

June 2019



BioPolitical

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SPOTLIGHT



New and Improved: Resource Hub on International Commercial Surrogacy

CGS recently unveiled the new and improved [Surrogacy360.org](#), a resource hub for anyone with practical and ethical questions about international commercial surrogacy. We invite you to visit the site and follow us on Facebook, Twitter, and Instagram

ANNOUNCEMENTS



Consider a Donation to the Center for Genetics and Society

Our [Spring Fund Drive](#) is almost over! Monday is your last opportunity to contribute to our \$5,000 goal—and to receive a copy of *Biotech Juggernaut* with a donation of \$200 or more. The landscape of human genetic technology is literally changing daily, and we need your support to stay at the forefront of these critical debates. Thank you for following our work, and please [consider supporting our ongoing efforts](#) to keep social and ethical considerations at the center of the debates surrounding advances in human biotechnologies.



Darnovsky and Obasogie Present on Policies, Politics, Publics

On Wednesday, June 5, CGS' Marcy Darnovsky and Osagie Obasogie participated in a panel discussion as part of a three-day workshop titled *Wrong at the Root: Racial Bias and the Tension Between Numbers and Words in Non-Internet Data*, hosted by the Simons Institute for the Theory of Computing. Panel participants examined the resurgence of false ideas about the biological origins of race and looked at examples of how algorithms and technology reinforce structural racism. You can listen to the discussion [here](#).

COMMENTARY



The Wrong Way to Make Policy About Heritable Genome Modification

Marcy Darnovsky, *The Hill* | 05.29.2019

Why did a House Appropriations subcommittee remove a budget bill rider that prevents heritable genome editing? When it was adopted in 2015, the provision brought the US into closer alignment with the dozens of countries that clearly prohibit altering the genes of future children. After objections were raised—including by CGS in this op-ed—the rider was reinstated.



Pernicious Optimism and Selective Science: A Review of *Hacking Darwin*

Pete Shanks, *Biopolitical Times* | 05.31.2019

A new book addressing the wisdom of genetically engineering humans encourages us to look at our species as “hackable” and cautions against attempting to regulate genetic enhancement of human embryos. By CGS' Pete Shanks' read, however, the author's argument relies far too heavily on “superficially plausible extrapolation.”



What Rider? Why the June 4 House Appropriations Committee Decision Matters

Adrienne van der Valk, *Biopolitical Times* | 06.05.2019

The House Appropriations Committee reinstated a 2015 rider—removed just weeks earlier from a budget bill—that prohibits the FDA from considering clinical trials that would edit the genomes of human embryos. This is good news in some ways, but it does not represent a definitive legislative stance nor does it define any consequences if doctors or scientists violate the provision.



CRISPR Regulation

Marcy Darnovsky, *Issues in Science and Technology* |

06.06.2019

Nearly everyone says they favor public engagement in the decision about heritable genetic modification, but there are important differences over just what kind of public engagement and deliberative process each has in mind.

CGS IN THE NEWS



Judge Poised to Advance Suit Over California DNA Collection

Nicholas Iovino, *Courthouse News Service* | 05.01.2019

Despite prior court rulings that police can collect DNA samples from people arrested but not convicted of crimes, a state court judge hinted that holding onto that DNA data might violate the California Constitution.



Whom Does your DNA belong to? Hint, It's Not Just You

Eoin O'Carroll, *The Christian Science Monitor* | 05.06.2019

Is the DNA you share with ancestry testing companies any safer than your other personal data? CGS' Katie Hasson warns, "Your personal information is monetized by private companies, it's used for all kinds of things that you didn't want."



Privacy Concerns with DNA Ancestry Tests: It's All Fun and Games Until...?

Kevin Brasler, *Consumers' Checkbook* | 05.15.2019

When people take DNA tests at home, it isn't just the company who "touches" the resulting samples and data. "It is being passed along to a lot of other companies," says CGS' Katie Hasson. "I can't imagine that every single company uses the most stringent methods to protect your data."



How a Home DNA Test Could Complicate Your Life Insurance Application

Lidia Davis, *Reviews.com* | 05.20.2019

Health insurance companies may not currently be able to discriminate based on DNA collected by ancestry test companies. But, says CGS' Katie Hasson, "We don't know — even in five years, what kinds of things people will be able to do or learn from our data."



House Committee Votes To Continue Research Ban On Genetically Modified Babies

Rob Stein, *NPR* | 06.04.2019

A Congressional committee voted Tuesday to continue a federal ban on creating genetically modified babies in the United States. "We need to weigh the societal risks of opening the door to those who aim to genetically 'enhance' children," says Darnovsky.

WHAT WE'RE READING

[Assisted Reproductive Technologies](#) | [Eugenics](#) | [Genomics](#) | [Heritable Gene Editing](#)

HERITABLE GENE EDITING

German Ethics Council Expresses Openness to Eventual Embryo Editing

Sharon Begley, *STAT* | 05.13.2019

A panel of government-appointed experts in Germany called for a moratorium on creating pregnancies with gene-edited IVF embryos and recommended that Germany work toward a binding international agreement on the circumstances under which it might ever be acceptable.

Human Genome Editing: Our Future Belongs to All of Us

Françoise Baylis, *Issues in Science and Technology* | 05.15.2019

It is important to educate and to engage the public in discussions about the ethics and governance of heritable human genome editing. It is also important, however, to move beyond education and engagement to empowerment.

We Have the Technology to Customize Our Babies. It Needs Regulation.

Editorial Board, *The Washington Post* | 05.21.2019

The world is at an inflection point not unlike that which gave rise to the Asilomar Conference on Recombinant DNA in February 1975. Something of similar scope and power is needed for germline editing of genes in human embryos, sperm and eggs.

He Jiankui Research Prompts U.S. Academies, U.K. Society to Create Germline Editing Commission

Staff Writer, *Genetic Engineering & Biotechnology News* | 05.22.2019

The commission would create a regulatory framework designed to identify scientific, medical, and ethical requirements for applying germline genome editing—subject to a societal consensus that heritable human genome editing applications are acceptable.

Fertility Clinics Around the World Asked 'CRISPR Babies' Scientist for How-to Help

Sharon Begley, *STAT* | 05.28.2019

Emails revealing that some clinics are eager to offer germline gene editing as a service highlight the

risks of commercialization.

Gene-Edited Babies Don't Grow in Test Tubes — Mothers' Roles Shouldn't Be Erased

Rachel Adams, *The Conversation* | 05.29.2019

Strikingly absent in the news coverage of Lulu and Nana has been any discussion of where the embryos developed, how the babies came into the world and who will care for them—that is to say, their mother.

Two Chinese Babies With Edited Genes May Face Higher Risk of Premature Death

Rob Stein, *National Public Radio* | 06.03.2019

It appears that the genetic variation a Chinese scientist was trying to recreate when he edited twin girls' DNA may be more harmful than helpful to health overall, according to a recent study.

ASSISTED REPRODUCTIVE TECHNOLOGIES

A Decades-Old Doctor's Secret Leads to New Fertility-Fraud Law

Sarah Zhang, *The Atlantic* | 05.07.2019

Indiana's governor has signed into the law the first piece of legislation holding fertility doctors accountable for using their own genetic material when treating patients.

IVF Couples Could Be Able to Choose the 'Smartest' Embryo

Hannah Devlin, *The Guardian* | 05.24.2019

A US scientist, whose company already offers a test aimed at screening out embryos with abnormally low IQ, says it will be possible to rank embryos by 'potential IQ' within 10 years.

EUGENICS

Eugenics Is Still a Dangerous Idea

Dorothy Roberts, *The Inquirer* | 05.01.2019

The condemnation of the eugenics-inspired Nazi Holocaust put an end to mainstream support for explicitly eugenicist science, but eugenics' ideological underpinning has survived.

GENOMICS

Not So Black And White: Dorothy Roberts On The Myth Of Race

Mark Leviton, *The Sun Magazine* | 05.20.2019

Race is not a natural division of human beings that can lead to unjust hierarchies. The very concept of race was invented to create and enforce such hierarchies.

A Waste of 1,000 Research Papers

Ed Yong, *The Atlantic* | 05.17.2019

Over two decades, one gene inspired at least 450 research papers. But when scientists revisited a

sample of these studies, they found that the fundamental assumptions underlying these studies were seriously flawed.

Controversial U.S. Bill Would Lift Supreme Court Ban on Patenting Human Genes

Kelly Servick, *Science* | 05.04.2019

The bill, which would overturn the landmark 2013 decision *Association for Molecular Pathology v. Myriad Genetics, Inc.*, is drawing fierce criticism from some scientific societies and patient advocates, including the American Civil Liberties Union.

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