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CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

August 10, 2017

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ANNOUNCEMENTS

[CGS Welcomes Katie Hasson](#)

We are delighted to announce that Katie Hasson has joined CGS as our new Program Director on Genetic Justice. She will be taking a lead role in managing work on gene editing for human reproduction. Katie comes to CGS from the University of Southern California, where she was an assistant professor of sociology and gender studies.



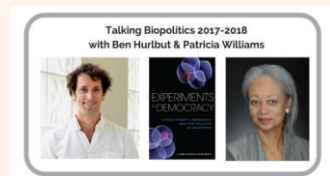
[Critical Reactions to Study of First Gene-Edited Human Embryos in the U.S.](#)

On August 3, *Nature* published a paper describing the use of CRISPR to modify human embryos. Critical comments by CGS were featured in dozens of newspapers, magazines, radio programs, and websites, including *The New York Times*, *Washington Post*, *Buzzfeed News*, NPR's *On Point*, BBC's *The Inquiry*, and *Mother Jones*. Included in this newsletter are CGS's press statements and blog post on the study, along with a number of representative news articles about it.



[Talking Biopolitics 2017 Kicks off with Ben Hurlbut and Patricia Williams](#)

For the past six years, CGS' [Talking Biopolitics](#) series has served as a platform for cutting-edge thinkers to discuss the meaning of emerging human biotechnologies. This year's series will begin on August 23 at 11 am PDT / 2 pm EDT featuring [Ben Hurlbut](#) and [Patricia Williams](#). For more information, register [here](#).



[CGS Launches New Column: Pop ART](#)

In September, CGS will be launching a new monthly column for *Biopolitical Times*, "Pop ART," discussing "what happens when pop culture and assisted reproductive technologies meet, by the experts who know both best." The goal of the column is to amplify the perspectives of reproductive health, rights, and justice advocates and scholars on ART issues.



[Work with CGS as a Fall Intern](#)

CGS is pleased to announce that it is currently accepting internship applications for Fall 2017. Applicants should demonstrate familiarity with or strong interest in the politics and social implications of human genetic and assisted reproductive technologies. Internships for 2-4 months are available, with stipend negotiable depending on skills and experience, or arranging course credit in cooperation with your institution. Find more information [here](#).



CGS COMMENTARY

[Report of First Gene-Edited Human Embryos in the US](#)

CGS Press Statement

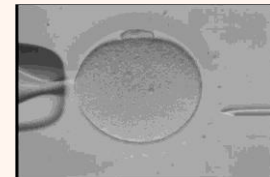
News that a controversial U.S. researcher has used CRISPR to create genetically-altered human embryos underscores the need for stronger policy protections against engineering the genes of future children and generations.



[Study on Gene-Edited Embryos Aims for Human Reproduction](#)

CGS Press Statement

A paper published in Nature reported on work led by Oregon Health & Society University researcher Shoukhrat Mitalipov to genetically edit human embryos, apparently with the goal of using this technique for reproductive purposes.



[On Embryos and Spin](#)

by George Estreich, *Biopolitical Times* Guest Contributor

Media reports about CRISPR'd embryos too often mislead the public, and undermine our understandings of the implications of gene-editing technology.



[FDA Reprimands Fertility Doctor for Marketing Genetic Modification of Human Embryos](#)

by Leah Lowthorp

John Zhang has finally been called to account. On August 4, the US Food and Drug Administration sent a [warning letter](#) demanding he cease and desist both the conduct and the marketing of an experimental genetic modification technique known as 3-person in vitro fertilization.



[California Plans Legislation to Compensate Sterilization Survivors](#)

by Emily Galpern, *Biopolitical Times* Guest Contributor

Assemblywoman Cristina Garcia, in partnership with [California Latinas for Reproductive Justice](#) and [Disability Rights California](#), will introduce a bill in 2018 to compensate survivors of California's state-sponsored sterilization law.



[Unmasking IVF 40 Years Later](#)

by Pamela Tsigidinos and Miriam Zoll, *Biopolitical Times* Guest Contributor

In anticipation of the 40th anniversary of Louise Brown's birth as the world's first "test-tube baby," several former IVF users are creating an online repository along with a social media campaign using the hashtag #UnmaskingIVF to discuss risks that are often overlooked.



[What Clones Think of CRISPR and Other Highlights from the Final Season of Orphan Black](#)

by Jessica Cussins, *Biopolitical Times* Guest Contributor

The latest and final season of Netflix's *Orphan Black* explicitly reckons with gene editing and one of the growing concerns raised by contemporary biotechnologies: human autonomy.



[Whatever Happened to #CRISPRfacts?](#)

by Leah Lowthorp

Using humor and a hashtag to put CRISPR hype in its place.



[The CSI Effect: How TV shapes DNA Forensics in the Courtroom](#)

by Jonathan Chernoguz

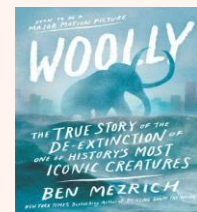
Forensic evidence is rarely considered faulty in shows like *Crime Scene Investigation*. But overconfidence in DNA, inspired by pop culture, leads to many innocent people being wrongfully convicted or jailed.



[Woolly is a Relentlessly Optimistic Book About De-Extinction](#)

by Pete Shanks

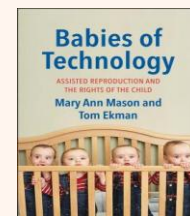
The new book about trying to revive mammoths is hazy, fuzzy, blurry, foggy, and more than a little fanciful.



[Factoring in the Rights of Children in Assisted Reproduction](#)

by Gina Maranto, *Biopolitical Times* Guest Contributor

While most books on the assisted reproductive industry focus on would-be parents, *Babies of Technology* instead surveys the field from the perspective of children's rights.



[Which Dots Get Connected in Biotech Education?](#)

by Tina Stevens, *Biopolitical Times* Guest Contributor

Children's exhibits like UC Berkeley Lawrence Hall of Science's "Biotech Learning Labs" may be engaging – but not for the right reasons.



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CGS in the NEWS

[Scientists Precisely Edit DNA In Human Embryos To Fix A Disease](#)

▶ [Gene](#)

[citing CGS' Marcy Darnovsky]

by Rob Stein, *NPR*

"I think it's extraordinarily disturbing...It's a flagrant disregard of calls for a broad societal consensus in decisions about a really momentous technology that could be used good, but in this case is being used in preparation for an extraordinarily risky application."



[First human embryo editing experiment in U.S. 'corrects' gene for heart condition](#)

▶ [heart condition](#)

[citing CGS' Marcy Darnovsky]

by Ariana Eunjung Cha, *Washington Post*

"Once those commercial dynamics kick in, we could all too easily find ourselves in a world where some people's children are considered biologically superior to the rest of us...We need to ask ourselves whether we want to add that new kind of excuse for extreme social disparities to the ones we already tolerate."



[A Gene Editing Breakthrough](#)

▶ [citing CGS' Marcy Darnovsky]

by Tom Ashbrook, *NPR On Point*

How far does this gene editing go? How fast? For whom? And for, or against, what human traits? Tom Ashbrook discusses these questions with guests Amy Dockser Marcus, Paula Amato, Arthur Caplan, and Marcy Darnovsky.



[Is Gene Editing Out of Control?](#)

▶ [citing CGS' Marcy Darnovsky]

by The Inquiry, *BBC*

Gene editing offers breathtaking promise: eliminating disability and disease. But with the rapid spread of this powerful technology, leading voices at the forefront of the research warn against unintended consequences, and question whether the rush for miracle cures could bring hellish side-effects.



[Gene Editing for 'Designer Babies'? Highly Unlikely, Scientists Say](#)

▶ [citing CGS' Marcy Darnovsky]

by Pam Belluck, *New York Times*

"Allowing any form of human germline modification leaves the way open for all kinds — especially when fertility clinics start offering 'genetic upgrades' to those able to afford them."



[Scientists Are Shocked About How Easy It Is To Tweak Genes In](#)

▶ [Human Embryos](#)

[citing CGS' Marcy Darnovsky]

by Dan Vergano and Tom Chivers, *BuzzFeed News*

"I think we are at a very pivotal moment with this study. These researchers have really taken it upon themselves to advance this technology this way without asking the rest of us if we really want to go along."



[A Future of Genetically Engineered Children Is Closer Than You'd](#)

▶ [Think](#)

[citing CGS' Marcy Darnovsky]

by Rowan Jacobsen, *Mother Jones*

"Sometimes I feel like we're not on a slippery slope—we're flying off a cliff.

People used to see this as a speculative science-fiction future, and now it's an urgent social-justice challenge."



[The 'three-parent baby' fertility doctor needs to stop marketing the procedure, FDA says](#)

[citing CGS' Marcy Darnovsky]

by Rachel Becker, *The Verge*

"This is a biologically extreme and risky procedure. If you're talking about using these techniques for age-related infertility, that's really moving the human experimentation to a very large scale."



NEWS

Bioethics

Gene Editing

Genetic Testing

Governance

Various

GENE EDITING

▶ [First Human Embryos Edited in U.S.](#)

by Steve Connor, *MIT Technology Review*

The first known attempt at creating genetically modified human embryos in the United States has been carried out by a team of researchers in Portland, Oregon, *Technology Review* has learned.

▶ [The Brave New World of Gene Editing](#)

by Matthew Cobb, *New York Review of Books*

The latest developments in gene editing raise complex and urgent questions about the kind of society we want and who we really are. A brave new world is just around the corner, and we had better be ready for it or things could go horribly wrong.

▶ [Gene Editing Might Mean My Brother Would've Never Existed](#)

by Joel Michael Reynolds, *Time*

The [ableist conflation](#) of disability with disease and suffering is age-old. Just peruse the history of medicine. These stories demonstrate over and over again how easily biomedical research and practice can mask atrocity with benevolence and injustice with progress. Which leads me to ask: What, precisely, are we editing for?

▶ [Who needs film when you can store a movie in bacteria DNA?](#)

by Deborah Netburn, *Los Angeles Times*

Encoding a short movie into cellular DNA is a neat trick, but the work only represents a stepping stone toward a bigger goal — building tiny biological recorders that can capture and store what is going on in a cell or in its environment.

GOVERNANCE

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▶ [The FDA Is Cracking Down on the Doctor Marketing 3-Parent Babies](#)

by Kristen V. Brown, *Gizmodo*

“Even though the FDA issued an untitled letter rather than a warning letter, the FDA is clearly indicating what kind of marketing claims and clinical research it will not permit.”

▶ [These cuts to forensic research will not combat violent crime](#)

by Susan R. Paisner, *Washington Post* [Letter to the Editor]

“[A]s a criminologist, I found myself stunned to read that Attorney General Jeff Sessions decided not to renew the National Commission on Forensic Science, which holds the responsibility for raising forensic standards.”

▶ [Gene Editing is Revolutionizing Medicine but Causing a Government Ethics Nightmare](#)

by Jessica Firger, *Newsweek*

Both Congress and the National Institutes of Health have explicitly said they would not fund research that uses gene-editing to alter embryos. But laws and guidelines are not keeping pace with this fast-moving and controversial work.

▶ [Patients With Pre-Existing Conditions Fear Bias Under GOP Health Proposals](#)

by Charlotte Huff, *Kaiser Health News*

In recent years, doctors have urged patients to be screened for a variety of diseases and predispositions to illness, confident it would not affect their future insurability. But the GOP attack on the Affordable Care Act raises concerns on whether this information will be wrongfully used against them.

▶ [Will Healthcare Inequality Cause Genetic Diseases to Disproportionately Impact the Poor?](#)

by Kristen V. Brown, *Gizmodo*

The inequality threat that prenatal testing, IVF and germline editing present, is of course a version of the same inequality that has always existed. If you are poor, there is a good chance your access to healthcare is not as good as someone who has more money.

BIOETHICS

- News TOP -

▶ [Human Gene Editing Is Leaving Ethics Dangerously Far Behind](#)

by Craig Calhoun, *The World Post*

Unless we pay much more attention to ethical and social choices, we risk turning the promise of gene editing into disaster.

▶ [Gene-editing tool raises questions about what is ‘disease’](#)

by Rachel Kolb and Dakota McCoy, *San Francisco Chronicle*

When we discuss gene editing, we need to ask: How are we valuing the perspectives that different embodiments bring to our world? Are we seeing these perspectives as humanity — or as pathology?

▶ [Gene Editing Controversy Reminds Us Just How Much Money Influences Science](#)

by Kristen V. Brown, *Gizmodo*

When scientists whose fortune and reputation hinges on a particular technology speak out against a paper questioning that technology, it's hard not to wonder how that bias might factor in.

▶ [Who will pay for CRISPR?](#)

by Jim Kozubek, *STAT*

The ruckus over the CRISPR gene-editing system hides a dark reality: its high cost may make it unaffordable and questions remain whether most insurance companies will pay for it.

GENETIC TESTING

- News TOP -

▶ [Why You Should Think Twice About Those DNA-By-Mail Results](#)

by Barbara J. King, *NPR*

In his new book *Is Science Racist?*, Jonathan Marks deconstructs one of the most popular biotechnologies of the past decade: genetic ancestry testing.

▶ [Scientists Push Back Against Booming Genetic Pseudoscience Market](#)

by Kristen V. Brown, *Gizmodo*

A growing number of scientists are pushing back against wild claims in the consumer genetics market, which is flush with tests promising to plumb the secrets of our DNA for answers to everything from what kind of wine we'll enjoy to what diseases we're at risk of developing.

▶ [A DNA App Store Is Here, but Proceed with Caution](#)

by Emily Mullin, *MIT Technology Review*

A Silicon Valley startup may be inflating customer expectations of DNA tests by promoting serious and pseudo-scientific tests alongside each other.

▶ [The uncertain future of genetic testing](#)

by Carrie Arnold, *Mosaic Science*

Bringing genetics into medicine leads to more accuracy, better diagnosis and personalised treatment – but not for all.

VARIOUS

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▶ [America's Long, Shameful History of Sterilizing Prisoners](#)

by Zoë Beery, *The Outline*

In an interview following his dismissal, an assistant district attorney in Nashville said he was “weighing public safety” when he introduced sterilization into the picture. Other states, including Virginia and Georgia, have incorporated permanent sterilization into plea deals in recent years, in cases with repeat-offender defendants whom prosecutors thought had too many children already. These justifications are just a shade away from being eugenic.

▶ [Did a U.S. Surgeon General come up with the idea of the notorious Tuskegee syphilis experiment?](#)

by William Bender, *Philly News*

Allen Hornblum, a Philadelphia author who has written about human experiments at Holmesburg Prison, says archived records indicate that a much more prominent figure in American medical history – a World War II-era surgeon general – was the study's driving force.

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