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# CENTER FOR GENETICS AND SOCIETY

## BIOPOLITICAL VIEWS & NEWS

June 8, 2017

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## ANNOUNCEMENTS

### [Register for the "Gene Editing and the Future of Reproductive Justice" Webinar](#)

CGS will be co-sponsoring a webinar, "Gene Editing and the Future of Reproductive Justice," with [Black Women for Wellness](#) and [In Our Own Voice National Black Women's Reproductive Justice Agenda](#) on June 13 at 10 am PDT/ 1 pm EDT. Featured panelists include [Dorothy Roberts](#), [Ruha Benjamin](#), and [Lisa Ikemoto](#). Find more information, including registration and closed captioning, on [Facebook](#).



### [Video of "A Conversation on Disability Justice and Human Genetic Engineering" Now Available](#)

On April 24, CGS co-hosted a webinar on disability justice and human genetic engineering alongside the [Paul K. Longmore Institute on Disability](#), the [Disability Visibility Project](#), and the [Disability Rights Education & Defense Fund](#). A video of the webinar is currently available to watch [on our website](#) with closed captioning.



### [Join CGS as a Program Director on Genetic Justice](#)

CGS is currently hiring a senior-level Program Director on Genetic Justice to bring a social justice framework to current debates and policy considerations on human biotechnology developments, with a focus on human gene editing for reproduction. The Program Director will foster collaboration among individuals in multiple academic and professional fields as well as a range of social justice and non-profit organizations; raise awareness among the public and the media; and influence state, national and international policy.



## CGS COMMENTARY

### [Why reproductive justice is essential to understanding gene editing](#)

by Victoria Massie

Nourbese Flint, the program manager for Black Women for Wellness and moderator of the upcoming "Gene Editing and the Future of Reproductive Justice" webinar, discusses why reproductive justice activists need to have a seat at the table in discussions around gene editing.



## [CGS Speaks on Human Germline Editing in India](#)

by Leah Lowthorp

CGS Program Manager Leah Lowthorp discusses her experience giving two talks on human germline editing in India in late May.



## [Questions about CRISPR Accuracy](#)

by Pete Shanks

A new research paper suggests that gene editing with CRISPR may cause unexpected changes in a genome.



## [Peer Pressure: Lord Winston decries egg sharing in the UK](#)

by Gina Maranto, Guest Contributor

In the midst of a recent egg-sharing scandal in the UK, Robert Winston, an IVF pioneer and member of the House of Lords, remains one of the country's most salient critical voices.



## [The Ongoing Tale About \*The Handmaid's Tale\*](#)

by Ayesha Chatterjee, Guest Contributor

Hulu's adaptation of Margaret Atwood's novel, *The Handmaid's Tale*, provides disturbing parallels to the realities of modern-day surrogacy.



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## CGS in the NEWS

### [California Today: Waiting on the Promise of Stem Cells](#)

[citing CGS' Marcy Darnovsky]

by Michael McPhate, *New York Times*

Few would argue for an end to the research itself. But if California taxpayers are asked to step up again, the governance problems must be fixed first, said Marcy Darnovsky, who runs the nonprofit Center for Genetics and Society in Berkeley. "I don't think they can just see it as a do-over," she added.



## NEWS

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## GENE EDITING

### [Researchers Discover Hundreds of Unexpected Mutations from New Gene Editing Technology](#)

by Jessica Wapner, *Newsweek*

The technology had accomplished the original intended task of correcting a gene that causes blindness in mice, but it had also resulted in 1,500 other small changes and 100 large changes. Not one of those changes had been predicted by the researchers.

▶ [Genome editing: That's the way the CRISPR crumbles](#)

by Nathaniel Comfort, *Nature*

[Review of *A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution* by Jennifer Doudna and Samuel Sternberg] Rather than guiding us through the ethical thickets of precision genetic engineering, or providing a candid, warts-and-all look at one of the great scientists of our time, the book mainly polishes her 'good scientist' image and rationalizes the unfettered self-direction of human evolution, within liberal bounds of safety, efficacy and individual choice.

▶ [Human Genome Editing: Who Gets to Decide?](#)

by Dietram A. Scheufele and David Beier, *Scientific American*

What are the ethical and moral boundaries of the human race editing its own genome? Who will have access to many of the potentially expensive medical treatments resulting from this new area of research? And where is the line between treating serious disease and enhancing humans beyond what society considers "normal?"

▶ [Gene Editing, "Cultural Harms," and Oversight Mechanisms](#)

by Erik Parens, *Bioethics Forum*

Is it reasonable to hope that concerns about "cultural harms" can be integrated into oversight mechanisms for technologies like gene editing? That question was raised anew for me by the recent National Academy of Sciences report on human genome editing and at a recent conference at Harvard on the international governance of genome editing technologies.

▶ [A national discussion on gene editing is urgently needed](#)

by Friends of the Earth, *Emerging Tech Project*

Most of the discussion so far has taken place between industry 'experts' behind closed doors. In order to catalyze discussion, the Academy released a discussion paper last week on gene drives.

▶ [Trying to Embrace the Cure](#)

by Sheila Black, *New York Times*

I can't predict where Crispr and the like will lead, but I do know that ethics and lived experience must be important guides, and that the very knowledge contained in the disability community is perhaps the best place to start, for who better to consider such questions than those of us who have lived with being different?

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▶ [A Year After Approval, Gene-Therapy Cure Gets Its First Customer](#)

by Emily Mullin, *MIT Technology Review*

On Tuesday, GlaxoSmithKline spokesperson Anna Padula said the company treated its first patient in March, nearly a year after Strimvelis was approved for sale in Europe in May 2016. The company declined to provide the nationality of the patient or say how the treatment was paid for.

▶ [First In Vivo Human Genome Editing to Be Tested in New Clinical Trial](#)

by Abby Olena, *The Scientist*

Researchers have edited the human genome before, but always in cells outside the body. Now, biotech company Sangamo Therapeutics is recruiting participants for clinical trials in which patients with hemophilia B, Hurler syndrome, or Hunter syndrome will have the gene coding for one of the

enzymes that is non-functional in them stitched into their genomes at double-stranded DNA breaks caused by zinc finger nucleases.

## ASSISTED REPRODUCTION

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### ▶ [Exploited by cash-for-eggs IVF clinics: \*Mail\* investigation finds desperate women are told to donate eggs for free treatment](#)

by Paul Bentley and Sara Smyth, *Daily Mail*

Undercover reporters from the *Mail* visited clinics posing as would-be parents who could not afford treatment.

### ▶ [Fertility regulator launches inquiry into 'cash for eggs' claims](#)

by Haroon Siddique, *The Guardian*

The fertility regulator has launched an investigation into allegations that IVF clinics are inducing women to donate eggs in return for free or discounted treatment.

### ▶ [Why I'm ashamed of the exploitation in the IVF industry](#)

by Robert Winston, *Daily Mail*

This newspaper has published evidence of widespread bad practice in my own medical specialty, infertility treatment. And I feel angry because the Government's regulatory body, the Human Fertilization and Embryology Authority (HFEA), has been inadequate. It has not prevented the disgraceful exploitation of patients, mostly women.

### ▶ [When pregnancy dreams become IVF nightmares](#)

by Bernice Yeung and Jonathan Jones, *Reveal*

The quest for speedy success by both patients and doctors has encouraged nearly 8 in 10 clinics nationwide to routinely use more than one fertilized egg at a time, according to Reveal's analysis of government data from 2015, the most recent year available. That's despite warnings against the practice from the government and industry groups worried about the country's high twin rate.

### ▶ [3 ways to address the problems with IVF](#)

by Bernice Yeung and Jonathan Jones, *Reveal*

Our reporting found that the law isn't having its intended effect – and is driving bad practices. Given the shortcomings of consumer protections, here are three ideas that could help fix the problems we found.

### ▶ [Uterus Transplants are Reinforcing Patriarchal Notions of 'Biological Motherhood'](#)

by Sneha Banerjee & Sarojini Nadimpally, *The Wire India*

Uterus transplants raise several ethical concerns drawing from the health risk posed to women, especially since the surgery is not meant to treat a life threatening condition. ... There is a need to question the premium that is placed on biological parenthood and the assumption that motherhood can only be linked to genes and gestation.

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## GENE TESTING

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### ▶ [There's no such thing as a 'pure' European—or anyone else](#)

by Ann Gibbons, *Science Magazine*

Few of us are actually the direct descendants of the ancient skeletons found in our backyards or historic homelands. Only a handful of groups today, such as Australian Aborigines, have deep bloodlines untainted by mixing with immigrants.

### ▶ [Ancestry.com takes DNA ownership rights from customers and their relatives](#)

by Joel Winston, *Medium*

To use the AncestryDNA service, customers must consent to the Ancestry.com Privacy Policy and Terms of Service. These are binding legal contracts. The most egregious of these terms gives Ancestry.com a free license to exploit your DNA for the rest of time.

► [Ancestry.com denies exploiting users' DNA](#)

by Harry Kretchmer, *You and Yours, BBC Radio 4*

The US company's DNA testing service has included a right to grant Ancestry a "perpetual" license to use customers' genetic material. A New York data protection lawyer spotted the clause and published a blog warning about privacy implications. Ancestry told BBC Radio 4's *You and Yours* its terms were being changed.

► [Genetic tests often overused and misinterpreted, sometimes with tragic consequences](#)

by Paul Sisson, *San Diego Tribune*

Doctors are often faced with sales pitches on these tests, which can gloss over key issues.

► [A Decade Later, a Patient Finds Out Her Genetic Test Was Wrong](#)

by Sarah Zhang, *The Atlantic*

Should scientists give results to participants in research studies if they haven't been validated in a clinical lab?

► [The direct-to-consumer genetic testing fog](#)

by Timothy Caulfield, *Policy Options*

This recommendation is based largely on concerns about the accuracy, reliability and clinical value of these tests. But another significant limitation (and one that I've written about often) is that they simply don't have an impact on health behaviours.

► [Insurers help make genetic testing widely available](#)

by Catherine Ho, *San Francisco Chronicle*

The technology is advancing quickly, and the cost of many types of tests is plummeting. Not all tests are covered. But increasingly, insurers are willing to cover screenings for genetic mutations linked to breast, colon and prostate cancer.

► [Thanks to Genetic Testing, Everyone Could Soon Have a Pre-Existing Condition](#)

by Maryam Zaringhalam, *Slate*

Our genomes provide a window into scores of genetic risk factors that have yet to present as full-fledged pre-existing conditions. If the GOP insists that people can be charged differently depending on their current health, what's to say they'll stop short of asserting that we could be charged according to our genomes?

► [New Gene Tests Pose a Threat to Insurers](#)

by Gina Kolata, *New York Times*

The issue for now is with long-term care insurance, not employment and not — at least so far — health insurance.

► [China moves to expand DNA testing in Muslim region](#)

by Matthew Brown, *Associated Press*

With at least \$8.7 million in equipment, China appears to be laying the groundwork for the mass collection of DNA samples from residents of a restive, largely Muslim region that's been under a security crackdown, rights observers and independent experts said Tuesday.

► [5 Things You Need To Know Before Taking an At-Home Genetic Test](#)

by Parminder Deo and Jacqueline Paulis, *NBC News*

With the Food and Drug Administration's approval of the first ever direct-to-consumer test, the company 23andMe can not only sell commercial DNA kits to determine ancestry, but they can test for 500,000 genetic variants to assess for risk of developing any one of 10 diseases. You can do this in the privacy of your home. But should you?

► [Can DNA Evidence Be Too Convincing? An Acquitted Man Thinks So](#)

by Eli Rosenberg, *New York Times*

Erin E. Murphy, a professor at New York University School of Law, who has written critically of the use of DNA in forensics, said studies had demonstrated that samples extracted from DNA mixtures of three or more people, like the one that investigators said yielded a match to Mr. Gills's DNA, were more likely to contain errors.

► [State forensic panel approves use of familial DNA to ID suspects](#)

by Anthony M. DeStefano, *Newsday*

A special state committee Friday approved a recommendation that New York State adopt the use of familial searching, an emerging DNA procedure employed in some states to identify potential suspects. ... The measure now goes to the full commission, which could vote on it next month.

► [Death row inmates granted direct DNA testing through Ohio Supreme Court under new rule](#)

by Jim Provance, *The Blade*

Under the new rule, if a Lucas County Common Pleas judge denies an application for DNA testing of evidence after a death sentence has already been imposed, an appeal of that decision would skip the Sixth District Court of Appeals and be fast-tracked to the Supreme Court.

## BIOETHICS

► [Hastings President Addresses National Conference on the Wise Use of Emerging Technologies](#)

by Mildred Solomon, *Hastings Center News*

Hastings Center president Mildred Solomon delivered a keynote address at the Future of Medicine conference, which focused on emerging biotechnologies and anticipated some of their social, ethical, and policy implications.

► [Generations later, the effects of the Tuskegee syphilis study linger](#)

by *Associated Press*

The litigation continues to this day, with a federal court currently considering a request that will help determine the study's final legacy. A key, unanswered question: What should be done with unclaimed settlement money that still sits in court-controlled accounts?

► [Guinea pigs or pioneers? How Puerto Rican women were used to test the birth control pill](#)

by Theresa Vargas, *Washington Post*

The truth was that little was known about the drug's effects when gynecologist John Rock and biologist Gregory Pincus – with the backing of birth control advocate Margaret Sanger and philanthropist Katherine McCormick – decided to launch the human trials.

► [Are we about to witness the most unequal societies in history?](#)

by Yuval Noah Harari, *The Guardian*

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With rapid improvements in biotechnology and bioengineering, we may reach a point where, for the first time in history, it becomes possible to translate economic inequality into biological inequality.

## GOVERNANCE

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### ▶ [The House Health Plan Makes Your Genes a Preexisting Condition](#)

by Adam Roger, *Wired*

If Congress and the President replace Obamacare with something like what the House has cooked up, that'll change, because GINA will be the only way to force insurance companies to cover people with preexisting conditions.

### ▶ [Trump's Proposed Budget Cuts Trouble Bioterrorism Experts](#)

by Emily Baumgaertner, *New York Times*

President Trump has promoted his first budget proposal as placing one mission above all else — keeping America safe. But the president has drawn a narrow definition of national security, and one aspect of defense would actually receive less money: protecting the nation from deadly pathogens, man-made or natural.

### ▶ [Beware the anti-science label](#)

by *Nature Editorial*

Presenting science as a battle for truth against ignorance is an unhelpful exaggeration. ... Science is only one of many factors and interests that a thoughtful politician needs to weigh when choosing a position on a complex topic.

### ▶ [Crispr Makes It Clear: The US Needs a Biology Strategy, and Fast](#)

by Amy Webb, *Wired*

Its trajectory necessarily involves government agencies and commissions, our elected officials, and the courts—and none of them are prepared for what's coming.

### ▶ [GOP reps to Trump: fire NIH Director Collins for stem cell research support](#)

by Paul Knoepfler, *The Niche Blog*

A few dozen super conservative Republican members of Congress have written a letter to President Trump saying he should fire NIH Director Francis Collins. Why? Because they claim that Collins is not conservative enough for their taste and in particular they don't like his support of embryonic stem cell research funding.

## SYNTHETIC BIOLOGY

### ▶ [The Fuzzy Regulations Surrounding DIY Synthetic Biology](#)

by Molly Olmstead, *Slate*

At the moment, there is a lot of uncertainty surrounding the regulation of the DIY biology movement. DIY biologists, a subset of the biohacker community, mess around with DNA, often in communal lab settings where they share their techniques, knowledge, and discoveries with other science enthusiasts.

### ▶ [DARPA's Synthetic Biology Initiatives Could Militarize the Environment](#)

by Todd Kuiken, *Slate*

Among other initiatives, researchers at DARPA are attempting to engineer insects to deliver protective genes to plants; to transform bacteria and yeast into factories to produce on-demand chemicals and fuels; and to develop methods to reverse any threats posed by gene drives.

### ▶ [Money still missing as the plan to synthesize a human genome takes](#)

## [another step forward](#)

by Ryan Cross, *Science Magazine*

Tuesday morning, more than 200 biologists, businesspeople, and ethicists will converge on the New York Genome Center in New York City to jump-start what they hope will be biology's next blockbuster: Genome Project-write (GP-write), a still-unfunded sequel to the Human Genome Project where instead of reading a human genome, scientists create one from scratch and incorporate it into cells for various research and medical purposes.

### ▶ [Next Generation of GMOs Escapes Regulation](#)

by Ken Roseboro, *EcoWatch*

Twenty years ago, proponents of genetic engineering promised that GMO foods would increase yields, reduce pesticides, produce nutritious foods and help feed the world. Today, those promises have fallen far short as the majority of GMO crops are engineered to withstand sprays of Roundup herbicide, which is increasingly documented as a risk to human health.

## STEM CELLS

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### ▶ [Babies From Skin Cells? Prospect Is Unsettling to Some Experts](#)

by Tamar Lewin, *New York Times*

The process, in vitro gametogenesis, or I.V.G., so far has been used only in mice. But stem cell biologists say it is only a matter of time before it could be used in human reproduction — opening up mind-boggling possibilities.

### ▶ [Stem Cell Trial Data Mostly Go Unpublished](#)

by Anna Azvolinsky, *The Scientist*

Less than half of completed stem cell studies in humans are published in peer-reviewed journals, according to an analysis of regenerative medicine trial

### ▶ [Scientists Dismayed as Texas Leans into Unproved Stem Cell Treatments](#)

by Andrew Joseph, *STAT*

The debate in Texas echoes a national discussion over how much access patients should have to experimental drugs.

### ▶ [California's stem cell agency confronts uncertain future](#)

by David Jensen, *Capitol Weekly*

Since the agency's inception, it has spent money at the rate of \$22,000 an hour. But it has yet to finance a stem cell therapy that is available to the general public. Nonetheless, there is talk of a new, \$5 billion stem cell bond measure on the November 2018 ballot.

## VARIOUS

### ▶ [‘Straight out of the Nazi playbook’: Hindu nationalists try to engineer ‘genius’ babies in India](#)

by Annie Gowen, *Washington Post*

The group's health officials claimed that their program — a combination of diet, ayurvedic medicine and other practices — has led to 450 of these babies, and they hope to have “thousands” more by 2020, the report said.

### ▶ [Oxitec Pioneered the GM Mosquito. Up Next? Moths. Of Course](#)

by Eric Niiler, *Wired*

USDA officials have already received more than 600 public comments on the GM diamondback moth proposal since the docket opened last month. Backers include ag scientists and biotechnology advocates like Nobel chemistry laureate Richard Roberts, who argues that reducing pesticides will boost food production. ... But other commenters, like Dana Marsh of Bloomington, Ind., worry about the



unintended consequences of releasing a GM moth. If a gene drive escapes beyond the targeted area and proliferates widely, it could engineer the destruction of an entire species.

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