is essential."

WHAT WE'RE READING

GENE EDITING | ASSISTED REPRODUCTION | EUGENICS | SURROGACY360
GENETIC TESTING | GENOMICS | STEM CELLS | ANIMAL TECHNOLOGIES | VARIOUS

GENE EDITING

Starting a Revolution Isn't Enough

Jennifer A. Doudna, *The Atlantic* | 09.12.2022

Jennifer Doudna is optimistic about gene editing and impatient to advance its applications, which leaves little time to discuss and address concerns for its social implications.

Bioethicist Françoise Baylis asks why humans think 'they can just take everything'

CBC Radio | 09.06.2022

"Why is it that we think we can just take everything, everything, and modify it for ourselves?" asks

Françoise Baylis, a world leader in the field of bioethics.

UK fertility watchdog considers laws for gene editing and lab-grown eggs

[Hannah Devlin](#), *The Guardian* | 08.26.2022

This alarming report claims that the UK's HFEA is considering recommending regulatory changes that would pave the way for heritable genome editing and lab-grown gametes—according to Robin Lovell-Badge, an advocate of heritable gene editing.

Reproductive Embryo Editing: Attending to Justice

[Inmaculada De Melo-Martín](#), *The Hastings Center Report* | 08.22.2022

Commitments to pursue justice may be compatible with the goal of helping people have healthy and genetically related children, but not through the investment of social resources into further development of reproductive gene editing.

Thence We Will Create Superhumans

[Corinne Othenin-Girard](#), *Philosophical Investigations* | 08.22.2022

“A genuinely inclusive and pro-equality society has no preferences between all possible future persons. Instead all existing and future individuals are perceived as having equal worth and value.”

Is heritable genome editing compatible with equality in an inclusive society?

[Scottish Council on Human Bioethics](#), *Science Animated* | 07.15.2022

Although heritable genome editing is often framed as contributing to social progress, these novel procedures are incompatible with the concept of equality in value of all human beings in a genuinely inclusive society.

ASSISTED REPRODUCTION

I took an international trip with my frozen eggs to learn about the fertility industry

[Anna Louie Sussman](#), *MIT Technology Review* | 09.12.2022

The booming global fertility industry has given rise to courier services that ferry frozen gametes and embryos around the world. Some people use them to access or afford donor gametes with desired genetic and phenotypic qualities.

What I learned about the ‘baby business’ more than 15 years after undergoing IVF

[Alisyn Camerota](#), *CNN* | 09.05.2022

Fertility medicine has worked miracles for some, but has also brought occasional horror stories and tragic mistakes. Now, as the multi-billion-dollar fertility industry booms, there are calls for more oversight, regulations, and legislation.

Is New Tax Bill The Key To Affordable And Equitable Fertility Treatment?

[Ellen Trachman](#), *Above the Law* | 08.24.2022

A proposed federal bill would allow LGBTQ and single parents to deduct expenses of gamete donation and surrogacy on their tax returns without having to demonstrate medical infertility.

EUGENICS

No public funding for the biologization of social inequality!

Gen-ethisches Netzwerk e.V. | 09.12.2022

Germany's Gene-SOEP project perpetuates the widespread falsity that social inequalities are biologically determined. The possibility that the results could be used to discriminate against people based on gene variants has been ignored.

How 'Longtermism' Is Helping the Tech Elite Justify Ruining the World

[Rohitha Naraharisetty](#), *The Swaddle* | 09.05.2022

Longtermism's utopia is a future where human beings are engineered to perfection — leading to the creation of posthumans who possess only the best and most superior of traits with no flaws at all. This is an idea rooted in eugenics.

Ken Burns Explores America's Inaction During the Holocaust

[Joseph Berger](#), *The New York Times* | 09.01.2022

Ken Burns' "The U.S. and the Holocaust" highlights the racism and antisemitism that was laced through the nation's purportedly democratic institutions and led to their inaction in response to Nazi persecution of Jews.

SURROGACY360



The Surrogacy Industry Braces for a Post-Roe World

[David Dodge](#), *The New York Times* | 08.23.2022

Concerned about losing access to pregnancy care, and fearful of legal consequences, surrogates and those who work with them are rewriting contracts and changing the way they operate.



Ukraine Conflict Highlights Legal Issues Surrounding International Commercial Surrogacy

[Sophie Cameron](#), *International Bar Association* | 07.29.2022

The recent US Supreme Court decision in *Dobbs* and the war in Ukraine illustrate how surrogates and children are affected by the absence of an international convention on laws related to parentage and surrogacy arrangements.

GENETIC TESTING

The controversial embryo tests that promise a better baby

[Max Kozlov](#), *Nature* | 09.21.2022

Some companies offer tests that rank embryos based on their "risk" of developing complex diseases such as schizophrenia or heart disease. Are they accurate — or ethical?

'Ticking away in the back of my mind': what does it mean to know the risk embedded in your DNA?

[Sophie Black](#), *The Guardian* | 09.04.2022

As technological advances and decreasing costs make genetic testing accessible to broader swaths of the population, what does it mean to know the risk embedded in our DNA?

Genetic Embryo Screening for Psychiatric Risk Not Supported by Evidence, Ethically Questionable

[Jenny Logan](#), *Mad in America* | 09.02.2022

Polygenic embryo screening tests are "being marketed with limited empirical data behind them and virtually no scientific or ethical discussion," write a group of researchers in *Lancet Psychiatry*.

Dobbs decision is a huge setback for genetic counseling and the people who need it

[Sonia M. Suter and Laura Hercher](#), *STAT* | 08.25.2022

State laws following the Dobbs decision effectively divide the country into zones with and without access to reproductive genetics, meaning that the demographics of genetic disease will increasingly be defined by regional abortion restrictions and socioeconomic status.

What to expect when you're expecting an extra X or Y chromosome

[Bonnie Rochman](#), *MIT Technology Review* | 08.16.2022

Most people with sex chromosome variations are unaware of them—they're not life threatening, or necessarily life limiting. New prenatal tests flag these variations, but can be inaccurate and alarm parents without providing support.

GENOMICS

Uncovering the genetic basis of mental illness requires data and tools that aren't just based on white people—this international team is collecting DNA samples around the globe

[Hailiang Huang](#), *The Conversation* | 09.12.2022

Ancestral diversity in genetic analyses hasn't improved in the two decades since the Human Genome Project announced its first results. A new effort to study the genetic basis of mental illness aims to change this.

Experts launch world's largest genetic study of ME

BBC | 09.12.2022

A new study aims to better understand the causes and symptoms of Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome. If genetic factors are found, they might be helpful in developing new treatments.

An Effort to ID Tulsa Race Massacre Victims Raises Privacy Issues

[Emily Mullin](#), *Wired* | 09.06.2022

A project that matches Tulsa Race Massacre victims' DNA to that of their descendants is raising privacy concerns because it uses a genealogy website that can be accessed by law enforcement.

“Genetics has a unique risk”: Interview with Dr. Krystal Tsosie about genetic research with Indigenous DNA

Gen-ethisches Netzwerk e.V. | 08.26.2022

Often, genetics research has been misused, abused, and used against Indigenous peoples. Privacy concerns related to genetics research reinforce the importance of Indigenous peoples having ultimate agency and authority over their people's DNA.

New Bill Would Bring Back Terrible Software and Genetic Patents

[Joe Mullin](#), *Electronic Frontier Foundation* | 08.18.2022

A recently introduced US Senate bill would overturn the landmark 2013 unanimous SCOTUS ruling against patents for isolating genes found in nature. Critics say the legislation, if passed, could hinder access to healthcare and redirect research during disease outbreaks toward patenting genome sequences.

STEM CELLS

Scientists have created synthetic mouse embryos with developed

brains

Rhiannon Williams, *MIT Technology Review* | 08.25.2022

Mouse embryos recently generated from stem cells in a lab show more brain development than any synthetic mouse embryos created previously. Scientists say this could help them learn more about human embryo development and provide insights into diseases.

Stem cell agency lists own board members with conflicts of interest

David Jensen, *Capitol Weekly* | 08.24.2022

In a first in its 18-year history, the California stem cell agency has listed board members with conflicts of interest. 25 of 35 have conflicts on an upcoming grant application.

Inside the race to make human sex cells in the lab

Jessica Hamzelou, *MIT Technology Review* | 08.23.2022

After success with mice, scientists are trying to make artificial human sex cells. But does their enthusiasm downplay the significant technical and safety challenges of this ethically dubious pursuit?

ANIMAL TECHNOLOGIES

Who Owns the Ocean's Genes? Tension on the High Seas

Olive Heffernan, *Scientific American* | 09.12.2022

Genetic material from ocean organisms and the data from sequencing their genomes could be used to develop new products potentially worth billions of dollars. But who owns these resources, and who gets to profit from their use?

Gene editing is not “precision breeding”—international scientists and policy experts

Claire Robinson, *GMWatch* | 09.08.2022

As the UK considers shifting regulations on gene editing in food & farming, international scientists and policy experts object that calling it “precision breeding” is “technically and scientifically inaccurate” and misleads “Parliament, regulators, and the public.”

The Guardian view on de-extinction: Jurassic Park may be becoming reality

The Guardian | 08.19.2022

Plans to “de-extinct” the Tasmanian tiger using genetic engineering raise concerns about unintended consequences and responsibility for them, and about funneling funding away from conservation efforts for existing animals.

VARIOUS

How disability advocate Alice Wong turned her anger into action

Anna Leahy, *The Washington Post* | 09.09.2022

In her new memoir of disability activism, Alice Wong argues that the pandemic is our moment to “re-envision the world, a world centered on justice, liberation, interdependence, mutual care, and mutual respect.”

Monsanto's smear merchant, the Genetic Literacy Project, is now Bayer's bully

Jonathan Matthews, *GMWatch* | 08.31.2022

The Genetic Literacy Project is defending the key ingredient in the herbicide Roundup, one of Bayer's most lucrative products. They don't disclose that Bayer helps fund GLP and that the author is a former Bayer consultant.

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

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