



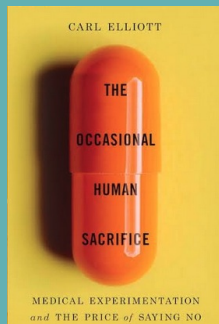
CENTER FOR
GENETICS
AND SOCIETY

BioPolitical

News&Views

May 16, 2024

SPOTLIGHT



The Unexpected Plight of Whistleblowers: Reflections on *The Occasional Human Sacrifice: Medical Experimentation and the Cost of Saying No* by Carl Elliott
Emily Beitiks, Guest Contributor, *Biopolitical Times* | 05.10.2024

Medical research scandals tend to risk or destroy the lives of those with less power in society, including women, disabled people, poor people, and people of color. The whistleblowers who expose these atrocities become vulnerable as well.

ANNOUNCEMENTS



Symposium: A Century of Eugenics on our Borders: Centennial of the Johnson-Reed Act / US Border Patrol

An online symposium on May 27-28 will look back at the US eugenics movement and look forward at how to disrupt the current alarming trajectories of eugenic thinking in immigration policy and attitudes. CGS Executive Director Marcy Darnovsky will discuss "Better Babies for Billionaires" on the panel "Population Bomb, Great Replacement Theory and Pronatalism" on May 28 at 8am PT / 11am ET. See the [full program](#); register [here](#).

Book Talk: The Occasional Human Sacrifice

Please join us to hear Dr. Carl Elliott talk about his important new book, *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*. He will discuss shocking cases of abusive medical research, with many disabled and BIPOC at the center, and the struggle

The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No
A Discussion with Author Carl Elliott

TO RSVP:
sluval.com/BookTalkMay28
3:30-4:30pm PT / 4:30-5:30pm ET
In-person at SFPL
2 Paul Leonard Library Room L11
Or on Zoom - ASU/CART provided.

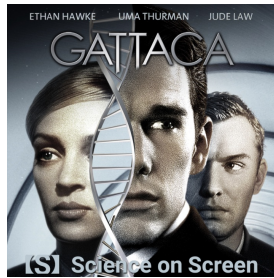
Carl Elliott

The Longmore Institute on Disability event is sponsored with support from the Center for Genetics and Society, and SFPL, STS Hub and Health Equity Institute.

Dr. Elliott will discuss shocking cases of abusive medical research, with many BIPOC and disabled people at the center, and the struggle whistleblowers face, not the kind of struggle that most people imagine.

Moderated by **Ashley Reynolds**

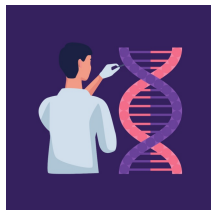
whistleblowers face — not the kind most people imagine. This Longmore Institute on Disability event is co-presented with the Center for Genetics and Society. Milton Reynolds will moderate the discussion. In person or online, May 28 at 3:30pm PT. [Learn more and register.](#)



Screening and Conversation: Picture Perfect: Wild Mistakes (And A Few Scary Truths) Science Fiction Makes in Tackling the Subject of Genetics

As part of the “Science on Screen” series at Smith Rafael Film Center, CGS Associate Director Katie Hasson will discuss the movie *Gattaca* and what it has to say about the social and ethical implications of human genetics. In person in San Rafael, CA, on June 13 at 7 pm. Purchase tickets for the film screening and conversation [here.](#)

COMMENTARY



Gene Therapy in a Capitalist Economy

Pete Shanks, *Biopolitical Times* | 04.29.2024

Multi-million dollar price tags limit the power of innovative gene therapies. Without innovations in research funding and product pricing, gene therapies will reinforce social inequalities in healthcare.



End of the Future of Humanity

Pete Shanks, *Biopolitical Times* | 04.25.2024

Oxford’s Future of Humanity Institute has been closed by the university. This is good news for the future of humanity.

WHAT WE’RE READING

GENE EDITING | GENE THERAPY | EUGENICS
ASSISTED REPRODUCTION | VARIOUS

GENE EDITING

After CRISPR baby scandal shut down work for years, China gene editing companies are restarting clinical trials

Ryan Cross, *Endpoints News* | 05.08.2024

Five years after He Jiankui’s reckless embryo gene editing experiment, researchers in China are once again performing human studies of the technology, this time to treat patients rather than alter the genes of embryos. At least three Chinese biotech companies have recently begun tests of CRISPR treatments for blood, eye, and liver diseases.

The one huge obstacle standing in the way of progress on gene-editing medicine

Charlotte Hu, *Vox* | 05.06.2024

The genetic databases and biobanks that scientists use for research and to develop new gene therapies are riddled with biases that make therapies less effective for communities of color.

A woman with failing kidneys receives genetically modified pig organs

Rob Stein, *NPR* | 04.24.2024

In response to recent transplants of genetically modified pig kidneys, bioethicist L. Syd Johnson commented, “I do worry about whether or not we are taking advantage of particularly vulnerable and desperate patients in conducting these experiments.”

Generative A.I. Arrives in the Gene Editing World of CRISPR

Cade Metz, *The New York Times* | 04.22.2024

As if CRISPR didn't bring enough risks, a biotech startup is using A.I. technology to generate synthetic biological mechanisms to edit DNA.

Prime editing deal flurry to nail down patent rights

Carrie Arnold, *Nature Biotechnology* | 04.17.2024

Patent and licensing concerns involving “gobsmacking sum[s] of money” have motivated some scientists and industry researchers to develop alternative base and prime gene editing strategies.

GENE THERAPY

The DNA Test Delusion

Kristen V. Brown, *Bloomberg* | 05.14.2024

The predictions that genomic data would revolutionize healthcare through prediction face skepticism with the decline of companies including 23andMe. A growing contingent of researchers is starting to question whether genetic data simply isn't of much use to the average person.

Boy Dosed with Pfizer DMD Gene Therapy Dies a Year after Phase II Trial

Alex Philippidis, *Genetic Engineering & Biotechnology News* | 05.07.2024

After a young boy died in a trial for Pfizer's experimental gene therapy for Duchenne muscular dystrophy, the company paused the study. It has not yet determined whether the death was linked to the experimental treatment.

First Patient Begins Newly Approved Sickle Cell Gene Therapy

Gina Kolata, *The New York Times* | 05.06.2024

A 12-year-old boy from a suburb of Washington became the first person in the world with sickle cell disease to begin a commercially approved gene therapy that may cure the condition. It will involve a lengthy and arduous process of removing, genetically modifying, and re-infusing his stem cells.

Gene Editing for Inherited Form of Blindness Shows Promise in Phase I/II Trial

Genetic Engineering & Biotechnology News | 05.06.2024

Results from a small clinical study suggest that a CRISPR-based gene editing therapy for an inherited form of retinal dystrophy, which causes vision loss, is safe and can improve vision.

EUGENICS

The Racist Origins of America's Broken Immigration System

Felipe De La Hoz, *The New Republic* | 05.01.2024

The fundamental template for how US immigration policy is written, communicated about, and implemented has its roots in the early 20th century eugenics movement.

A Eugenicist History of the County Fair

William Schulz, *The Boston Globe* | 05.01.2024

Baby contests, popular in the early 20th century in the United States, were aligned with and often sponsored by organizations espousing eugenics, which hoped to promote racist notions of white infants' superiority.

'Eugenics on steroids': the toxic and contested legacy of Oxford's Future of Humanity Institute

[Andrew Anthony](#), *The Guardian* | 04.28.2024

Set up for the noble purpose of "preserving humanity," Oxford's Future of Humanity Institute—now defunct—did anything but: Nick Bostrom instead fostered a cultish ideological framework trafficking in eugenic racism.

The Far Right's Campaign to Explode the Population

[Gaby Del Valle](#), *Politico* | 04.28.2024

Natalism is becoming a unifying force among conservatives who mask eugenic aspirations behind concerns about declining birth rates.

ASSISTED REPRODUCTION

Americans overwhelmingly say access to IVF is a good thing

[Gabriel Borelli](#), *Pew Research Center* | 05.13.2024

An April survey conducted by Pew Research Center survey finds that 7 in 10 US adults say having access to IVF is a good thing.

A gay couple couldn't access IVF benefits. They're suing New York City.

[Maham Javaid](#), *The Washington Post* | 05.09.2024

A class-action lawsuit filed by a same-sex married couple alleges that New York City is discriminating against male couples and violating federal, state and local laws by denying them IVF insurance benefits that other city employees are able to access.

The Parents Who Want Daughters—and Daughters Only

[Emi Nietfeld](#), *Slate* | 05.07.2024

Although using IVF for sex selection is banned in many countries, it is legal—and popular—in the US.

The Body She's In

[Lauren Quinn](#), *Hazlitt* | 05.01.2024

Prenatal genetic screenings claim to give parents more information about their future children, but tests that flag fetal anomalies are often accompanied by ableist assumptions that see people with disabilities as burdens.

America's IVF Failure

[Emi Nietfeld](#), *The Atlantic* | 05.02.2024

Polygenic risk assessments, which clinics pitch to parents as providing the ability to select embryos at lowest genetic risk for obesity, bipolar disorder, and other conditions, have been dubbed "Eugenics 2.0." Such tests are banned in several countries, but proceed unregulated in the US.

Inside the opaque world of IVF, where errors are rarely made public

[Lenny Bernstein and Yeganeh Torbati](#), *The Washington Post* | 04.28.2024

Most IVF errors and accidents go unreported in the largely self-regulated fertility industry. There is no requirement that errant episodes be reported to the government, the public, any professional organization, or even patients.

VARIOUS

In Medicine, the Morally Unthinkable Too Easily Comes to Seem Normal

[Carl Elliott](#), *The New York Times* | 05.07.2024

From the Tuskegee syphilis study and the Willowbrook hepatitis studies to the more recent revelations about pelvic exams conducted on people under anesthesia without their consent,

medical contexts encourage healthcare providers to accept atrocity as a medically justified status quo.

Scientists are trying to get cows pregnant with synthetic embryos

[Antonio Regalado](#), *MIT Technology Review* | 05.06.2024

Researchers are trying to use stem-cell based “synthetic embryos” to start pregnancies in cows. They claim this would revolutionize cattle breeding, but ethical issues with the practice and its potential uses abound. The implications for research using synthetic human embryo models are also alarming.

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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