

MAY 2019



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GENETICS  
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# BioPolitical

# News&Views

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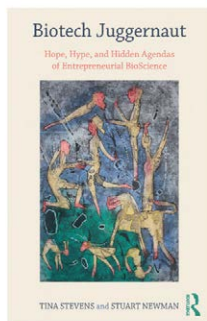
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## SPOTLIGHT

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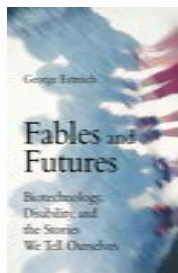


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### Help CGS Start a Podcast

Help us fight for a just and equitable human future. For our spring fundraising campaign, we're offering a copy of *Biotech Juggernaut* to supporters who donate \$200 or more. Contribute today and support the launch of our new podcast!

## ANNOUNCEMENTS



### Fables and Futures: Video Online

Catch up on this lively conversation between Marsha Saxton and George Estreich, author of *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*. Recorded at the San Francisco Public Library; now [available online](#).

**Spread the Word!**



Forward this newsletter to a friend who cares about what's happening at the intersections of biotechnology and social justice.

## COMMENTARY



### **Moratorium on Germline Gains Momentum**

**Pete Shanks**, *Biopolitical Times* | 05.09.2019

The American Society of Gene and Cell Therapy has issued a letter to the Department of Health and Human Services calling for a global moratorium on heritable genetic modification. The signatories also include over 40 prominent academics and representatives of a dozen companies involved in gene editing, gene therapy, and biotechnology financing.



### **Dani Shapiro's *Inheritance* and the Consequences of Genetic Ancestry Testing**

**Gina Maranto**, Guest Columnist, *Biopolitical Times* | 04.19.2019

In her new memoir, Dani Shapiro tells the story of how a DNA ancestry test forever altered her sense of her own identity. Given the ubiquity of these tests, should we think more seriously about how they are accessed?



### **Pro/Con: Should a Moratorium Be Imposed on Human Germline Editing?**

**Marcy Darnovsky and Katie Hasson**, *CQ Researcher* | 04.26.2019

CGS staff weigh in on the call for a moratorium, arguing it is a minimal but welcome step that affords the time necessary to engage in democratic decision-making about whether to allow human germline editing.

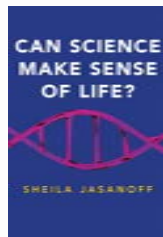


### **Shaq's New Ad Campaign Revives the Dangerous Push for Race-Specific Medicine**

**Jonathan Kahn**, Guest Columnist, *Biopolitical Times* | 04.29.2019

The heart failure medication BiDil is once again being marketed specifically to black patients. Given that race is neither a genetic nor a biological category, how did this happen?

**Book Review: *Can Science Make Sense of Life?***



**Pete Shanks**, *Biopolitical Times* | 05.03.2019

In her new book, Sheila Jasanoff seeks to understand how biologists have come to “claim ownership of the meaning of life,” and then to show why that matters.



**Talking Biopolitics: A Conversation With Tina Stevens and Stuart Newman**

**Adrienne van der Valk**, *Biopolitical Times* | 05.06.2019

The authors of *Biotech Juggernaut: Hope, Hype, and Hidden Agendas of Entrepreneurial BioScience* talk about what inspired them to write the book and how they see bioentrepreneurialism playing out in 2019.

## CGS IN THE NEWS



**Two Moms and a Dad Give Birth to Healthy ‘Three-person Baby’**

**Muri Assunção**, *New York Daily News* | 04.11.2019

A fertility clinic in Athens, Greece, announced the birth of what is believed to be the first baby born in a clinical trial using a “three-person” IVF technique called spindle nuclear transfer. Although the birth is being heralded by some fertility doctors as a step toward giving parents their “inalienable right” to a genetically related child, CGS Executive Director Marcy Darnovsky calls it an “irresponsible kind of human experimentation.”



**U.S. Researcher Says He’s Ready to Start Four Pregnancies With ‘Three-parent’ Embryos**

**Emily Mullin**, *STAT* | 04.18.2019

Currently, the FDA cannot approve applications for human research applications “in which a human embryo is intentionally created or modified to include a heritable genetic modification.” Doctors are petitioning to lift the ban on three-person IVF, in a move CGS Executive Director Marcy Darnovsky describes as “clearly a warmup to germline editing.”



**Should Athletes Be Allowed to Enhance Their Genes?**

**Nick Busca**, *One Zero by Medium* | 04.26.2019

The World Anti-Doping Agency banned gene doping in 2003. Now, a bioethicist is challenging the assumption that gene editing for athletic enhancement is inherently wrong. CGS Executive Director Marcy Darnovsky

cautions: enhancing humans could be disastrous for a society where inequality is already on the rise



## Is a Therapy Designed to Treat Mitochondrial Disease Setting its Sights on Age?

**Alison Motluk**, *HeyReprotech* | 04.30.2019

The link between mitochondrial transfer treatments and infertility is tenuous at best, but more clinics want to use “three-person IVF” to treat women who do not carry mitochondrial diseases. As CGS has reported, this is an example of a “nimble fertility industry tapping bigger markets in what could be described as an off-label use.”

## WHAT WE'RE READING

[Animal Technologies](#) | [Assisted Reproduction](#) | [Eugenics](#) | [Gene Therapy](#)  
[Genomics](#) | [Genetic Testing](#) | [Heritable Gene Editing](#) | [Stem Cells](#)

### HERITABLE GENE EDITING

#### **Scientific Leaders Call For Global Moratorium on Germline Gene Editing** **Editor**, *American Society of Gene & Cell Therapy* | 04.24.2019

In a letter to U.S. Department of Health and Human Services Secretary Alex Azar, sixty-two individual scientists, bioethicists, and biotechnology executives state they “strongly believe the editing of human embryos that results in births carries serious problems for which there are no scientific, ethical, or societal consensuses.”

#### **Moratorium on Human Genome Editing: Time to Get It Right**

**Landon J. Getz and Graham Dellaire**, *The Hastings Center* | 03.29.2019

A moratorium on human germline editing would provide time to address societal and ethical issues as well as human safety.

#### **Gene-Edited Babies: What a Chinese Scientist Told an American Mentor**

**Pam Belluck**, *The New York Times* | 03.29.2019

Stephen Quake claims he was ethically opposed to He Jiankui’s CRISPR baby experiment—but he didn’t do anything to stop it.

### GENETIC TESTING

#### **The Risky Business of Embryo Selection**

**Julianna LeMieux**, *Genetic Engineering & Biotechnology News* | 04.01.2019

A genetic testing start-up will offer polygenic risk scores for screening embryos during IVF.

## **Prenatal Testing Can Ease Minds Or Heighten Anxieties**

**Lesley McClurg**, *National Public Radio* | 04.08.2019

Expecting parents have more information than ever about the health of their fetus, but is more information always better?

## **Researchers Want to Link Your Genes and Income—Should They?**

**Megan Molteni**, *Wired* | 04.12.2019

Bolstered by a global boom in biobanking, researchers have more data than ever before to probe connections between people's DNA and their socioeconomic circumstances.

## **Don't Count on 23andMe to Detect Most Breast Cancer Risks, Study Warns**

**Heather Murphy**, *The New York Times* | 04.16.2019

23andMe's testing formula for BRCA is built around just three genetic variants, most prevalent among Ashkenazi Jews. Most people carry other mutations of the gene.

## **Chinese Scientists Have Put Human Brain Genes in Monkeys—and Yes, They May Be Smarter**

**Antonio Regalado**, *MIT Technology Review* | 04.10.2019

The engineered monkeys have extra copies of a human gene that plays a role in intelligence, raising serious ethical questions.

## **The Engineering Of Living Organisms Could Soon Start Changing Everything**

**Oliver Morton**, *The Economist* | 04.04.2019

Synthetic biology has grown more capable, and its products have begun to alter nature in more extreme ways.

## **GENOMICS**

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### **'Race-Biased Dragnet': DNA From 360 Black Men Was Collected to Solve Vetrano Murder, Defense Lawyers Say**

**Jan Ransom and Ashley Southall**, *The New York Times* | 03.31.2019

The New York Police Department is being asked to account for some disturbing DNA collection practices allegedly used during the search for Karina Vetrano's killer.

### **The Myth of Fingerprints**

**Clive Thompson**, *Smithsonian* | 04.01.2019

Police have long used fingerprinting as an integral tool for fighting crime; its reliability has since come into question. Will the same thing happen with DNA?

### **We Tried To Find 10 BuzzFeed Employees Just Like Cops Did For The Golden State Killer**

**Peter Aldhous**, *Buzzfeed* | 04.09.2019

A BuzzFeed reporter used a genealogy database to identify fellow employees from their DNA, revealing

multiple privacy and racial profiling issues.

## GENE THERAPY

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### **Gene Therapy Was Hailed as a Revolution. Then Came the Bill**

[James Paton](#), *Bloomberg* | 04.06.2019

Beneath the excitement about these potential cures lies an important question: Who can afford them?

## ASSISTED REPRODUCTION

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### **IVF Industry Trade Group Uses Advocacy Non-Profit to Push Money-Making Agenda**

[Editor](#), *ReproTech Truths* | 04.10.2019

RESOLVE used to be a grassroots network of women helping women. Now, it's a tool of big pharma.

### **Great Eggspectations**

[Jasmin Rosemberg](#), *The New York Times* | 04.05.2019

Fear of infertility led Jasmin Rosemberg to freeze her eggs. While she doesn't regret the decision, she wishes she had better understood its complexity.

### **Adoption and Sperm and Egg Donations Are No Longer Anonymous**

[Ellen Matloff](#), *Forbes* | 04.07.2019

For around \$100, people in the United States can now send their saliva sample to a direct-to-consumer testing company in search of a biological match.

### **Is Your Pregnancy App Sharing Your Intimate Data With Your Boss?**

[Drew Harwell](#), *The Washington Post* | 04.10.2019

Bosses' top medical question? How soon the new moms they employ plan to return to work.

## EUGENICS

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### **California Lawmakers Seek Reparations For People Sterilized By The State**

[Samantha Young](#), *The Washington Post* | 04.25.2019

The bill would establish the Eugenics Sterilization Compensation Program for the living survivors of state-sponsored sterilization from 1909 to 1979.

## STEM CELLS

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### **FDA, New York Attorney General Go After Stem Cell Clinics**

[Chia-Yi Hou](#), *The Scientist* | 04.08.2019

Regulators are cracking down on clinics that lure in patients desperate for treatment, then offer "cures" that are unproven to work

## ANIMAL TECHNOLOGIES

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### **Introducing the World's First Gene-Edited Lizard**

**Heather Murphy**, *The New York Times* | 04.05.2019

In a breakthrough experiment, scientists have produced an albino lizard.

### **Chinese Scientists Have Put Human Brain Genes in Monkeys—and Yes, They May Be Smarter**

**Antonio Regalado**, *MIT Technology Review* | 04.10.2019

The engineered monkeys have extra copies of a human gene that plays a role in intelligence, raising serious ethical questions.

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