

CENTER FOR GENETICS

# BioPolitical News&Views

August 18, 2022

# SPOTLIGHT



# Now online: The 'Perfect' Baby?: The Dangers of Gene Editing in Assisted Reproduction

CGS and UC Berkeley's Othering and Belonging Institute co-hosted a virtual conversation on the societal and ethical implications of human gene editing in the context of assisted reproduction. <u>Read</u> <u>our recap</u>, then <u>watch the full video</u>. The event was based on the report "<u>Engineering for Perfection: The</u> <u>False Promises of Gene Editing in Assisted</u> <u>Reproduction</u>."

# COMMENTARY

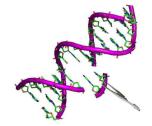


### The 'Perfect' Baby?: The Dangers of Gene Editing in Assisted Reproduction

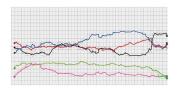
**Daisy Boyd**, *Biopolitical Times* | 08.18.2022 In a lively and wide-ranging conversation, Françoise Baylis, Nourbese Flint, and Karen Nakamura raised concerns about the potential use of CRISPR in assisted reproduction, including researchers' lack of engagement with civil society, efforts to downplay the social implications of the technology, and the risk of further exclusion of marginalized groups.

### James Wilson Is in Trouble. Again.

**Pete Shanks**, *Biopolitical Times* | 08.16.2022 Not for the first time, gene therapy developer James M. Wilson is



facing well-documented criticism. He is accused of serious workplace abuse at the Penn Gene Therapy Program, which he directs. Once again, his employer seems to be enabling his wrongdoing.



**How Can We Assess Public Opinion? Pete Shanks**, *Biopolitical Times* | 07.29.2022 It's widely agreed that heritable genome editing should not go forward unless and until there is broad societal consensus. Can opinion polls tell us if that goal has been achieved?

# WHAT WE'RE READING

GENE THERAPY | GENOME EDITING | ASSISTED REPRODUCTION EUGENICS | GENOMICS | ANIMAL TECHNOLOGIES | VARIOUS

### **GENE THERAPY**

# FDA approves one of the priciest new treatments of all time — bluebird's gene therapy for beta thalassemia

Zachary Brennan, Endpoints News | 08.17.2022

The FDA approved the first gene therapy for a chronic condition as a potentially curative treatment for people with transfusion-dependent thalassemia, but the company plans to charge up to \$2.8 million for the therapy.

### Novartis Reveals Two Deaths Related to SMA Drug Zolgensma

Mark Terry, BioSpace | 08.12.2022

Two patients receiving Novartis' gene therapy for spinal muscular atrophy have died from acute liver failure. Clinical trials of the therapy in 2019 also resulted in two deaths.

# U.K. charity gives \$36 million boost to gene editing for inherited heart diseases

#### Jocelyn Kaiser, Science | 07.28.2022

The British Heart Foundation announced an award of £30 million (\$36 million) over 5 years to CureHeart, an international team that is developing gene-editing treatments for genetic cardiomyopathies.

# Searching for Profits Stymies Gene Therapies: A California Perspective on an International Problem

David Jensen, California Stem Cell Report | 07.27.2022

Should money provided by the people of California be used to financially support companies that may not be ready or willing to take a successful gene therapy to patients via the marketplace?

### CRISPR gene editing may cause permanent damage - study

Judy Siegel-Itzkovich, The Jerusalem Post | 07.24.2022

A new study indicates that "CRISPR therapeutics, in which DNA is cleaved intentionally as a means for treating cancer, might, in extreme scenarios, actually promote malignancies."

### This startup wants to copy you into an embryo for organ harvesting

Antonio Regalado, MIT Technology Review | 08.04.2022

After success with mouse embryos, Renewal Bio will create artificial human embryos in mechanical wombs, perhaps for use in transplant treatments. To "help avoid ethical dilemmas," they will genetically engineer the starting cells so that no head develops.

# Researchers revive abandoned technique in effort to make artificial human eggs in a test tube

#### Megan Molteni, STAT | 07.28.2022

Shoukrat Mitalipov aims to make artificial human eggs for reproduction using somatic cell nuclear transfer, a cloning technique. The eugenic potential of in vitro gametogenesis is just one of its many alarming safety, ethical, and social risks.

# From Gene-Edited Embryos to Covid: China Faces Regulatory and Ethical Challenges

Yuting Zhu and Jonathan D. Moreno, The Hastings Center | 07.28.2022

China's updated regulations on human genetic engineering and assisted reproduction can strengthen its ethical governance of new technologies, but motivations to encourage new research leave legal gaps and may weaken regulatory enforcement.

### ASSISTED REPRODUCTION

# Donate women's unused eggs to research instead of rubbish bin, bioethicists propose

#### Kate Aubusson, The Age | 08.07.2022

Bioethicist Catherine Mills argues that unclaimed eggs in Australia's IVF clinic freezers should be donated by default to a clinical trial of nuclear genome transfer, also known as mitochondrial donation or "three-person IVF."

### Pitfalls, fallacies in embryo testing for health and intelligence

#### Alexis Heng, The Sun Daily | 07.30.2022

Genetic testing companies marketing embryo testing and selection for better "health" and greater "intelligence" perpetuate dangerous myths about genetic superiority and downplay the techniques' risks and unknowns.

### **Postmortem Sperm Retrieval Is Turning Dead Men Into Fathers**

Ethan Bronner and Chen Shalita, Bloomberg | 07.19.2022

In Israel, parents of slain soldiers are pushing for their right to be future grandparents through postmortem sperm extraction. Critics call it "planned orphanhood."

# For fertility doctors, a moral question: Will they help protect IVF from abortion bans?

Chabeli Carrazana, The 19th News | 07.18.2022

Reproductive endocrinologists are joining the abortion rights movement to protect IVF and fertility care. But would they help write laws to ban abortions if it meant saving IVF?

### EUGENICS

## The Legacy of Scientific Racism

#### Prabir Purkayastha, LA Progressive | 08.10.2022

Major genetics research institutions and journals claim to have shed their eugenic pasts, but theories of eugenics are very much alive in recurring race and IQ debates, sociobiology, white replacement theory, and the rise of white nationalism.

#### Penn Museum to Bury Skulls of Enslaved People

Remy Tumin, The New York Times | 08.09.2022

The Philadelphia museum hopes to provide a formal burial to 13 Black Philadelphians whose remains were used by a 19th century anatomist to formulate racist theories that laid the groundwork for the eugenics movement.

### Viktor Orban: Eugenics and the GOP

Robert Reich, LA Progressive | 08.07.2022

Hungarian Prime Minister Viktor Orban has adopted eugenics by another name: White Christian nationalism. Fear-mongering about "racial mixing" between white Christians of European descent and others also defines the Republican Party.

#### The hidden anti-Black history of Brazilian butt lifts

Daniel F. Silva, The Washington Post | 08.01.2022

The popularity of Brazilian butt lift surgery has its roots in the eugenics movement, which promoted anti-Black conceptions of beauty and helped create a plastic surgery industry that would reconstruct bodies to conform to White standards of beauty.

# She survived a forced sterilization. She fears more could occur post-Roe.

Meena Venkataramanan, The Washington Post | 07.24.2022

With 31 states allowing people with disabilities to be sterilized without their consent, forced sterilization is hardly a thing of the past. The Dobbs decision could give states further power to forcibly sterilize people from marginalized populations.

#### Legacies of eugenics: confronting the past, forging a future

Marius Turda, Ethnic and Racial Studies | 07.20.2022

Eugenics was not an historical anomaly, but rather an integral aspect of global modernity, one in which the state and the individual embarked on an unprecedented quest to create an idealized future defined by the promises of evolutionary biology and genetics.

**GENOMICS** 

# Hospital and Drugmaker Move to Build Vast Database of New Yorkers' DNA

Joseph Goldstein, The New York Times | 08.12.2022

Mount Sinai Health System will ask to add patients' genetic sequences to a database that will be shared with a pharmaceutical company, in the name of curing disease. The database raises significant privacy concerns.

#### NJ police used baby DNA to investigate crimes, lawsuit claims

Corin Faife, The Verge | 07.29.2022

New Jersey requires all newborns to have their blood drawn to screen for disease, but state police may be using some samples to investigate crimes—effectively entering babies into a DNA database with no ability to opt out.

#### Hacks of genetic firms pose risk to patients, experts say

Aaron Schaffer, The Washington Post | 07.21.2022

Since 2021, over a dozen genetic testing companies, labs, and fertility firms have disclosed data breaches affecting more than 3.5 million people. It's not clear what the data consists of, how hackers might use it, or how firms will protect data going forward.

### 'Time to invest in genomics' in poorer countries — WHO

#### Dann Okoth, *SciDev.Net* | 07.14.2022

A new WHO report calls for rapid expansion of access to genomics, especially in resource-poor countries: "It's not justifiable ethically or scientifically for less-resourced countries to gain access to such technologies long after rich countries do."

### ANIMAL TECHNOLOGIES

### Project plans to bring back the extinct thylacine

James Fair, BBC Wildlife | 08.16.2022

Colossal Biosciences announced its early-stage effort to "de-extinct" the Tasmanian tiger using genetic material from dead animals and living relatives. Conservation experts doubt that restoring the thylacine would benefit wildlife and worry that it could divert resources from conservation efforts.

# A 'Reversible' Form of Death? Scientists Revive Cells in Dead Pigs' Organs.

#### Gina Kolata, The New York Times | 08.03.2022

A Yale research team pumped a solution called OrganEx through the bodies of dead pigs, restoring blood circulation and some organ function. Further research is needed to see if OrganEx could make more human organs viable for transplantation.

### Why Did the First Human Patient to Receive a Pig Heart Transplant Die?

#### Simar Bajaj, Smithsonian Magazine | 07.14.2022

The surgeon who first transplanted a pig heart into a human considers why the patient died. He may have been too sick to receive the heart, the organ may have been rejected, or a pig virus or anti-pig antibodies may have attacked the heart.

### VARIOUS

# Claims that "supercharged biotech rice" yields massively more grain debunked

Jonathan Matthews and Claire Robinson, GMWatch | 08.14.2022

In a recent Twitter thread, a doctoral student at the University of Hawaii systematically demolished hyperbolic claims in *Science* of the benefits of genetically modified rice.

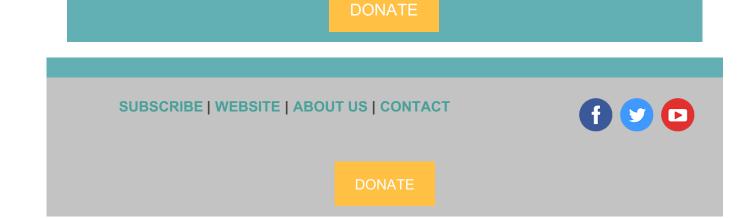
# There are two factions working to prevent AI dangers. Here's why they're deeply divided.

#### Kelsey Piper, Vox | 08.10.2022

Al poses present and future risks, but the public is only dimly aware that experts have serious safety concerns. Companies don't often prioritize these concerns, which contributes to a divide in efforts to address Al bias and alignment.

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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