



CENTER FOR  
GENETICS  
AND SOCIETY

# BioPolitical

## News&Views

January 19, 2023

### SPOTLIGHT

#### Genetic Justice from Start to Summit



CGS is gearing up for a two-part virtual symposium that will challenge the Third International Summit on Human Genome Editing on its failure to center social justice and human rights voices and perspectives, and critique its moves that encourage heritable genome editing. Mark your calendars to [join us](#) on Feb 27 (9–10:30am PST) and Feb 28 (9–11am PST) for conversations on genetic justice that you won't hear at the Summit! More details to come.

### ANNOUNCEMENTS

#### summit counter- events

March 3–4



#### Summit Counter-Events in London

Several organizations in addition to CGS will be hosting events meant to broaden the perspectives on gene editing beyond those featured at the Summit. [Stop Designer Babies](#) is organizing a teach-in on March 4, in person and online, featuring perspectives from black/anti-racist, disability rights, working class, feminist, parents and human rights movements. (More details to come.) On March 3–4, the Centre of Bioethics and Emerging Technologies at St Mary's University, Twickenham will host [an international conference on heritable genome editing and equality](#) in partnership with the Scottish Council for Human Bioethics.



## Thank you, CGS supporters!

Thank you to all our colleagues, friends, and subscribers who contributed to our end-of-year campaign and lifted us to **126% above our fundraising goal!** We are truly grateful for your generosity in supporting CGS' mission.

## COMMENTARY



### Is Gene Therapy Delivering On Its Promises?

**Pete Shanks**, *Biopolitical Times* | 01.18.2023

New developments in gene therapy are promising, but significant questions remain: Is it safe enough? How many people might benefit? And, crucially, how much will gene therapies cost and who will pay?



### The Center for Genetics and Society: 2022 Highlights

**CGS Staff**, *Biopolitical Times* | 01.14.2023

Throughout 2022, CGS hosted public events, collaborated with advocates and scholars, and curated and analyzed news to amplify concerns regarding the social justice implications of human biotechnologies. Here are a few highlights.



### Bespoke Babies Without the Hassle of Pregnancy! Yeah, Right

**Pete Shanks**, *Biopolitical Times* | 12.23.2022

A new concept video envisions a future in which parents can select traits for their future children and use an artificial womb facility to avoid the hassle of pregnancy. Like other “designer baby” ventures, this approach could have dire societal consequences.

## WHAT WE'RE READING

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

### GENE EDITING

#### Sickle Cell Cure Brings Mix of Anxiety and Hope

**Gina Kolata**, *The New York Times* | 01.17.2023

Two gene therapies hold promise for treating sickle cell disease, but the resources it takes to afford the costly and intensive one-time gene therapies make patients and their advocates concerned about access—along with the unknowns of an experimental treatment.

#### Scientists create genetic ‘pen’ that corrects common heart conditions

**Manuel Ansede**, *El País* | 01.15.2023

A team of researchers used a “genetic pen” to modify two letters in mouse DNA, silencing a protein linked to multiple cardiovascular problems. Researchers hope the technique can work in humans as well.

## **FDA Increasingly Halting Human Trials as Companies Pursue Risky, Cutting-Edge Drugs**

**Liz Essley Whyte**, *The Wall Street Journal* | 01.10.2023

As biotech companies pursue more experimental cell and gene therapies, the FDA is pressing pause on some clinical trials to evaluate risks and safety concerns that new technologies may pose.

## **The Crispr Baby Scientist Is Back. Here’s What He’s Doing Next**

**Emily Mullin**, *Wired* | 12.21.2022

Now released from prison, He Jiankui plans to develop gene therapies for rare genetic diseases. Should the scientific community give researchers who engage in extreme misconduct a second chance?

## **How gene therapy is emerging from its ‘dark age’**

**Gemma Conroy**, *Nature* | 12.14.2022

New gene therapy approvals and clinical trials suggest that better treatments may be on the horizon for people with complex genetic diseases, including macular degeneration, hemophilia, and spinal muscular atrophy.

## **CRISPR gene-editing may boost cancer immunotherapy, new study finds**

**Rob Stein**, *NPR* | 12.13.2022

A recent clinical trial found that reprogrammed donor T cells could destroy tumor cells in some patients with hard-to-treat cancers. These “off-the-shelf” therapies are cheaper and faster because they don’t require removing, editing, and re-infusing a patient’s own cells.

## **GENOMICS**

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### **How Police Actually Cracked the Idaho Killings Case**

**Heather Tal Murphy**, *Slate* | 01.10.2023

Investigators used forensic genealogy, a relatively new and somewhat controversial method that relies on ancestry databases to identify DNA from crime scenes, to zero in on the suspect now in custody on charges of murdering four University of Idaho students.

### **A new kind of blood test can screen for many cancers—as some pregnant people learn**

**Nell Greenfieldboyce**, *NPR* | 12.23.2022

A now-common prenatal test analyzes DNA free-floating in a pregnant person's bloodstream to screen for genetic anomalies in the fetus. It may also function as an unasked-for cancer screening by finding genetic evidence of cancer from the pregnant person’s own cells.

### **In a first, children with rare genetic diseases get mitochondrial transplants from their mothers**

**Megan Molteni**, *STAT* | 12.21.2022

A new approach to treating mitochondrial disorders, which involves transplanting healthy mitochondria from mothers into their affected children’s blood stem cells, was tried in six children who showed small improvements in their symptoms.

### **Sequencing projects will screen 200,000 newborns for disease genes**

**Jocelyn Kaiser**, *Science* | 12.12.2022

New projects in the UK and in NYC will sequence newborns’ genomes in the hopes of catching

treatable diseases, but these efforts raise questions related to ethics and cost.

## EUGENICS

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### **Prominent AI Philosopher and ‘Father’ of Longtermism Sent Very Racist Email to a 90s Philosophy Listserv**

[Matthew Gault and Jordan Pearson](#), *Vice* | 01.12.2023

The transhumanist philosopher Nick Bostrom apologized for a racist email he sent in the mid-90s, in which he stated, “Blacks are more stupid than whites,” adding, “I like that sentence and think it is true,” and used a racial slur. His apology stopped short of critiquing eugenic pursuits in genomics and reproduction.

### **Russia's Eugenic War**

[Timothy Snyder](#), *Thinking about...* | 01.08.2023

In Ukraine, Russia has pursued ambitious policies of racial transformation—Russian eugenics. Putin has used mass deportations and other tactics to make Russia's multiethnic population more white and more Russian.

### **California is trying to pay reparations to the victims of forced sterilization. It may not find all of them**

[Adam Beam and the Associated Press](#), *Fortune* | 01.04.2023

About 600 people alive today can't have children because California's government sterilized them against their will or without their knowledge. Now the state is trying to find them so it can pay them reparations, but has only approved 51 people who have applied.

### **Ableism Enables All Forms of Inequity and Hampers All Liberation Efforts**

[George Yancy](#), *Truthout* | 01.03.2023

Ableism is the untamed and too often unnamed force behind eugenics and white supremacy.

### **Eco-Fascism, Uncovered**

[Ruxandra Guidi](#), *Sierra* | 12.27.2022

American eco-fascism scapegoats immigrants for environmental degradation, luring environmentalists into the folds of the nativist movement. In reality, immigrants often bear the brunt of climate impacts.

### **UCSF apologizes for experiments done on prisoners in the '60s and '70s**

[Salvador Hernandez](#), *Los Angeles Times* | 12.22.2022

UC San Francisco issued a public apology after investigating experiments performed by two faculty members in the 1960s and '70s on prisoners, some of whom were mentally ill. In many cases, there was no record that the prisoners had provided informed consent.

### **A Statue of Henrietta Lacks Will Replace a Monument to Robert E. Lee**

[Derrick Bryson Taylor](#), *The New York Times* | 12.20.2022

A life-size bronze statue of Henrietta Lacks, whose cancer cells were taken without her consent and used to develop medical discoveries and treatments, will replace a monument to Confederate general Robert E. Lee in Roanoke, VA.

### **Draper's Millions: The Philanthropic Wellspring of Modern Race Science**

[Angela Saini](#), *Undark* | 12.16.2022

Wickliffe Draper used his inheritance to cultivate dangerous, pseudoscientific networks promoting eugenics in the 20th century. The legacies of these ideas linger in academic journals cited by white supremacists.

### **Race is a Biological Fiction, and Potent Social Reality**

**Charles M. Blow**, *Undark* | 12.15.2022

“The failure to abandon the concept of race in this country is not rooted in a lack of knowledge. It is rooted in a persistent urge for dominance. And until we reckon with that urge, science is unlikely to deliver us.”

## Q&A: Jonathan Kahn on New Frontiers in Racial Profiling

**Jonathan Moens**, *Undark* | 12.14.2022

While controversial police DNA phenotyping techniques are only about 20 years old, racially discriminatory uses of forensic science go back to the late 19th and early 20th centuries.

## SURROGACY360

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### Colombia’s surrogacy market: Buying a baby for \$4,000

Lucia Franco, *El País* | 01.04.2022

Surrogacy is unregulated in Colombia and businesses take advantage of the vacuum to offer services. The absence of regulation leaves surrogates vulnerable to exploitation and allows clinics to make false claims.



### Global surrogacy agency accused of putting women at risk with ‘unethical’ medical procedures

Shanti Das, Simon Bowers and Malia Politzer, *The Guardian* | 12.18.2022

Women recruited by an international surrogacy agency to carry babies for wealthy clients are expected to undergo unethical medical procedures that increase their risk of serious complications, a joint investigation by international media outlets suggests.

## ASSISTED REPRODUCTION

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### Russian troops sent to Ukraine given opportunity to freeze sperm

**Maria Botcharova**, *PET* | 01.09.2023

Russian troops mobilized to fight in Ukraine will be offered sperm freezing and fertility treatment, which some see as an incentive to join the military. However, Russia has no specific legislation about the use of sperm after death.

### Warning for UK women over physical and financial toll of egg freezing

**Miranda Bryant**, *The Guardian* | 01.08.2023

The UK’s fertility regulator has called for an urgent update to the law around egg freezing as rapidly growing numbers of women choose to undergo the procedure—often without being warned of the full financial, emotional and physical costs.

### EU-wide recognition of surrogacy and same-sex parenthood proposed

**Blair Sowry**, *PET* | 12.19.2022

The European Commission has proposed new regulation to allow parenthood rights to follow families across member states, meaning that all states would be obliged to recognise parenthood through surrogacy that was legally established in other EU jurisdictions.

### Senators move to protect IVF treatments

**Caitlin Huey-Burns**, *CBS News* | 12.15.2022

In the wake of the decision to overturn *Roe v. Wade*, many states have passed vague abortion bans that might limit use of IVF. In response, Senate Democrats have introduced new legislation to

protect IVF treatments.

## The Quest to bring IVF to Africa

Jenni Quilter, *Slate* | 12.13.2022

Researchers in Belgium have been working to expand IVF access to African countries by lowering the cost of the technique. Although the clinic they set up in Ghana has proven successful, they have faced challenges in getting funding to support infertility treatment in Africa.

## VARIOUS

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### A California Search: Forging a Path to Pay for Multimillion-Dollar Gene Therapies for Rare Diseases?

David Jensen, *California Stem Cell Report* | 01.11.2023

UCLA and UCSF are considering creating an entity that would cover the multimillion-dollar price tags of gene therapies for the life-threatening bubble baby disease—a venture that would likely involve funding from CA’s stem cell agency.

### The entrepreneur dreaming of a factory of unlimited organs

Antonio Regalado, *MIT Technology Review* | 01.11.2023

After failures last year, some startups hope that more trials of xenotransplantation will prove successful, opening up a vast supply of genetically modified pig organs to help more people on transplant lists.

### The reproducibility issues that haunt health-care AI

Emily Sohn, *Nature* | 01.09.2023

We have to ask, “Are we deploying a bunch of algorithms in practice that we can’t understand, for which we don’t know their biases, and that might create real harm for people?”

### Male and Female Stem Cells Derived from One Donor in Scientific First

Dan Robitzski, *The Scientist* | 12.22.2022

Scientists have developed a new line of stem cells—all derived from the same person, who had a rare version of Klinefelter syndrome—that can be used to study sex differences without the confounds of interpersonal genetic differences.

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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