CENTER FOR GENETICS

# BioPolitical News&Views

February 9, 2023

### SPOTLIGHT /////



#### **Genetic Justice from Start to Summit**

Join CGS for a two-part virtual symposium that will challenge the failure to center social justice and human rights voices and perspectives at the Third International Summit on Human Genome Editing. We'll bring together feminist, disability rights, reproductive rights and justice, racial justice, environmental, and human rights advocates and scholars for a discussion of heritable genome editing. Feb 27 (9-10:30am PST) and Feb 28 (9-11am PST). <u>Register today!</u>

### ANNOUNCEMENTS



#### Call for Applications: Emerge Workshop for Disabled Activists, Artists, Cultural Producers, Filmmakers, and Academics

Applications are open for the July 2023 cohort of the Paul K. Longmore Institute on Disability's hybrid Disability Studies Workshop. Enrich your practice as a scholar-activist, gain new connections and mentorship, and deepen your relationship with disability studies! Find out more **here**—applications are due February 28.

#### 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.

### COMMENTARY





## The transhumanist philosopher, Silicon Valley money, and lab-made gametes

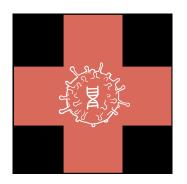
**Jennifer Denbow**, Guest Contributor, *Biopolitical Times* | 02.09.2023

Nick Bostrom's racist email is no surprise given his central role in the toxic stew of longtermism, transhumanism, and eugenics. The embrace of these ideas among wealthy effective altruists investing heavily in emerging reprogenetic technologies needs scrutiny and critique.

## Techno-eugenics: Two Books and a Movie, Reviewed

**Pete Shanks**, *Biopolitical Times* | 02.02.2023 Two books and a documentary on the prospect of heritable human gene editing begin their discussion with the case of He Jiankui. Whether they focus specifically on He or tackle broader questions about the future of society, all consider the grave societal risks of allowing heritable genome editing.

### CGS IN THE NEWS



#### California and the Multimillion-Dollar Costs of Gene Therapies that the State is Helping to Finance

**David Jensen**, *California Stem Cell Report* | 02.05.2023 The multimillion-dollar costs of gene therapies—the type that the state of California is helping to finance—received some national, mainstream attention during the last few weeks, including Pete Shanks' *Biopolitical Times* piece on developments in gene therapy.

### WHAT WE'RE READING

#### **GENE EDITING**

#### Scientist who edited babies' genes says he acted 'too quickly'

Hannah Devlin, *The Guardian* | 02.04.2023 In a recent interview, He Jiankui did not apologize or express regret for his rogue and reckless gene editing experiments.

## After a decade, CRISPR gene editing is a 'revolution in progress.' What does the future hold?

Karen Weintraub, USA Today | 01.30.2023

"Most scientists and medical ethicists...recoil in horror at the concept of editing the genome of a human embryo, making a change that will be passed down through the generations."

#### A Dilemma for Governments: How to Pay for Million-Dollar Therapies

**Rebecca Robbins and Stephanie Nolen**, *The New York Times* | 01.24.2023 With sales of its gene therapy for spinal muscular atrophy slowing in richer countries, pharmaceutical giant Novartis is pushing for coverage in middle-income countries, where public health systems are often fragile and underfunded.

#### Intellectual property and assisted reproductive technology

David Cyranoski, Jorge L. Contreras, and Victoria T. Carrington, *Nature Biotechnology* | 01.18.2023

Scientists and biotech startups are racing to patent their research into in vitro gametogenesis. IVG would enable production of hundreds of embryos that could be genetically characterized, ranked, or altered. Will it be marketed and used to select for—or to engineer—"desirable" traits?

#### **GENOMICS**

#### The human genome needs updating. But how do we make it fair?

Ida Emilie Steinmark, The Guardian | 01.29.2023

Since its publication in 2003, the reference genome has revolutionized genome sequencing. But the code meant to represent the human species contributes to the Eurocentric bias of much of genomics: it's mostly based on just one man from Buffalo, New York.

#### World's largest body of human geneticists apologizes for eugenics role

Sydney Trent, The Washington Post | 01.24.2023

The American Society of Human Genetics' new report examines its own complicity in the eugenics movement and pseudoscientific racism. It recognizes the need for further efforts to denounce and oppose racist misuses of genetics research.

#### American Society of Human Genetics Statement on "Facing Our History: Building an Equitable Future Initiative"

**Board of Directors**, *American Society of Human Genetics* | 01.24.2023 The eugenic horrors of WWII made human genetics controversial. ASHG's founders "recognized this and established the Society [in 1948] to restore credibility to the field of human genetics. However, ASHG could not fully distance itself from the legacy of eugenics."

#### **EUGENICS**

#### The Dark History of the Eugenics Movement in Northern California Has Chilling Implications for Today

Julie Zigoris, The San Francisco Standard | 01.26.2023

Eugenic crimes of forced sterilization in California were largely committed by a class of affluent dogooders, who cloaked their pursuits in the language of scientific and human progress. We should scrutinize scientific efforts today that espouse those same values.

#### The Anti-Abortion Movement and the Ghost of Margaret Sanger

Melinda Cooper, Dissent | 01.25.2023

Religious conservatives are framing their efforts to ban abortion and establish legal recognition of fetal personhood as "anti-eugenics." Much of the feminist left is ill-equipped to deal with this threat.

#### Autism research at the crossroads

Brady Huggett, Spectrum News | 01.25.2023

Autistic self-advocates sound the alarm as advances in autism research threaten to repeat the eugenic mistakes of the past. But some researchers find that these efforts only partially represent the concerns of the diverse neurodiverse population.

#### Japan court orders gov't to pay damages over forced sterilization

*Kyodo News* | 01.23.2023

The Japanese government will provide about 22 million yen (\$170,000) in compensation to two people sterilized under a Japanese eugenics law that authorized the sterilization of 25,000 people with intellectual disabilities, mental illnesses or hereditary disorders.

### What the next 50 years of reproductive rights activism can learn from the last 50

Felicia Kornbluh, The Washington Post | 01.20.2023

*Roe v. Wade* didn't secure full reproductive rights for communities of color facing forced sterilization. Post-*Dobbs* reproductive freedom efforts can't forget this history—or current laws permitting forced sterilization of people with disabilities.

#### **Eugenics Was Wrong Even When It Got It Right**

#### Maren Linett, Nursing Clio | 01.17.2023

Many contemporary popular and academic writers fail to attack the ableism at the heart of eugenics. This approach—criticizing eugenics for everything except its ableism—reproduces eugenic evaluations of fitness and of human value.

#### ASSISTED REPRODUCTION

#### Victim Advocates Convene In DC Over It's-About-Time Federal Fertility Fraud Bill

#### Ellen Trachman, Above the Law | 01.25.2023

Intended to curb all-too-common fertility fraud, the proposed "Protecting Families From Fertility Fraud Act" would establish a new federal crime for knowingly misrepresenting the nature or source of DNA used in any assisted reproductive procedure.

#### China Needs Couples to Have More Babies: Can I.V.F. Help?

Alexandra Stevenson and Zixu Wang, *The New York Times* | 01.22.2023 The Chinese government has promised to cover some of the cost of IVF under national medical insurance, one of more than a dozen policy measures enacted in response to anxiety about China's declining fertility rate.

VARIOUS

## Now is the Moment for a Systemic Reset of AI and Technology Governance

Anja Kaspersen and Wendell Wallach, Carnegie Council for Ethics in International Affairs | 01.24.2023

Al could bring health benefits, but it's increasingly used to exacerbate existing forms of inequity. How can we ensure that the technologies currently being developed are used for the common good, rather than for the benefit of a select few?

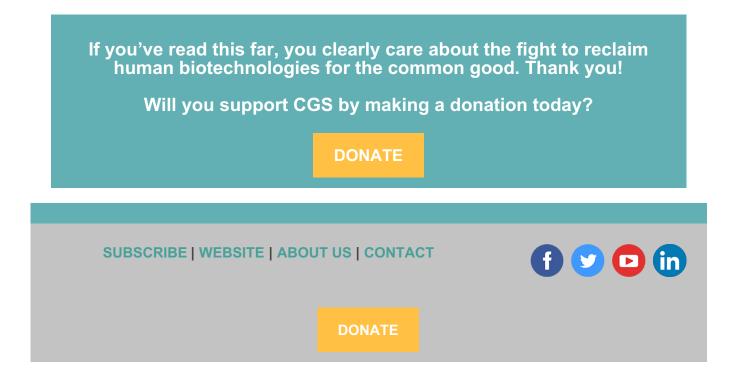
## Article debunks claims that gene editing will revolutionise crop breeding in Africa

Claire Robinson, *GMWatch* | 01.24.2023

New research concludes that genetically modified crops in Africa do not live up to the hype. GM crops are imprecise, costly, and inaccessible to African farmers.

#### What Do We Owe Lab Animals?

**Brandon Keim**, *The New York Times* | 01.23.2023 The standard ethical guidelines encourage minimizing the use of animals in research and the harm done to them. Some experts propose an additional courtesy: repayment.



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