

CENTER FOR GENETICS

BioPolitical News&Views

November 17, 2022

SPOTLIGHT



Support CGS on Giving Tuesday, November 29th!

Your <u>contribution</u> helps bring social justice to the center of public and policy debates on human biotechnologies. The Center for Genetics and Society is the leading US nonprofit confronting the cutting-edge challenges of human genetics and assisted reproduction. Your support for genetic justice is essential, and it is deeply appreciated.

ANNOUNCEMENTS

Forging New Disability Rights Narratives about Heritable Genome Editing



Watch the video! Forging New Disability Rights Narratives about Heritable Genome Editing

How can new narratives challenge uses of genetic and reproductive technologies based on ingrained ableism? On November 14, CGS and Disability Rights Education and Defense Fund (DREDF) hosted Silvia Yee, Teresa Blankmeyer Burke, Larkin Taylor-Parker, and Rebecca Cokley for a rich conversation tackling that question. The **recording** and **transcript** are now available.

CGS Welcomes Three New Advisory Board Members

CGS warmly welcomes three new advisory board members:





legal scholar Lisa C. Ikemoto, gender equity and justice advocate Kavita N. Ramdas, and educator and activist Milton Reynolds. We are grateful for their expertise in support of CGS, alongside current advisory board members Francine Coeytaux, Dorothy Roberts, and Alexandra Minna Stern. **Find out more** about each member of the advisory board.

Challenges posed by current ART practices, surrogacy arrangements, and gene editing: are new public policies needed?

On Tuesday, November 29 at 8 am PDT, CGS Associate Director Katie Hasson and Our Bodies, Ourselves co-founder Judy Norsigian will share insights on public policies for reproductive technologies and gene editing. **Register here** for this free webinar hosted by Maternal and Infant Health Canada and the Global Women's Health Network.

COMMENTARY



New Reports on Agricultural Gene Editing From UK Campaigners

Pete Shanks, *Biopolitical Times* | 11.01.2022 Three UK advocacy organizations recently released substantial reports about genetically modified food crops, critically assessing their impacts and demonstrating the need for more public engagement in policy formation and the regulatory process.

WHAT WE'RE READING

GENE EDITING | GENOMICS | ASSISTED REPRODUCTION EUGENICS | SURROGACY360 | VARIOUS

GENE EDITING

Perfection is too high a bar for CRISPR treatments, says STAT Biomedical Innovation Award winner David Liu

Megan Molteni, STAT | 11.15.2022

Biochemist David Liu argues that somatic gene editing research should move forward despite the fact that the risks posed by off-target effects can only be minimized, not eliminated.

This Personalized Crispr Therapy Is Designed To Attack Tumors

Emily Mullin, Wired | 11.10.2022

Researchers edited cancer patients' immune cells using CRISPR to help them effectively fight tumors. A new study shows that this approach is feasible and safe, but it was successful only in a handful of patients.

Death in US gene therapy study sparks search for answers

Laura Ungar, AP News | 11.04.2022

The lone volunteer in a study involving a gene-editing technique has died, and those behind the trial are now trying to figure out whether CRISPR played a part in his death.

Gene Treatment for Rare Epilepsy Causes Brain Side Effect in 2 Children

Erika Check Hayden, The New York Times | 10.26.2022

A once-promising gene therapy that could turn off the gene causing a rare form of epilepsy is more dangerous than originally thought. The treatment resulted in a buildup of fluid in the brains of two children, causing the death of one.

Podcast or Perish Episode 040: Françoise Baylis

Cameron Graham, Podcast or Perish | 10.03.2022

"We are always committed to trying to make ourselves better." But when it comes to heritable genome editing, "do the means matter morally?" Is there a difference between things that are reversible or not; things people choose, others that they can't?

GENOMICS

Cops Might Already Have Your DNA, Without Your Consent

Albert Fox Cahn, The Daily Beast | 11.14.2022

Much of our DNA isn't private anymore, at least not from the police. While we can still protect against the nightmare of persistent genetic surveillance, we first have to change our focus from preventing DNA collection to preventing misuse and managing access.

This toddler is the first to have been treated for her disease before she was born

Jessica Hamzelou, MIT Technology Review | 11.11.2022

Ayla was successfully treated as a fetus for a genetic disorder, which prevented complications once she was born. Researchers see potential in developing more fetal therapies, but they face a number of ethical challenges.

She was convicted of killing her four children. Could a gene mutation set her free?

Nicky Phillips, Nature | 11.09.2022

Kathleen Folbigg was convicted of killing her four infant children and has spent 19 years in prison. A new analysis will investigate whether a genetic mutation may have caused a fatal heart problem that resulted in the children's deaths.

ASSISTED REPRODUCTION

These strangers all have the same biological father: the fertility doctor who helped their parents have a baby

Vanessa Caldwell, CBC | 11.03.2022

In the documentary *Seeds of Deceit,* a group of "Karbaat children" meet for the first time. Their biological father is Jan Karbaat, a Dutch fertility doctor who secretly inseminated patients with his own sperm.

What does the booming sperm-donor industry owe to people it helps conceive?

Sarah Todd, Quartz | 11.03.2022

Newly enacted legislation in Colorado ended anonymous sperm and egg donation in the state. Conversation around the new law, including perspectives from donor-conceived persons, underscores ethical issues with gamete donation and challenges in regulating it.

Historic Meeting Ushers In New Era In US Donor Conception

Ellen Trachman, Above the Law | 11.02.2022

At a recent meeting on gamete donation regulation, a diverse set of stakeholders discussed donor identity disclosure, family unit limits, and donor eligibility criteria. More opportunities are needed to continue public conversation around regulation.

Why gay men and other groups are banned from donating sperm

Amber Ferguson, The Washington Post | 10.20.2022

Sperm banks are reporting a shortage of donors of color, in part because an FDA ban—based on outdated data on HIV from the early 90s—means they cannot accept sperm from gay men.

America has a Black sperm donor shortage. Black women are paying the price.

Amber Ferguson, The Washington Post | 10.20.2022

Because sperm banks have so few Black sperm donors, some women and couples are turning to unregulated online groups or individuals, which can result in unforeseen disputes about health screenings and custody agreements.

Racial disparities in neonatal mortality even wider with tools like IVF, study finds

Andrew Joseph, STAT | 10.19.2022

New research indicates that neonatal mortality rates for children conceived through IVF were four times higher among infants of Black women versus those of white women. This is an even wider racial disparity than for children who were spontaneously conceived.

EUGENICS

Breeding for Britain

Angelique Richardson, London Review of Books Blog | 11.04.2022

Anxieties in Parliament about global overpopulation, which inform policies that seek to encourage differential class fertility, are inflected by eugenic ideas about which groups should be allowed to reproduce—and should be consigned to history.

John Fetterman gives us a chance to banish eugenic ideas of fitness

Jaipreet Virdi, The Washington Post | 11.04.2022

Media responses to Senator-elect John Fetterman's debate performance following a stroke draws on conventional standards of fitness for office that are deeply rooted in eugenics. Rethinking them could produce better policies and insights.

SURROGACY360



'Rent My Womb': Women Are Desperate to Become Surrogates in Mexico

Emily Green, *Vice* | 10.28.2022

Increasing demand from U.S. couples for cheaper surrogacy options has contributed to a surrogacy boom in Mexico, where women are signing up to be surrogates despite the lack of regulations to oversee it, which leaves them <u>vulnerable to exploitation</u>.

Here's why we're not prepared for the next wave of biotech innovation

Matthew Herper, STAT | 11.03.2022

New biotechnologies are developing at rapid speed, outpacing our ability to assess them. We are at risk of losing sight of what works and what doesn't, scuttling our own progress, wasting money, and missing opportunities to save lives.

High Containment: Lab That Created Risky Avian Flu Had 'Unacceptable' Biosafety Protocols

Mara Hvistendahl, The Intercept | 11.01.2022

In America's biolabs, hundreds of accidents have gone undisclosed to the public. Scrutiny of lab incident reports underscores that the patchwork of regulations for lab safety leaves substantial gaps in the oversight of research with dangerous pathogens. This article is part of the series "Experimenting with Disaster."

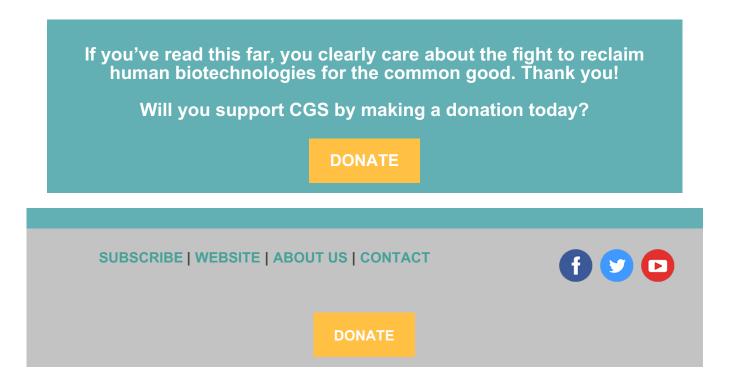
How scientists want to make you young again

Antonio Regalado, *MIT Technology Review* | 10.25.2022 Although little evidence supports the idea that technology to "reprogram cells" could reverse aging, investors are clamoring to fund Silicon Valley startups tinkering with the technique.

These Doctors Admit They Don't Want Patients With Disabilities

Gina Kolata, The New York Times | 10.19.2022

In anonymous focus groups, physicians admitted they attempted to discharge people with disabilities from their care because they found it challenging to accommodate them. Discrimination against these patients only adds to healthcare disparities.



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