

November 20, 2021

SPOTLIGHT



November 30th is Giving Tuesday!

You can make a real difference by donating to the Center for Genetics and Society, the *only* independent US nonprofit dedicated to genetic justice. <u>Your gift</u> will help prevent the emergence of a new eugenics and reclaim human biotechnologies for the common good.

ANNOUNCEMENTS



We're Hiring!

CGS is seeking a skilled Communications Coordinator to help us spread the word about our work. This is a part-time (15-20 hrs/week) contract position for 10-12 months, with potential to lead to a full-time and/or permanent position. We are looking for someone who is enthusiastic about our mission, goals, and values, and savvy about using traditional and social media to reach a range of audiences. Find out more **here**.

COMMENTARY



A Note on the Upcoming Human Genome Editing Summit

Marcy Darnovsky, *Biopolitical Times* | 11.19.2021 The Third International Summit on Human Genome Editing will be held in London on March 7–9, 2022. Recent reports from the World Health Organization and others have set the stage for discussions about science and oversight. The Center for Genetics and Society's Associate Director Katie Hasson has been invited to speak.

The Planning Committee for the Third Summit: Now Who Decides?



Regulation Details in the United States



Updated Map of US Surrogacy Policies Highlights Patchwork of State Regulation

Emily Galpern, *Biopolitical Times* | 11.17.2021 The updated map provides the most comprehensive and accurate representation of US surrogacy policy available online. The Center for Genetics and Society partnered with the National Center for Lesbian Rights to offer this resource on Surrogacy360, a website that grapples with the complexities of cross-border surrogacy.

WHAT WE'RE READING

GENOME EDITING | ASSISTED REPRODUCTION | EUGENICS | MARKETING | VARIOUS

GENOME EDITING

CRISPR-Cas9 Gene Editing May Select for Cells With Cancer-Related Mutations

Sophia Ktori, Genetic Engineering and Biotechnology News | 11.12.2021

A study published in *Nature Communications* has shown that after being edited with CRISPR, cells with pre-existing mutations in cancer-associated genes like p53 may be able to grow and divide more quickly than cells without such mutations, giving them a competitive advantage. This highlights the need to monitor patients for cancer-related mutations when they are undergoing CRISPR-Cas9-based gene therapy.

Imagine CRISPR cures

Fyodor D. Urnov, Molecular Therapy | 11.03.2021

CRISPR/Cas can potentially treat Mendelian diseases, but developing therapies is so time-consuming and expensive that some companies have given up even on successful trials. The process could be streamlined by developing a vertically integrated platform that could be used for different indications. Doing so would require public and philanthropic funding.

For me, IVF and other fertility programs can have a darker and less happy side

Blake Turck, The Washington Post | 11.13.2021

"At a recent baptism, the priest exclaimed that babies were life's happiness and couldn't be bought. In actuality, a U.S. woman undergoing IVF to have a baby spends an average of more than \$12,000, plus the cost of drugs, according to various estimates, just for an attempt to create a life, with no assurance it'll work."

'Nightmare' IVF mix-up leaves L.A. couple giving birth to other family's baby

Hayley Smith, The Los Angeles Times | 11.08.2021

DNA testing at seven weeks confirmed that a couple's second daughter was not genetically related to them. They connected with the other family involved, who remain anonymous, and eventually exchanged babies and filed for legal custody. They are suing the fertility clinic, its medical director, and a third-party embryology center he owns.

I sold my eggs for an Ivy League education – but was it worth it?

Ellie Houghtaling, The Guardian | 11.07.2021

"I wasn't the patient. I was the product... The clinic was not just assessing my predisposition for genetic disorders, it was also weighing up other attributes: my blonde hair, my blue eyes and my fair skin. I had concerns this was sanitized eugenics."

Hounded by fertility ads on Instagram? Don't let them stress you out.

Rachel Kraus, Mashable | 10.31.2021

Well-financed tech-oriented companies are advertising hormone tests for fertility that are not even predictive for someone who has not struggled to become pregnant. So while education and proactive testing sounds like a good idea, it is also a way to commodify worry.

EUGENICS

What Dune Reveals about Reproductive Control and Eugenics

Andrew J. Mongue and Caitlin E. McDonough-Goldstein, *Scientific American* | 10.22.2021 The biology, sociology, and ethics of reproduction as depicted in the novel and movie deserve more discussion. The concept of eugenics is left largely unexamined, but the course of events offers an indirect rebuke by revealing the inherent flaws in eugenic practices.

MARKETING

Q&A: Bioethicist Leigh Turner on the worrisome boom in unregulated stem cell clinics

Megan Molteni, STAT | 11.08.2021

The grace period offered to clinics by the FDA was "a good idea that had a disastrous outcome," says Leigh Turner. In 2016, there were 537 clinics; now there are 2,754. There is no robust reporting mechanism for adverse events and the clinics' rhetoric is that the FDA doesn't have to approve what they're selling. When is the crackdown coming?

All Those 23andMe Spit Tests Were Part of a Bigger Plan

Kristen V Brown, *Bloomberg* | 11.04.2021 The original pitch document Anne Wojcicki showed potential investors 15 years ago envisaged 23andMe becoming a new kind of health-care business, an amalgam of a Big Pharma lab, a Big Tech company, and a trusted neighborhood doctor. Some of this still sounds as far off now as it did then, but the company has rounded second base and is heading for third.

VARIOUS

Biden Chooses Robert Califf to Lead F.D.A., Despite Drug Industry Ties

Sheryl Gay Stolberg and Sheila Kaplan, The New York Times | 11.12.2021

Califf is a respected academic and clinical trial researcher who ran the agency during the last year of the Obama administration. But like others who were reportedly being considered for the post, he has been criticized for his ties to the drug industry. Califf has worked as a senior adviser to Verily Life Sciences and Google Health, serves on the board of a biopharmaceutical company, and has received consulting fees from other drug and biotech companies.

A Vision for the Future of Science Philanthropy

Evan S. Michelson and Adam F. Falk, *Issues in Science and Technology* | 11.09.2021 The total impact of philanthropy on science is estimated to be as much as \$20 billion per year, which will play a critical role in shaping the conduct of science over the coming decades. Getting it right will require adopting practices that further the scientific enterprise while simultaneously helping to move society toward greater collective well-being.

