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# CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL  
VIEWS & NEWS

June 3, 2016

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## ANNOUNCEMENTS

### [Should We Genetically Modify Our Children?](#) [VIDEO]

Marcy Darnovsky unpacks the controversies that have erupted in recent months about how we should - and should not - use gene editing tools, and explores the technical, social, and ethical stakes of these imminent decisions.



### [We're almost at 6,000 followers on Twitter!](#)

Join the conversation by following us [@C\\_G\\_S](#) on Twitter and help us spread the word about [#biopolitics](#)! You can also glimpse discussions at our recent events by checking out [#TalkingBiopolitics](#) and [#BeingHumanUCB](#).



### [California Legislature Considers Bill to Expand the Market in Women's Eggs](#)

The California Senate Health Committee will vote June 8 on a bill that would overturn existing safeguards of the health of women who provide eggs for research. AB 2531 would expand the commercial market in women's eggs, allowing researchers to pay for eggs in amounts beyond reimbursing women for their expenses. The bill is opposed by women's health, reproductive rights and justice, and public interest organizations, including the Center for Genetics and Society. For more information, see CGS's [letter of opposition](#), and [comment](#) at *Biopolitical Times*. The report from the California Senate Health Committee legislative analyst will be available shortly on the [AB 2531 Bill Information page](#).



### [GMOs 2.0: Reengineering Life, from Plants to People.](#) [VIDEO]

In case you missed it, the recording of the webcast is now [online](#), along with:

- the speakers' slide shows
- answers to the questions and comments submitted by participants
- links to more resources and information



### [ONLINE NOW: Synthetic Biology – DIY Tinkering Meets Big Capital](#) [VIDEO]

In case you missed it, video of "Synthetic Biology: DIY Tinkering Meets Big Capital" is now available online at C-Span. CGS's Elliot Hosman and Pete Shanks present along with BioCurious' Tito Jankowski on CRISPR gene editing, biohacking, the threat of heritable human genetic modification, and the politics of technological innovation.



### [Fall Internships Available](#)

The Center for Genetics and Society is accepting applications for Fall internships. Please click [here](#) for the complete intern announcement.



## CGS COMMENTARY

### [CGS Comment on Synthetic Human Genome Project](#)

[Press statement]

Twenty-five scientists and corporate figures call for a ten-year project to construct a synthetic human genome from scratch.



### [Comment - Closed Harvard Meeting on Human Genome Synthesis](#)

[Press statement]

A new low for scientific accountability, the semi-secret meeting looks like a move to privatize the current conversation about heritable genetic modification.



### [Genome games: A secret meet and a controversy](#)

by Pete Shanks, *Deccan Chronicle*

A complete lack of transparency around a gathering to discuss synthetic human genomes triggers anger worldwide.



## [Will Modern Genetics Turn Us Into Gene “Genies”?](#)

[Collection of brief essays]

by Marcy Darnovsky, Dan Sarewitz, Samuel Weiss Evans, Arvis Sulovari,  
Eric A. Widra, *Zócalo Public Square*

Contributors discuss their stances on the dangers and potential benefits of gene manipulation.



## [On Cyborgs and Gene Editing: Lessons from Orphan Black](#)

by Jessica Cussins, *Biopolitical Times* Guest Contributor

The television show takes a cue from science fiction author Donna Haraway and engages the dangers of human genetic modification.



## [Forgotten Stories of the Eugenic Age #5: Creating Super-People](#)

by Natalie Oveyssi

Advocates of eugenics in the early twentieth century thought that careful mating would produce smarter, stronger, better people. What would these people look like? How would they behave? What kind of society would they form? Could making a better world be so simple?



# CGS in the NEWS

### ▶ [Scientists Say They Hope To Create A Human Genome In The Lab](#)

[citing CGS' Marcy Darnovsky]

by Rob Stein, *NPR*

"The worry is that we're going to be synthesizing entire optimized human genomes... to produce synthetic human beings that they see as improved models," said Marcy Darnovsky.

### ▶ [Secret Harvard meeting on synthetic human genomes incites ethics](#)

#### ▶ [debate](#)

[citing CGS' Marcy Darnovsky]

by Joel Achenbach, *Washington Post*

A secret meeting of 150 scientists at Harvard about creating a synthetic genome is generating ethics objections.

### ▶ [Top scientists hold closed meeting to discuss building a human genome from scratch](#)

[citing CGS' Marcy Darnovsky]

by Ike Swetlitz, *STAT*

If we can build a synthetic genome — and eventually, a creature — from the ground up, then what does it mean to be human?

### ▶ [What the man in the street thinks about human enhancement](#)

[citing CGS consultant Pete Shanks]

by Michael Cook, *BioEdge*

Polls show that more than 80% of people surveyed thought babies should not be genetically modified for increased intelligence or sporting ability.

## NEWS

### ▶ [Scientists Announce HGP-Write, Project to Synthesize the Human Genome](#)

by Andrew Pollack, *The New York Times*

Synthesizing a human genome "immediately raise[s] numerous ethical and philosophical red flags," NIH director Francis Collins said.

### ▶ [25 Scientists Just Made A \\$1 Billion Pitch To Build A Human Genome From Scratch](#)

by Nidhi Subbaraman, *BuzzFeed*

Drew Endy and Laurie Zoloth argue the project fails to ask a basic question: "Is developing capacities to synthesize human genomes a good idea?"

### ▶ [Should We Synthesize A Human Genome?](#)

by Drew Endy and Laurie Zoloth, *DSpace@MIT*

Human genome synthesis could redefine what now joins all of humanity together as a species. Discussions should not take place without open and advance consideration of whether and under what circumstances it is morally right to proceed.

### ▶ [Ethical Questions Loom Over Efforts to Make a Human Genome from Scratch](#)

by Antonio Regalado, *MIT Technology Review*

Printing genomes on demand could mean custom-built organisms, difficult ethical questions, and profits for a handful of companies.

### ▶ [Synthetic Biology's Second World](#)

by Andy Balmer, *PLOS Synbio Community*

A closed-door meeting of scientists to discuss the creation of a synthetic human genome suggests a secret world for synthetic biology in which decisions are made away from public scrutiny and governance.

### ▶ [Scientists Hold Secret Meeting to Consider Creating a Synthetic Human Genome](#)

by Andrew Pollack, *The New York Times*

An invitation to the Harvard meeting said the primary goal "would be to synthesize a complete human genome in a cell line within a period of ten years."

### ▶ [What It Means To Be Human Is Changing Thanks To Gene Editing](#)

by Joe Matthews (Zócalo Public Square), *Huffington Post*

"We might be splitting in class between those who can afford to manage our children eugenically and those who cannot."

▶ [British scientist can genetically modify human embryos, ethics committee says](#)

by Lydia Willgress, *The Telegraph*

Following HFEA approval in February, a local ethics committee approves Kathy Niakan's program to CRISPR human embryos for basic research.

▶ [Netherlands gives green light for growing human embryos](#)

by Agence France-Presse, *The Guardian*

The Dutch government sanctions "limited research" to help infertile couples and to tackle hereditary or congenital diseases.

▶ [In Search For Cures, Scientists Create Embryos That Are Both Animal And Human](#)

by Rob Stein, *NPR*

"You're getting into unsettling ground that I think is damaging to our sense of humanity."

▶ [Gene Therapy's First Out-and-Out Cure Is Here](#)

by Antonio Regalado, *MIT Technology Review*

A genetic therapy treatment for severe combined immune deficiency, also known as "bubble boy" disease, is now pending approval in Europe.

▶ [How should we pay for gene therapy?](#)

by Aaron Carroll (The Incidental Economist), *Academy Health Blog*

Unless pricing is regulated, gene therapies will likely be too expensive for most people to afford.

▶ [Huntington's disease: the new gene therapy that sufferers cannot afford](#)

by Dara Mohammadi, *The Guardian [UK]*

Efforts to treat Huntington's disease involve costly drugs way beyond the reach of the poor communities in South America who take part in research studies

▶ [After rivals' IPOs, will CRISPR Therapeutics go public or stay buttoned-down?](#)

by Damian Gard, *STAT*

Like CRISPR Therapeutics, Intellia and Editas were once cagey about their development pipelines, but in documents filed with the government prior to their IPOs, they had to spell out the what, when, and how of their work.

▶ [Three Cambridge startups are on a mission to fix broken genes](#)

by Robert Weisman, *The Boston Globe*

Editas, Intellia, and CRISPR Therapeutics aim to cure diseases from cancer to blood disorders, but these would-be gene editors also must navigate a new round of ethical questions.

▶ [UK should freeze mitochondrial replacement as Egli paper ID's serious problem](#)

by Paul Knoepfler, *The Niche*

New research, which shows that transfer of one egg's nucleus into another egg might bring along diseased mitochondria, warrants putting an immediate hold on

all efforts to use the technique in humans.

▶ [Bill Banning Mitochondrial Replacement Therapy Considered](#)

by Tanya Lewis, *The Scientist*

A US Senate committee is considering extending a ban on federal funds for research involving genetically modifying human embryos, which includes germline mitochondrial manipulation techniques.

▶ [Debate rages over use of fresh stem cell eggs](#)

by Shin Sung-Sik, Kang Ki-Heon, and Esther Chungn,  
*Joongang Daily [South Korea]*

Some South Korean scientists want the government to let them use fresh women's eggs for cloning-based stem cell research.

▶ [Orphan Black emphasizes the science in its sci-fi with a disturbing chapter on eugenics](#)

by Caroline Framke, *Vox*

The BBC America series about human clones is now tackling the personal, scientific, and societal implications of eugenics, gene editing, and germline engineering.

▶ [White Southern Girlhood and Eugenics: A Talk With Historian Karin Zipf](#)

by Tina Vasquez, *Rewire*

The same white supremacy that declared Black men and women to be hypersexual also subjected troubled or abused white girls to incarceration and state-sponsored sterilizations to make sure the teens did not pass on "bad" genes.

▶ [Genes Are Overrated](#)

by Nathaniel Comfort, *The Atlantic*

The discovery of DNA wasn't predestined, nor does it dictate our destiny—and current ideas about it may die.

▶ [The False Promise of DNA Testing](#)

by Matthew Schaer, *The Atlantic*

The forensic technique is becoming ever more common—and ever less reliable.

▶ [How Gene Testing Forced Me to Reveal My Private Health Information](#)

by Jody Allard, *Vice*

Genetic testing can yield inconclusive results and undermine people's privacy and access to life, disability, and long-term care insurance.

▶ [Opioids: Can a Genetic Test Identify an Addict in the Making?](#)

by Kristina Fiore, *MedPage Today*

Two companies engage in "laboratory developed tests" to determine the role of genetics in addiction.

▶ [The disturbing thing that happens when you tell people they have](#)



## [different DNA](#)

by Ana Swanson, *Wonkblog [The Washington Post]*

A new study suggests emphasizing essential differences based on genetics can encourage aggression between groups and stir support for war.

### ▶ [Meet The Scientists Fighting For More Studies On Genes And Racial Differences In Health](#)

by Peter Aldhous, *BuzzFeed*

Many question if medicine should seek genetic differences based on a social construct like race, diverting research away from environmental health impacts.

### ▶ [A book about the superiority of mixed-race people is going into a second printing, and the internet is pissed](#)

by Charles Pulliam-Moore, *Fusion*

*Breeding Between the Lines* relies on eugenic ideas to assert that mixed-race people are more attractive and healthy.

### ▶ [Tales of African-American History Found in DNA](#)

by Carl Zimmer, *The New York Times*

Can genetic analyses map histories of African American migration, slavery, and health? Critics argue such histories and identities cannot be reduced to genotype.

### ▶ [Mayo Clinic lands \\$142 million from NIH to build precision medicine biobank](#)

by Bernie Monegain, *Healthcare IT News*

Mayo Clinic will provide infrastructure to store, analyze, and host data as part of a program that aims to enroll one million people to boost President Obama's Precision Medicine Initiative.

### ▶ [California's StemCells, Inc., Flatlines: A Look at the Implications](#)

by David Jensen, *California Stem Cell Report*

The company's sudden shutdown surprised and shocked some, but it also demonstrated the level of risk in stem cell research.

### ▶ [It's not just stem cell research that's overhyped—medical science spin is a widespread problem](#)

by Kelly Crowe, *CBC News*

The International Society for Stem Cell Research is urging scientists to manage public expectations.

### ▶ [Fertility watchdog 'increasingly concerned' about dubious treatments sold by private clinics as experts warn childless couples are being exploited](#)

by Ian Johnston, *The Independent [UK]*

Private fertility clinics may be offering "add-on" treatments that are unwarranted and ineffective, with consequences for patients' health and finances.

### ▶ [Indian woman gives birth at ~70 with help of IVF](#)

by Andrew Marszal, *The Telegraph [UK]*

A Post-menopausal births with donor eggs are increasingly common in India,

where couples are often under intense social pressure to have children.

▶ [Finally allowed 2nd child, older Chinese parents turn to IVF](#)

by Louise Watt, *US News & World Report*

China's decision to allow all married couples to have two children is driving a surge in demand for fertility treatment among older women.

▶ [The Dwindling Options for Surrogacy Abroad](#)

by Danielle Preiss & Pragati Shahi, *The Atlantic*

As developing nations clamp down on the practice, hopeful parents are struggling to find women to carry their children.

▶ [Controversial Italian fertility doctor accused of stealing patient's egg](#)

by Stephanie Kirchgaessner, *The Guardian [UK]*

A patient has accused an Italian fertility doctor of forcibly operating on her and harvesting her eggs.

▶ [Surrogacy laws for single parents to change after court ruling](#)

*BBC*

UK surrogacy laws that prevent single people from claiming parental rights are set to change following a ruling by the Family Division of the High Court.

▶ [Is Egg Freezing Only for White Women?](#)

by Reniqua Allen, *The New York Times [Opinion]*

In the context of egg freezing's unknown risks and success rates, black women are being excluded from "fertility insurance" conversations and face stigma.

▶ [Should Women Be Able to Abort a Fetus Just Because It's Female?](#)

by Emma Green, *The Atlantic*

A new wave of state legislation that prohibits abortion based on sex, race, and genetic abnormality, is "meant to put women in this queasy position of having to justify two things that might not fit together in one political belief."

▶ [Is academic achievement written into your DNA? It's complicated](#)

by Sharon Begley, *STAT*

Behavioral genetics has long been notorious for claiming complex behaviors are the inevitable product of inherited genes. Altogether 74 genes explain less than .05% of differences in education levels.

▶ [In science, follow the money – if you can](#)

by Paul D. Thacker & Curt Furberg, *The Los Angeles Times*

Disclosure and restrictions do not harm academic freedom. These policies still allow scientists to pursue research, while ensuring that public health is not put at risk in service of corporate profit.

▶ [Federal Microbiome Project Aims to Solve Tiny Riddles of Science](#)

by Gardiner Harris, *The New York Times*

The latest federal scientific "moonshot" will focus on microbiomes, with the hope



of medical, environmental, and agricultural benefits.

▶ [Why is Congress trying to weaken the FDA's oversight of dangerous drugs?](#)

by Michael Hiltzik, *Los Angeles Times*

With looser standards for drug approval, the "21st Century Cures Act" would grant pharmaceutical companies greater leeway in selling their products.

▶ [Bayer Offers to Buy Monsanto for \\$62 Billion](#)

by Michael J. de la Merced & Chad Bray, *The New York Times*

The merger would increase Bayer's scale of operations, whose politics and practices are similar to those of Monsanto.

▶ [Four steps to rebuild trust in biology](#)

by Filippo Lentzos & Nicholas Evans, *The Guardian*

Secrecy, safety breaches and controversial experiments are risking the reputation of biomedical science.

▶ [In dramatic statement, European leaders call for 'immediate' open access to all scientific papers by 2020](#)

by Martin Enserink, *Science Magazine*

The Competitiveness Council admits the task may be difficult, but a consensus has been reached.

▶ [As an industry giant invests in science fairs, we all invest \(for better or worse\) in biotech](#)

by Carl Zimmer, *STAT*

School science fairs have evolved into sites of biotech and biomedical sponsorship and cultivation.

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