



# BioPolitical News&Views

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### SPOTLIGHT //



Planning to Profit from Designer Babies. Now.

Pete Shanks, Biopolitical Times | 05.25.2021

Two prominent groups of scientists at two major American universities are trying to patent methods for editing human embryos, with reproductive use clearly intended.

### **ANNOUNCEMENTS**



### California Eugenics Symposium, June 4-5

Be sure to check out "Eugenics in California & the World: Race, Class, Gender/Sexuality, & Disability." An exciting line-up of speakers, including CGS' Marcy Darnovsky, Osagie Obasogie, and Alexandra Minna Stern, will be confronting eugenics past, eugenics now, and the threat of eugenic futures. Join on Zoom or YouTube; ASL and live captioning provided. Find more info here.



# Dropping Limits, Pushing Envelopes: Stem cell research organization wants fewer rules

Marcy Darnovsky and Katie Hasson, Biopolitical Times | 05.28.2021

An organization of scientists is recommending that limitations on several research procedures – including heritable genome editing, artificial gametes, and growing human embryos in the lab – be loosened or rolled back, even though these recommendations run counter to laws or regulations in numerous countries and erase widely observed boundaries.

### **CGS IN THE NEWS**



## Change may allow scientists to grow human embryos longer

Maria Cheng, Associated Press | 05.26.2021

New guidelines from the International Society for Stem Cell Research recommend removing a decades-old limit on using human embryos for research, known as the 14-day rule. Marcy Darnovsky pointed out that the guidelines don't include any new limit.

### WHAT WE'RE READING

STEM CELLS AND EMBRYO RESEARCH | HERITABLE HUMAN GENOME EDITING |
GENE THERAPY | ASSISTED REPRODUCTION | SCIENTIFIC RACISM | EUGENICS

#### STEM CELLS AND EMBRYO RESEARCH

### Stem cell research community drops 14-day limit on human embryo research

Françoise Baylis, The Conversation | 05.27.2021

The decision to jettison the established 14-day rule is a mistake. There is good reason to recommend public discussion and debate on the merits of this rule. There is no legitimate reason, however, for this discussion to focus narrowly on extending the time limit.

### Limit on lab-grown human embryos dropped by stem-cell body Nidhi Subbaraman, *Nature* | 05.26.2021

The international body representing stem-cell scientists has torn up a decades-old limit on the length of time that scientists should grow human embryos in the lab, giving more leeway to researchers who are studying human development and disease. The ISSCR made this change and others to its guidelines for biomedical research in response to rapid advances in the field, including the ability to create embryo-like structures from human stem cells.

### Stem cell guidelines open door to more permissive research on human embryos

Kelly Servick, Science | 05.26.2021

While the guidelines aren't legally enforceable, several countries – including the United Kingdom, Sweden, and South Korea – do have laws limiting embryo research to either 14 days or formation of a structure called the primitive streak. The guidelines call for public conversations about the "societal and ethical issues raised by allowing such research."

## Controversial New Guidelines Would Allow Experiments On More Mature Human Embryos

Rob Stein, NPR | 05.26.2021

In response to new guidelines that could permit growing human embryos in the lab for longer than two weeks and creating human-animal chimeric embryos for research, bioethicist Benjamin Hurlbut criticized the "breathtakingly expansive" approach, while some scientists argued that it would be unethical not to do such research.

### Mixed messages: is research into human-monkey embryos ethical?

Philip Ball, The Guardian | 05.15.2021

Biologists recently created a chimera with both human and monkey cells. But not all scientists are happy to blur species boundaries. When the research has a well-motivated, humanitarian goal, bans based purely on an instinctive aversion need to consider what potential benefits are lost. But some scientists might want simply to make a self-aggrandizing splash.

#### HERITABLE HUMAN GENOME EDITING

#### The Risks of Gene Editing

**Stuart A. Newman and M.L. Tina Stevens**, *The New York Review of Books* | 5.23.2021 "Safety" means entirely different things when therapeutic alterations of the tissues of a mature body are considered, in contrast to those that are administered at early embryonic stages. Embryos simply cannot be reliably engineered, despite the bioentrepreneurial hype and misinformation that accompany the manufactured need for these questionable procedures.

# Need Public Policy for Human Gene Editing, Heatwaves, or Asteroids? Try Thinking Like a Citizen

Nicholas Weller, Michelle Sullivan Govani, Mahmud Farooque, Issues in Science and Technology | 05.19.2021

Participatory technology assessment is a deliberative process designed to break down the walls between "experts" and citizens to gain insights into public policy dilemmas involving science, technology, and uncertainty. Policymakers have relied on scientific authority, but citizens must be involved in navigating pressing postnormal questions.

# The Brave New World: Should we tread down the path to human germline editing?

Sheetal Soni, South African Journal of Bioethics and Law | 04.19.2021

Human germline editing requires global discussion between all stakeholders: between ourselves. The global discussion has begun, and this article considers extant law, the value of community engagement informing legal reform, and the most prominent recent approaches in the debate.

#### **GENE THERAPY**

#### **Therapy**

David Jensen, The California Stem Cell Report | 05.25.2021

Orchard Therapeutics suspended a clinical trial being conducted at UCLA, citing financial reasons, despite \$40 million in support from the public funds controlled by CIRM. A patient advocate group said the therapy should be "released back to CIRM" and made available to children who need it to survive.

### Scientists Partially Restored a Blind Man's Sight With New Gene Therapy

Carl Zimmer, New York Times | 05.24.2021

Using a technique called optogenetics, researchers added light-sensitive proteins to a man's retina that, in combination with special goggles, gave him a blurry view of objects. The authors of the report say that the trial is a proof of concept for more effective treatments to come.

### One-time CRISPR hit lowers cholesterol in monkeys

Alla Katsnelson, Chemical & Engineering News | 05.19.2021

A single shot of gene therapy using base editing to incapacitate one gene lowers "bad" cholesterol by about 60% for at least 8 months in monkeys. The next step could be clinical trials in humans, which would test the efficacy of this approach.

### Decades after a tragic failure, gene therapy successfully treats a rare liver disease

Jocelyn Kaiser, Science | 05.18.2021

A fresh effort to cure the disease from which Jesse Gelsinger suffered is bearing fruit, 22 years after he died in a gene therapy experiment. This trial did not help all of the 11 participants but several have been able to relax dietary restrictions and drop medications. Gelsinger's father applauds the success, even though it is limited.

#### ASSISTED REPRODUCTION

### The Promise and Perils of the New Fertility Entrepreneurs

Anna Louie Sussman, The New Yorker | 05.19.2021

Startups are pushing a breezy attitude toward reproduction, centered on preemptive treatments during one's most fertile years. "It's a little too casual," said one client, describing a retail experience that left her on bed rest for a month.

#### SCIENTIFIC RACISM

### These Sisters With Sickle Cell Had Devastating, and Preventable, Strokes

Gina Kolata, New York Times | 05.23.2021

Kyra and Kami never got a simple test that could have protected them. Their story exemplifies the failure to care for people with the disease in the US, most of whom are Black. Francis Collins, director of the National Institutes of Health, said the lack of attention paid to sickle cell historically "is one more reflection of the fact that we do not have equity in our country."

### University of Cape Town's battle to tackle a racist legacy

Linda Nordling, Nature | 05.18.2021

Six years after a statue of Cecil Rhodes was toppled, students and staff are still working to improve equity and representation. Their experiences are relevant to institutions worldwide as they grapple with #BlackLivesMatter and #ShutDownSTEM protests over racial inequalities in society and the colonial foundations of many universities.

### How a Genetic Trait in Black People Can Give the Police Cover

Michael LaForgia and Jennifer Valentino-DeVries, New York Times | 05.15.2021

Sickle cell trait has been cited in dozens of police custody deaths ruled accidental or natural, even though the condition is benign on its own. In roughly two-thirds of the cases, the person who died had been forcefully restrained by the authorities, pepper-sprayed, or shocked with stun guns. The presence of the trait often created enough doubt for officers to avert criminal or civil penalties.

#### **EUGENICS**

#### The Eugenics Roots of Evangelical Family Values

Audrey Clare Farley, Religion & Politics | 05.12.2021

The specific history of eugenics helps to explain how procreative, heterosexual marriage became enshrined as the most important moral duty for some evangelicals—one that believers are enticed to pursue from a young age and then to perform at all costs, including physical and psychological harm. It also fuels modern fears of "white replacement."

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