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July 2019



# BioPolitical News&Views

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## SPOTLIGHT



### Take Our Survey!

Got a minute? Take our four-question [survey](#) and help us make the CGS newsletter more useful and user-friendly. Thank you for your feedback.

## ANNOUNCEMENTS



### CGS Welcomes Kayla Hinkson-Grant

CGS is pleased to have Kayla Hinkson-Grant with us for the summer as part of the Civil Liberties and Public Policy 2019 Reproductive Rights Activist Service Corps Internship Program. Kayla is a rising junior at Mount Holyoke College in Massachusetts where she majors in anthropology and minors in gender studies. She brings to her role a background in disability rights and reproductive justice with a particular interest in the intersections of disability and blackness. Welcome, Kayla!



### Darnovsky Delivers Keynote Speech at Southeastern Association of Shared Resources Annual Conference

On June 13, CGS Executive Director Marcy Darnovsky presented "Heritable Gene Editing: What's at Stake and Where Should We Draw the Lines?" to a professional

community of scientists and lab administrators in Atlanta, Georgia. Her talk focused on the history of the debates surrounding human genome editing and the technical developments that have brought us to where we are today. The audience responded enthusiastically and asked many questions about how decisions regarding the use of CRISPR in humans will be made forward.

## COMMENTARY

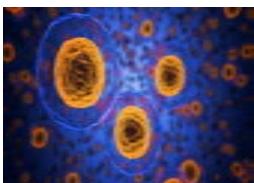
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### We Don't Need More Reasons to Reject Heritable Genome Modification

**Katie Hasson, *The Hill* | 06.10.2019**

A study highlighting the dangers of He Jiankui's "CRISPR babies" experiment drew numerous comments and wide coverage. While the findings are cause for real concern, they don't change the fact that no one alive today will ever truly know if using CRISPR technology in humans is safe.



### CGS Statement on Russian Biologist's Plan to Produce Gene-Edited Babies

**CGS Press Statement | 06.11.2019**

The journal *Nature* has reported molecular biologist Denis Rebrikov's plans to use CRISPR to edit the genes of human embryos and bring them to term, which would make him the second known scientist to do so. The announcement makes clear that neither scientific self-regulation nor 'soft law' is enough to deter scientists willing to defy the worldwide opposition to pursuing reproductive uses of human genome modification.



### The Russian Threat to Perform Human Germline Editing

**Pete Shanks, *Biopolitical Times* | 06.25.2019**

Another scientist has grabbed global headlines by proclaiming his willingness to circumvent broad societal consensus and push human germline modification forward. Scientists, bioethicists, advocates, and others are weighing in on what to do about Denis Rebrikov.



### Russia's CRISPR "Deaf Babies": The Next Genome Editing Frontier?

**Jackie Leach Scully & Teresa Blankmeyer Burke, *Biopolitical Times* | 07.09.2019**

Not all deaf people consider themselves disabled. Many consider themselves members of a cultural group that uses signed language to communicate. Audiological deafness is highly variable; its effects on people's well-being are similarly variable and influenced by the surrounding social attitudes, culture, and laws, including civil rights protections. Given that reality, it is irresponsible to name deafness as a "serious" condition that justifies heritable genome editing. (This post appears with generous permission from [Impact Ethics](#).)



## What Now? Grappling with Compensated Surrogacy Beyond the New York Bill

**Emily Galpern, *Biopolitical Times* | 06.28.2019**

The failure of the New York State Legislature to pass the Child-Parent Security Act highlights the complexities of crafting surrogacy policy grounded in social justice principles. It's not easy to simultaneously support LGBTQ family formation and safeguard the rights and health of surrogates, egg providers, and children born from surrogacy, but it's crucial: Efforts to legalize and regulate compensated surrogacy are ramping up in other states and will likely return to New York next year.



## No One Should Own Our Genes

**Pete Shanks, *Biopolitical Times* | 05.31.2019**

A small but influential coalition in Congress is trying to overturn the 2013 Supreme Court Myriad decision, which found that human genes could not be patented. But a letter of opposition to the effort has already been signed by at least 170 organizations, including the American College of Medical Genetics and many other professional societies, as well as the American Civil Liberties Union and numerous organizations that represent the interests of patients.



## Congress Wants to Give Companies the Right to Own Our Genes

**Lori Andrews, *Biopolitical Times* | 06.18.2019**

Patents are supposed to be granted on inventions, not on naturally-occurring substances. Six years ago, the US Supreme Court affirmed this notion in *AMP v. Myriad* when they unanimously ruled that human genes could not be patented. Now, a bipartisan group of US Senators and Representatives has released a bill that would reverse this decision. (This post appears with generous permission from [Our Bodies Ourselves](#).)



## The UC-GlaxoSmithKline Deal Should Be Surrounded by Red Flags. Where Are They?

**Tina Stevens, *Biopolitical Times* | 07.03.2019**

Pharmaceutical giant GlaxoSmithKline has inked a \$67 million partnership deal with UC San Francisco and UC Berkeley to use CRISPR gene editing to search for new medicines. The arrangement raises obvious questions not only about conflicts of interest but also about handing a private corporation the benefits of research incubated by a public university.

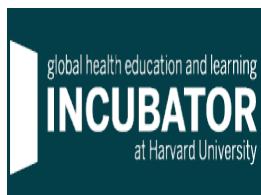


## Born This Week: Dolly the Sheep

**Pete Shanks, *Biopolitical Times* | 07.03.2019**

When Dolly's birth was announced in 1997, she became a global sensation. As news of the first successfully cloned mammal spread, public imagination quickly turned to pet and even human cloning.

# CGS IN THE NEWS



## The Ethics of Gene Editing from a Human Rights Perspective

Staff, *GHELI News and Stories* | 06.12.2019

Harvard's Global Health Education and Learning Incubator recently convened a cross-disciplinary roundtable discussion with CGS' Katie Hasson and Marcy Darnovsky to address a variety of ethical and societal questions related to gene editing.



## Russian Scientist Plans to Create More Genetically-edited Humans

Carmen Leitch, *Labroots* | 06.12.2019

Like He Jiankui, Russian biologist Denis Rebrikov says he will target the CCR5 gene. His bold claim indicates it is "well past time to initiate meaningful, broadly inclusive, and unrushed discussions of whether heritable genome editing should be permitted," says CGS' Katie Hasson.



## CRISPR in Russia: The Next Gene-edited Babies May Not Be Far Away

Edd Gent, *SingularityHub* | 06.20.2019

Denis Rebrikov says he will persist with his experiments despite outcry from many corners of the scientific community and beyond who insist he can't guarantee the safety of his human subjects. Not only that, says CGS' Katie Hasson, Rebrikov is overlooking the fundamental social risks inherent in using CRISPR in humans, risks that "cannot be mitigated in a lab."



## DNA-collecting Agencies Use Genetic Data for Research

Isabelle Altman, *The Dispatch* | 07.06.2019

In a world where increasing numbers of people are voluntarily submitting their DNA to ancestry companies for analysis, some legislators and activists are questioning the ethics of police using publicly available genealogy databases to match a suspect's DNA to that of a family member. As CGS' Katie Hasson explains, "You're not just revealing your own genetic information but also all of your family members."



## 'Unimaginable Mishap:' Parents Sue CHA Fertility Center Alleging Babies Born Were Not Theirs

CBS Los Angeles | 07.09.2019

IVF is offered mainly through fertility clinics in the private sector, which means "there's very little oversight of it," says CGS' Marcy Darnovsky. A New York couple charges that a clinic in Los Angeles used someone else's embryos to initiate their twin pregnancy. They have been forced to give up both babies.

# WHAT WE'RE READING

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Animals | Assisted Reproductive Technologies | Genomics  
Heritable Gene Editing | Stem Cells | Surrogacy

## HERITABLE GENE EDITING

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### Russian Biologist Plans More CRISPR-edited Babies

**David Cyranoski, *Nature* | 06.10.2019**

Molecular biologist Denis Rebrikov has told *Nature* he is considering implanting gene-edited embryos into women, possibly before the end of the year.

### Act Now on CRISPR

**Nature Editorial Board, *Nature* | 06.10.2019**

Should the scientific community engage with Denis Rebrikov rather than labeling him a maverick? Some scientists feel that doing so opens the door to working with him to identify and discuss the risks of his proposed experiment on human embryos.

### A Russian Biologist Wants To Create More Gene-Edited Babies

**Rob Stein, *National Public Radio* | 06.21.2019**

Denis Rebrikov wants to create babies from embryos whose DNA he would edit to protect the resulting children from HIV.

### Alarmed by New 'CRISPR Babies' Plan, Top Science Figures Say They're Powerless to Stop It

**Rick Berke, *STAT* | 06.24.2019**

Officials at the U.S. National Academy of Medicine and on the international advisory committee on genome editing are deeply troubled by Denis Rebrikov's announcement that he'll produce gene-edited babies, but say it's beyond their authority to intervene.

### Five Couples Lined Up for CRISPR Babies to Avoid Deafness

**Michael Le Page, *New Scientist* | 07.04.2019**

Despite recently announcing his plan to edit embryos to confer HIV resistance, Dennis Rebrikov now claims he has recruited five sets of would-be parents who each have a recessive form of deafness. Rebrikov says he plans to apply for the necessary permits to conduct the experiments within a couple of weeks.

### Bill McKibben's 'Falter' Arrives Just in Time

**Bill Lueders, *The Progressive* | 06.18.2019**

McKibben's new book stresses the urgency of the moment regarding our current climate crisis and addresses a fresh threat to humankind: that of genetically reconfiguring the species.

## ANIMALS

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### For the First Time, Researchers Eliminated HIV from Genomes of Living Animals

**Alice Park, *Time* | 07.02.2019**

The two-step process uses the gene-editing tool CRISPR-cas9 and antiviral drugs to remove HIV from cells infected with viral genes. Neither step was entirely effective by itself, but together eliminated the virus in clinical trials conducted on mice.

## ASSISTED REPRODUCTIVE TECHNOLOGIES

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### **Here's Why Many Black Women Are Silent About Their Struggle With Infertility**

**Danielle Bruff, Chicago Tribune | 06.29.2019**

The silence surrounding black women's infertility experiences reflects painful stereotypes and stigma and can interfere with their access to support and services.

## GENOMICS

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### **Want to See My Genes? Get a Warrant**

**Elizabeth Joh, The New York Times | 06.11.2019**

Genetic genealogy uncovers clues that can link crime scene evidence to DNA ancestry data. While the practice has led to some high-profile arrests, that doesn't mean the government should be allowed to use it in all cases.

### **DNA-testing Firms Are Lobbying to Limit Your Right to Genetic Privacy**

**David Lazarus, Los Angeles Times | 07.02.2019**

As Congress ponders a federal consumer genetic privacy rule, DNA-testing firms have come together to make sure lawmakers keep the industry's interests front and center.

### **Why the 'Molecular Scissors' Metaphor for Understanding CRISPR is Misleading**

**Elinor Horte, The Conversation | 07.04.2019**

The simplicity of the scissors metaphor belies the complexity of the relationship between health, the human body, and DNA.

## STEM CELLS

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### **Some Stem Cell Experts Want Out of Documentary After Funding Source Revealed**

**Erin Allday, San Francisco Chronicle | 06.15.2019**

Filmmakers say they may delay the premiere because some people interviewed for the project no longer want to be involved after learning that the movie was funded in part by for-profit stem cell providers who are under federal investigation.

### **Scientists Make Model Embryos From Stem Cells to Study Key Steps in Human Development**

**Rob Stein, NPR | 07.01.2019**

As the models become much more complete, scientists and ethicists wonder: At what point do they effectively become real human embryos?

## SURROGACY

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### **Surrogate Pregnancy Battle Pits Progressives Against Feminists**

**Vivian Wang, The New York Times | 06.12.2019**

Supporters presented the proposal to legalize surrogacy in New York as an unequivocal progressive ideal. But some

women's rights advocates and scholars argued that the bill didn't include sufficient safeguards for gestational mothers; others say paid surrogacy turns women's bodies into commodities.

## **Surrogacy Is Complicated. Just Ask New York**

**Christina Caron, New York Times Parenting | 06.26.2019**

Under current New York law, paid surrogacy is punishable by a fine, and unpaid surrogacy agreements are not legally binding or enforceable. A recent bill would have changed that, but didn't make it out of the State Assembly.

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