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January 2020 Biopolitical News&Views

COMMENTARY CGS IN THE NEWS WHAT WE'RE READING

SPOTLIGHT



<u>Read our comments</u> on the latest development in the "CRISPR babies" scandal. While we applaud the sentencing, as CGS' Katie Hasson observes, "The risks of heritable genome editing extend beyond individual countries. It is a global concern and therefore a global responsibility."

COMMENTARY

Reactions to Jail Sentences for "CRISPR Babies" Scientists, and What



Comes Next

Pete Shanks, Biopolitical Times | 01.09.2020

How should the sentencing of "CRISPR Babies" scientist He Jiankui be interpreted? Benjamin Hurlbut, Françoise Baylis, and others from across the spectrum of human biotechnology and bioethics stakeholders weighed in immediately after the news broke over the western New Years holiday.



CGS Year In Review: The Fight for Genetic Justice in 2019

CGS Staff, *Biopolitical Times* | 12.31.2019 CGS covered a lot of ground this year: from protesting heritable genome modification, to pursuing a genetic privacy lawsuit, to exposing fertility scams, to relaunching a project focused on international commercial surrogacy, and much more.



The Best of Biopolitical Times: 2019 Edition

CGS Staff, *Biopolitical Times* | 12.24.2019 *Biopolitical Times* highlights the latest developments in the social, political, and ethical implications of human biotechnologies. This list offers the highlights of a year that saw many historic developments.

CGS IN THE NEWS



The U.S. Government's Mass Collection of Immigrant DNA Hints at Surveillance Future

Emily Mullin, Medium One Zero | 01.08.2020

The US government has been critical of forced DNA collection in China, where DNA and other biometric data is being gathered from Muslim Uighurs. Now, it's happening domestically as well, a practice that, as CGS' Katie Hasson notes, "exposes not only individuals, but also their families in the U.S. and abroad, to serious privacy risks."



The Corrupting Syndrome of the Super-rich

Anis Chowdhury, The Financial Express | 01.07.2020

All indicators are that only the wealthy would be able to afford gene-edited babies. Says CGS Executive Director Marcy Darnovsky, "Genome editing for human embryos is an unnecessary threat to society," and would produce a population of genetic "haves" and "have nots."



Scientist Behind First CRISPR-Modified Babies Sentenced to Three Years in Prison

Theresa Machemer, *Smithsonian Magazine* | 12.31.2019 He Jiankui wasn't the only scientists sentenced over New Year's. Two other scientists, Zhang Renli and Qin Jinzhou pled guilty and received jail sentences for participating in what CGS' Marcy Darnovsky called a "reckless and self-serving" experiment.



Chinese Researcher Who Created Gene-Edited Babies Sentenced To 3 Years In Prison

Merrit Kennedy, NPR | 12.30.2019

After hearing of He's sentencing, CGS Executive Director Marcy Darnovsky commented she hopes the scientist's "reckless and self-serving acts [...] highlight the broader and deeper risks — and the pointlessness — of any proposal to use gene editing in human reproduction."

WHAT WE'RE READING

Animals | Assisted Reproduction | Genomics Heritable Genome Editing | Stem Cells | Surrogacy

ANIMALS

Scientists Aren't Sure Why Identical Twins Differ. Armadillo Quads Offer an Answer.

Sharon Begley, STAT | 12.20.2019

Armadillos always have genetically identical quadruplets, which make them unique test subjects for inquiries about why mammals born with the same genes don't always share physical characteristics.

Eyeing Organs for Human Transplants, Companies Unveil the Most Extensively Gene-edited Pigs Yet

Kelly Servick, Science | 12.19.2019

CRISPR is allowing researchers to make increasingly elaborate genetic tweaks to deal with issues that cause human immune rejections of transplant organs grown in animals

Two Pigs Engineered to Have Monkey Cells Born in China

Michael Le Page, New Scientist | 12.06.2019

Two piglets born in Beijing are reported to be the first full-term pig-monkey chimeras.

ASSISTED REPRODUCTION

What Happened to All Those Frozen Eggs?

Sarah Elizabeth Richards, The New York Times | 12.21.2019

The medical establishment advertised egg freezing as a way to prolong fertility and mitigate gender inequity by giving women more freedom to pursue their careers. In reality, it's not clear whether egg freezing will really allow a significant number of women to have children later in life.

GENOMICS

A Genetic Test Led Seven Women in One Family to Have Major Surgery. Then the Odds Changed.

Amy Dockser Marcus, The Wall Street Journal | 12.20.2019

As the science surrounding the BRCA gene has evolved, some women who took drastic surgical measures to protect themselves from breast and ovarian cancer are discovering they may never have been at high risk.

We're Entering a New Phase in Law Enforcement's Use of Consumer Genetic Data

Nila Bala, Slate | 12.19.2019

Genetic genealogy has ushered in a new era devoid of rules concerning genetic privacy. With no legal regulations providing clarity on how and when genetic genealogy should be used to fight crime, private entities are left in charge of the decision-making.

The Dark Side of Our Genealogy Craze

Honor Sachs, The Washington Post | 12.13.2019

Even as genealogy offers belonging to those who have been historically denied access to knowledge of their ancestry, it empowers those who seek to divide, deny, and marginalize segments of society.

10 Years Ago, DNA Tests Were the Future of Medicine. Now They're a Social Network—and a

Data Privacy Mess.

Peter Aldhous, *Buzzfeed News* | 12.11.2019 Personalized medicine was the dream, but the reality of direct-to-consumer DNA testing looks more like "Facebook for genes."

A DNA Firm That Caters to Police Just Bought a Genealogy Site

Megan Molteni, Wired | 12.09.2019

GEDmatch was the site used to identify a suspect in the Golden State Killer case. Now, what was once a hobbyist genealogy site has been purchased by the forensic genomics firm Verogen, which specializes in next-generation DNA testing services catered to law enforcement.

HERITABLE GENOME EDITING

Scientific Ethics and Gene Edited Babies

Françoise Baylis, The Boston Globe | 01.05.2020

China's response to He's reckless experiment indicates that the government takes it seriously and is willing to send a message. But it should be noted that He was trained in the United States—not China—and that some of his US colleagues knew about the experiment and did nothing.

Prison Sentence for Creator of First CRISPR Babies Reignites Ethical Debate

Françoise Baylis, The Conversation | 01.05.2020

The prison terms given to He Jiankui and his colleagues will not bring closure to the "CRISPR babies" scandal. The birth of three genome-edited babies was not just the work of three scientists, and there is still no agreedupon, ethically sound reason to pursue using this technology for reproduction.

Chinese Bioethicists: He Jiankui's Crime is More than Illegal Medical Practice

Ruipeng Lei and Renzong Qiu, *The Hastings Center Bioethics Forum* | 01.04.2020 It is ridiculous that the He Jiankui incident has been reduced to a case of illegal medical practice. But the violations of administrative regulations and ethical norms that He and his accomplices committed constitute no other crime in China.

Chinese Scientist Who Genetically Edited Babies Gets 3 Years in Prison

Sui-Lee Wee, The New York Times | 12.30.2019

In a private trial, the court found He Jiankui guilty of forging approval documents from ethics review boards to recruit couples in which the man had H.I.V. and the woman did not.

A Year After the First CRISPR Babies, Stricter Regulations Are Now in Place

Françoise Baylis, The Conversation | 12.10.2019

Despite the absence of a moratorium, there are indications that the governments of China and Russia and the World Health Organization are taking heritable genome editing seriously and attempting to prevent another reckless human experiment.

STEM CELLS

The California Stem Cell Program's \$5.5-Billion Funding Request Might Be Its Downfall

Michael Hiltzik, Los Angeles Times | 12.08.2019

The ballot initiative fails to justify nearly doubling CIRM's funding and renders the program immune to legislative oversight, despite its immense demand on taxpayer resources.

Buyer Beware: A Maryland Surrogacy Agency Was Scamming Vulnerable Hopeful Parents

Ellen Trachman, Above the Law | 01.08.2020

The Surrogacy Group promised its clients services like matching intended parents with gestational surrogates, assisting clients with the surrogacy process, and managing funds. In many cases, however, the group's owner pocketed the money, leaving both surrogates and intended parents high and dry.

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