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# CENTER FOR GENETICS AND SOCIETY

## BIOPOLITICAL VIEWS & NEWS

September 6, 2018

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## ANNOUNCEMENTS

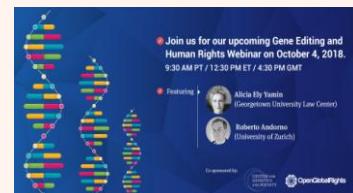
### Center for Genetics and Society is hiring!

Interested in a unique opportunity to work on issues of social justice and biotechnologies? We're hiring a Communications and Program Manager. Read more about the position [here](#).



### Webinar: Gene Editing and Human Rights

What does human gene editing have to do with human rights? ...Quite a lot! Join us on October 4th for a free webinar on Gene Editing and Human Rights, co-sponsored with [OpenGlobalRights](#) and featuring speakers Alicia Ely Yamin (Georgetown University Law Center) and Roberto Andorno (University of Zurich), with OpenGlobalRights' David Petrasek and the Center for Genetics and Society's Katie Hasson.



### Updates on a California Bill to Compensate Survivors of Eugenic Sterilization

Unfortunately, SB 1190 will not become law this year. Despite having been unanimously approved by the full California Senate and an Assembly committee, it did not pass through an August 16 meeting of the Assembly Appropriations Committee. The bill had the support of a large coalition of social justice organizations (see a full list on this [fact sheet](#)). CGS and our allies are disappointed at this outcome, but look forward to the possibility of advancing a powerful campaign on behalf of the survivors of California's eugenics laws in 2019, with a new governor and new legislators. A victory already sparked by the effort to pass SB 1190 is [a resolution](#) by the Los Angeles County Board of Supervisors to support the bill, issue an apology to the women who were involuntarily sterilized in Los Angeles County+USC Medical Center between 1968 and 1974, and install a plaque on the campus. Read more about SB 1190 [here](#).

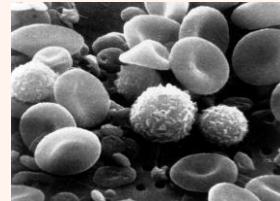


## CGS COMMENTARY

### The Evolving State of Human Germline Gene Editing

By Katie Hasson, *GeneWatch*

What can we make of opposing trends in the gene editing conversation: seeming normalization in scientific and policy discussions, alongside intensified calls for engaging the public? And how can we ensure that debates about germline editing result in empowered public participation with meaningful results?



### **CIRM Faces Its Future**

By Pete Shanks, *Biopolitical Times*

The California Institute for Regenerative Medicine is running out of money. What next? A new \$5 billion ballot proposition?



### **Is Silence Consent?**

By Pete Shanks, *Biopolitical Times*

Technical advances in gene editing of human embryos deserve more attention than they seem to be receiving.



### **Steinberg, Still Starting to Sell Eugenics**

By Pete Shanks, *Biopolitical Times*

At irregular intervals over the last decade or so, Dr. Jeffrey Steinberg of The Fertility Institutes has used the media to promote eugenic ideas to make money. After briefly offering selection of eye, skin, and hair color about a decade ago, he is again starting to sell a choice of eye color, in addition to sex selection.



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## **CGS in the NEWS**

### **► Genetic Testing Kits: Unprecedented Privacy Risks**

[cites CGS' Katie Hasson]

by Sarah Russo, *The Technoskeptic*

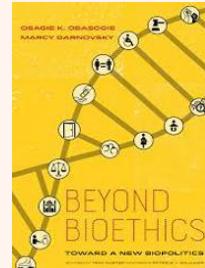
"There should be a broader public conversation about how our genetic information should be protected, who can access it, and under what circumstances. These large private companies must be held accountable for what they are doing with this information," says CGS' Katie Hasson.



### **► Review of "Beyond Bioethics: Toward a New Biopolitics"**

by Daniel Bojar, *The Biologist*

As the editors Marcy Darnovsky and Osagie K. Obasogie argue, the age of bioethics which focused on the individual is drawing to a close, and should be superseded by biopolitics focusing on whole societies.



### ► [\*\*Officials remove special rules for gene therapy experiments\*\*](#)

[cites CGS' Marcy Darnovsky]

by Marilynne Marchione, Associated Press

"We need to strengthen rather than weaken the review apparatus" for gene therapy experiments, cautions Darnovsky.

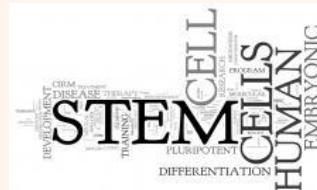


### ► [\*\*Lofty promises, limited results: After 14 years and \\$3 billion, has California's bet on stem cells paid off?\*\*](#)

[cites CGS' Marcy Darnovsky]

by Erin Allday and Joaquin Palomino, *San Francisco Chronicle*

Critics and supporters alike say those who pushed Prop. 71 significantly oversold the short-term medical and financial prospects of stem cells.



### ► [\*\*A Harsher Look at California's Stem Cell Program: No More Cash Without Changes\*\*](#)

[cites Pete Shanks at *Biopolitical Times*]

by David Jensen, *California Stem Cell Report*

A post on the CGS blog argues that CIRM should not receive additional funds as it is presently constituted.



### ► [\*\*Podcast: Why We Need to Discuss Gene Editing and Ethics\*\*](#)

[cites CGS' Marcy Darnovsky]

by Jack Murtha, *Health Care Analytics*

This episode of Data Book discusses what's at stake and how society and healthcare organizations and providers may frankly and effectively navigate these issues.



### ► [\*\*Why Are So Many Parents Picking Their Baby's Sex?\*\*](#)

[cites CGS' Marcy Darnovsky]

by Rebecca Gale, *Dame*

"Why is it so important to control the sex of the child?" asks CGS' Marcy Darnovsky.



## NEWS

[Assisted Reproduction](#)

[Eugenics](#)

[Genetic Testing](#)

[Human Gene Editing](#)

[Various](#)

## HUMAN GENE EDITING

### ► [Building bioethics into the future of life sciences innovation](#)

by Rick Mullin, *Chemical and Engineering News*

Most people, scientists included, view social justice as a matter of determining which groups in society have access to beneficial technologies. But there is also the question of which groups in society decide which technologies will be developed, says Jenny Reardon of the Science and Justice Research Center at UC Santa Cruz.

### ► [The Patients Who Don't Want to Be Cured](#)

by Sarah Zhang, *The Atlantic*

I am hemophilia. I don't have it. I am hemophilia. So when they come to me and say, "We've got a genetic cure for hemophilia," to me, that's just as weird as if you said you've got a genetic cure on the horizon for your left foot. This is really who I am. So I don't necessarily see it as something that needs a cure.

### ► [With Embryo Base Editing, China Gets Another Crispr First](#)

by Megan Molteni, *Wired*

A team of scientists in China have used base editing, a Crispr-based gene editing technique, in viable human embryos to modify a variant that causes Marfan Syndrome.

### ► [US scientist who edited human embryos with CRISPR responds to critics](#)

by Antonio Regalado, *MIT Technology Review*

*Nature* published two critiques of the human embryo editing experiments done by Shoukrat Mitalipov, as well as his team's reply.

## GENETIC TESTING

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### ► [Ancestry Tests Pose a Threat to Our Social Fabric](#)

by John Edward Terrell, *Sapiens*

Even if people don't take commercial genetic testing seriously, they risk internalizing the outdated social and scientific assumptions about race hidden behind these reported results.

### ► [23andMe's Pharma Deals Have Been the Plan All Along](#)

by Megan Molteni, *Wired*

23andMe has access to an ever-expanding supply of their customers' valuable genetic, health, and behavioral information. Selling access to this information to drug companies has been their business plan from the beginning.

### ► [DNA ancestry tests may look cheap. But your data is the price](#)

by Adam Rutherford, *The Guardian*

By tinkering with some fun ancestry trinkets, you relinquish control over information that is unique to you, and allow it to become a commodity to be traded. Do customers realize that genetic genealogy companies like 23andMe profit by amassing huge biological datasets?

## EUGENICS

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### ► [Mountain View Commemorates Lab of William Shockley, Acclaimed Physicist and Vocal Racist](#)

by Sam Harnett, *The California Report*

Last week, nearly 400 people attended the unveiling of a large statue of a silicon atom and a plaque honoring the Shockley Semiconductor Laboratory, which many regard as the birthplace of Silicon Valley. But the person who started the lab, William Shockley, was a eugenicist who advocated for the voluntary sterilization of black Americans.

### ► [University accepted \\$458K from eugenics fund](#)

by Michael Kunzelman, *Associated Press*

The University of Arizona has accepted years of funding from a foundation infamous for promoting research linking race and intelligence — even after other universities and organizations, including white nationalist groups, stopped receiving support from the group, records show.

## ASSISTED REPRODUCTIVE TECHNOLOGIES

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### ► [IVF children at far greater risk of dangerous high blood pressure, study suggests](#)

by Sarah Knapton, *The Telegraph*

Children born through IVF may be six times more likely to suffer high blood pressure than naturally conceived children, putting them at greater risk of heart attacks and strokes.

### ► [Risk vs. Reward: Two women's health care professionals offer insight to the dangers of egg harvesting](#)

by Judy Norsigian & Dr. Gary Richwald, *Golden Gate Xpress*

We need to strengthen current efforts to produce better long-term safety data for all the young women thinking about providing eggs. In the meantime, faculty members should not be using their positions of influence and ready email access to students to advise engagement in the potentially risky proposition of egg provision.

### ► [Spanish couples undergoing surrogacy processes left in legal limbo in Ukraine](#)

by Silvia Blanco, *El País*

A total of 30 families are unable to secure passports for their children, after the Foreign Affairs Ministry says it has detected reports of malpractice and possible trafficking.

### ► [When treating and researching infertility, let's not forget the men](#)

by Vardit Ravitsky and Sarah Kimmings, *The Globe and Mail*

Because men have been largely neglected in fertility research, diagnosis and treatment, women are disproportionately exposed to the risks of egg retrieval and IVF.

## VARIOUS

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### ► [A Radical '70s-Era Group Is Relaunching to Help Scientists Get Political Under Trump](#)

by Rebecca Onion, *Slate*

Scientism—a blanket defense of science as a virtuous and almost holy exercise of objectivity and rationality—can feel like the only natural response to the times. But, tempting as it might be, cheerleading for capital-S “Science” can’t be the answer. Science for the People, and its awareness of how science fits into policy and politics, is deeply necessary in 2018.

### ► [Franken-algorithms: the deadly consequences of unpredictable code](#)

by Andrew Smith, *The Guardian*

Between “dumb” fixed algorithms and true AI lies the problematic halfway house we’ve already entered with scarcely a thought and almost no debate, much less agreement as to aims, ethics, safety, best practice.

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