BioPolitical News&Views

CENTER FOR GENETICS AND SOCIETY

December 18, 2020

Dear Friend of CGS,

As this turbulent year draws to a close, we're ready to wish 2020 good riddance. But before we do, we're taking a moment to reflect on what this year has taught us about the work ahead to build a just and inclusive future. Here's some of what we've seen this year.

Eugenic legacies and practices persist. So does resistance to them.

- The Trump administration coddled white supremacists. The president lauded "**good genes**"—especially his own.
- **Coerced sterilizations** linked an ICE detention center to the long history of eugenic sterilization **in California** and **elsewhere**.
- COVID-19 **triage proposals** put people with disabilities at the back of the line, while "**herd immunity**" schemes suggested culling the vulnerable so that the strong may survive.

Heritable genome editing enthusiasts are undeterred.

- The "CRISPR babies" scientist **was sentenced** to three years in prison.
- Researchers uncovered **previously unrecognized dangers** of human embryo editing.
- An international commission **proposed a "pathway"** to bring CRISPR-baby technology to fertility clinics.

The global fertility industry continues to push boundaries.

- Pandemic travel restrictions left hundreds of surrogate-born babies **stranded**, highlighting longstanding problems in the industry.
- Unscrupulous clinics offered **risky and controversial procedures** without evidence.

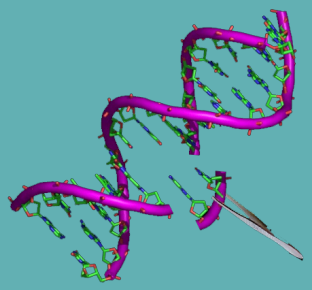
These are huge challenges. But we are eager for the opportunities we'll have to create real change in 2021 and beyond. We deeply appreciate **your support** and look forward to continuing to fight for genetic justice with you.

Wishing you a holiday season filled with love, community, and gratitude for all we have overcome this year.

Center for Genetics and Society

Support CGS

SPOTLIGHT

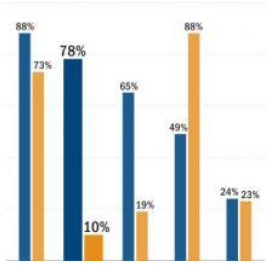


Heritable Human Genome Editing? It May Never Be Safe

By **Katie Hasson**, *Impact Ethics* | 12.04.20

Safety is far from the only thing we need to discuss in making decisions about whether to pursue heritable genome editing, but recent scientific findings confirm that the question of whether it will ever be safe is far from settled.

COMMENTARY



A Misleading Poll on Human Genetic Technologies

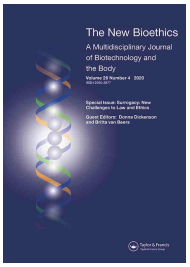
Pete Shanks, *Biopolitical Times* | 12.16.2020

Pew has released a poll of opinions in 20 countries about attitudes to biotechnology research. Unfortunately, there are several problems with its methodology, notably a complete failure to distinguish clearly between germline and somatic gene editing, which leads to some contradictory results.

Transhuman Selfishness as Governing Principle

Pete Shanks, *Biopolitical Times* | 12.16.2020

Transhumanist participation in electoral politics often seems like a complete farce, worthy of nothing but laughter. Sometimes, however, the transhumanist vision seems more like a dire warning of disasters ahead if we do not, as a society, change our course.



Surrogacy: New Challenges to Law and Ethics

Donna Dickenson, *Biopolitical Times* | 12.08.2020

In the case of surrogacy, it is not new biotechnologies themselves that have challenged well-established principles in law and ethics, but rather a range of political and social phenomena. A special issue of *The New Bioethics* explores some of the ways these pressures challenge existing law and ethics of surrogacy arrangements, giving rise to new legal initiatives and controversies in countries around the world.

Business Not As Usual: Surrogacy in the Time of COVID and Beyond

Emily Galpern, *Biopolitical Times* | 12.03.2020

Before COVID, changes to the surrogacy industry were urgently needed. Myriad issues that have surfaced during the pandemic reflect pre-existing challenges and difficulties. What can stop the industry from hurtling back to “business as usual” after the pandemic?

CGS IN THE NEWS

California's Proposition 14: shot in the arm for stem cell research

Patrick Foong, *BioNews* | 12.14.2020

The recent close-call US presidential election grabbed headlines, but no less closely fought was the California ballot initiative to pour $5.5 billion of public funding into the state's stem cell agency. It is not surprising that Californians were so torn. Perhaps it's wiser to allocate the pot to more pressing matters like job creation, housing and other urgent needs?

New York Lawmakers Seek Curbs on Collecting—and Storing—Kids' DNA

Rachel Rippetoe, *The Imprint* | 12.03.2020

CGS' Marcy Darnovsky warned that broad DNA collection protocols will "disproportionately impact communities that already have disproportionate interactions with the criminal justice system. It's really a racial justice issue."

WHAT WE'RE READING

GENE THERAPY | HUMAN GENOME EDITING | GENOMICS | EUGENICS | ASSISTED REPRODUCTION | DISCRIMINATION

GENE THERAPY

1st Patients To Get CRISPR Gene-Editing Treatment Continue To Thrive

Rob Stein, *NPR* | 12.15.2020

Three sickle-cell patients and seven patients with beta thalassemia all have responded well to gene therapy, after between three and eighteen months. The only side effects have been from the intense chemotherapy they had to undergo before getting the billions of edited cells infused into their bodies.

Gene therapy injected in one eye can travel to the other eye

Clare Wilson, *New Scientist* | 12.09.2020

In a gene therapy trial for a form of hereditary vision loss, many participants experienced improved vision in both the eye that received the treatment and the eye that received a placebo. The discovery has implications for safety, as well as for how the therapy's effectiveness is measured, because such trials usually compare the treated eye's vision with that of the untreated eye.

CRISPR and another genetic strategy fix cell defects in two common blood disorders

Jocelyn Kaiser, *Science* | 12.05.2020

Two new techniques point to cures for sickle cell disease and beta-thalassemia, though they are unlikely to help patients in developing countries and may be extraordinarily expensive. An expected price tag of $1.8 million is based on "a patient's gains in lifespan and quality of life."

The New Coronavirus Vaccine Is Changing The Future Of Medicine

Caroline Seydel, *Forbes* | 12.02.2020

The two new vaccines are the first ever to use mRNA to generate immunity. This approach could usher in a new era of medical science — not just for vaccines, but for cancer treatments, blood disorders, and gene therapy.

HUMAN GENOME EDITING

China Is Reportedly Developing ‘Biologically Enhanced’ Soldiers. So Is the U.S.

Emily Mullin, *Medium* | 12.07.2020

Emerging technologies like CRISPR present new and possibly scary possibilities for enhancement. Research being conducted in both the United States and China raises concerns about how this technology will be used on our own military — and on our enemies — in the future.

Nobel chemistry laureate Jennifer Doudna on the promise and peril of the genetic editing revolution

John Mecklin, *Bulletin of the Atomic Scientists* | 12.07.2020

Doudna estimates that within five to ten years, it will be possible to manipulate embryos or germ cells in precise ways. She anticipates governance that relies on a “framework that can’t be legally enforced, but can certainly be enforced at the level of funding and publications and scientific recognition.”

GENOMICS

We Call DNA a Language. Is It?

Luke Shors, *Neo.Life* | 12.10.2020

As the famous 20th century philosopher of science Thomas Kuhn recognized, metaphor is part of theory. If our understanding of a thing like DNA changes, the metaphors we use to describe it should change as well, or else they can encumber further scientific discovery.

A Geneticist’s Dilemma

Oscar Schwartz, *Washington Post* | 11.23.2020

A growing number of scientists believe that the cure for disease can be found in our DNA. But that poses a unique problem for some Native Americans. A tribal-wide moratorium on genetic research, instituted by the Navajo Nation government for both medical and religious reasons, put a stop to any genetic research taking place on the reservation and holds to this day.

All Your Genes Are Belong To Us

Karen Duffin and Alexi Horowitz-Ghazi, NPR | 11.20.2020

Public radio’s *Planet Money* interviews Chris Hansen of the ACLU, Sean Tavtigian of Myriad Genetics, and others about the 2013 Supreme Court decision that invalidated patents on human genes.

EUGENICS

When does genomics become eugenics?

Eben Kirksey, *Financial Review* | 12.11.2020

As the tools to identify human traits and manipulate them become more refined, ideas about normalcy and deviancy, fitness and disability, are subtly changing.

U.S. mishandling of COVID echoes the 20th century eugenics movement

Knute Berger, *Crosscut* | 12.01.2020

A false belief in the genetic superiority of virus survivors may help explain the Trump administration's failure to handle the coronavirus pandemic. The mismanagement is at best negligent and at worst a conscious act of negative eugenics.

Court rules Japan's eugenics law unconstitutional but rejects damages claim

Japan Times | 11.30.2020

About 25,000 people were sterilized in Japan under the eugenics protection law, including around

16,500 who were operated on without their consent, according to government data. However, none of the three rulings so far has ordered the government to pay any damages to plaintiffs.

ASSISTED REPRODUCTION

"Three-Parent IVF" Might Open the Door to Human Genome Editing

Diana M. Bowman, Karinne Ludlow, and Walter G. Johnson, *Slate* | 12.01.2020

If the rationale for using "mitochondrial donation" to make heritable changes in embryos can be bent — and shifted from metabolic disorders in mtDNA to nuclear DNA — why couldn't the very strict conditions proposed for using human germline editing with tools like CRISPR also be distorted in the future?

Why we should use mild stimulation in egg donation

Professor Guido Pennings, *BioNews* | 11.30.2020

At the moment, many possible candidate donors are deterred because they fear the high dosages of hormones and the unknown long-term effects. The reason that high stimulation is still used appears to be profit.

Continuing issues and debate concerning transnational commercial surrogacy during the COVID-19 pandemic and beyond

Yuri Hibino, Sonia Allan, and Damian Adams, *BioNews* | 11.30.2020

The regulation of surrogacy varies greatly around the world. The 2019 draft International Principles for Donor Conception and Surrogacy called for prohibition of commercial surrogacy and paid gamete donation, but the Hague Conference of 2020 proposed several alternatives that contradict these Principles and have provoked strenuous opposition.

DISCRIMINATION

Social Inequities Explain Racial Gaps in Pandemic, Studies Find

Gina Kolata, *New York Times* | 12.09.2020

Higher rates of infection and mortality among Black and Hispanic Americans are explained by exposure on the job and at home, not genetics.

We read the paper that forced Timnit Gebru out of Google. Here's what it says.

Karen Hao, *MIT Technology Review* | 12.04.2020

The co-leader of Google's ethical AI team has left the company. She was forced out in a dispute over a paper she co-wrote that highlighted the social and ecological risks of large language models, which are key to Google's business. Gebru is a champion for diversity in tech and the co-author of a groundbreaking paper that showed facial recognition to be less accurate at identifying women and people of color.