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December 2019

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# BioPolitical

# News&Views

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## SPOTLIGHT

**IS CGS IN  
YOUR  
END-OF-YEAR  
GIVING  
PLANS?**

**Is CGS in Your Plans?** 2020 will be a pivotal year in the ongoing controversy about heritable genome editing. CGS is the only independent US nonprofit focused on confronting dangerous misuses of human genetic technologies, including the emerging threat of a new eugenics. Your support makes this work possible. Make an end-of-year contribution today, and join the fight for genetic justice!

## COMMENTARY

**Scientist on the Loose: George Church Strays Into Eugenics—**



## Again

**Pete Shanks**, *Biopolitical Times* | 12.11.2019

In a recent *60 Minutes* interview, George Church talked about developing an app to match couples via their DNA, thereby preventing the births of children with inherited diseases. It's not the first time Church has unleashed his eugenic ideas in the mainstream.

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## Do Not Open the Door

**Marcy Darnovsky**, *Southwestern Medical Perspectives* | 12.04.2019

The claim that heritable genome editing is necessary to “reduce human suffering in profound and meaningful ways” is misleading for several reasons. In fact, there is no compelling medical reason to develop heritable genome editing. Unless we want to build a world divided into genetic “haves” and “have nots,” let’s keep the door shut.

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## Meet the Republican Transhumanist, Zoltan the Magnificent!

**Pete Shanks**, *Biopolitical Times* | 12.06.2019

Zoltan Istvan is running for president of the United States—for the second time. His platform includes paving the way for human heritable genome editing, human cloning, and the widespread use of artificial wombs.

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## Polygenic Traits, Human Embryos, and Eugenic Dreams

**Pete Shanks**, *Biopolitical Times* | 12.04.2019

The primary function of polygenic risk scores is to identify a person’s or embryo’s risk of developing a particular disease. However, a new study calls into question whether such predictions can ever be accurately validated, and points to the fact that scores for height and intelligence have not held up under scrutiny.

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## CRISPR Babies – One Year Later

**Katie Hasson & Adrienne van der Valk**, *Biopolitical Times* | 12.02.2019

We might have expected heritable genome editing to be a top issue for politicians this year given the outcry over the CRISPR babies scandal—yet, we remain at a tipping point. If we are to counteract the small but vocal group of techno-enthusiasts determined to pursue heritable genome editing, we need to take decisive and immediate action.



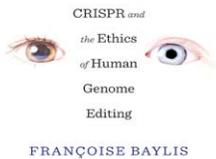
## The Year After the “CRISPR Babies” Bombshell

**Pete Shank**, *Biopolitical Times* | 11.22.2019

The “CRISPR babies” announcement made headlines around the world, and the response is still developing. Looking back at key events surrounding the human germline editing debate, it’s clear we need better and more concrete proposals for regulation if we are to head off more bombshells.

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## Altered Inheritance



## Book Review: *Altered Inheritance—CRISPR and the Ethics of Human Genome Editing*

**Gina Maranto**, *Biopolitical Times* | 11.15.2019

Françoise Baylis’ new book offers an “incisive, insightful, and rigorous” examination of the issues surrounding heritable genome editing. Rather than avoiding the arguments in favor of the technology, she tackles them head-on, correcting misconceptions, reframing misrepresentations, and offering nuanced perspectives honed over years of thoughtful study.



## Climate Crisis, Designer Babies, Our Common Future

**CGS Staff**, *Biopolitical Times* | 11.13.2019

The public conversation between John A. Powell and Bill McKibben drew enthusiastic responses from a full-house audience eager to talk about the connections between climate change and heritable genome editing. The learning continues via the on-demand recording, transcript, and highlights from the evening.

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## CGS IN THE NEWS

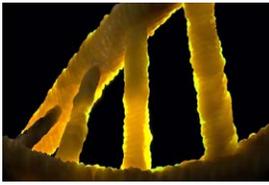


## IVF Add-on Procedures Offer False Hope

**Kelly Glass**, *Medium Elemental* | 11.06.2019

Many fertility clinics offer an expensive “à la carte” menu of services advertised to increase the likelihood of IVF success. However, as CGS’ Marcy Darnovsky notes, new evidence suggests that some clinics inflate their success rates through “extensive and persuasive marketing that is sometimes misleading about one’s chances of taking home a baby.”

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## Debating Human Gene Editing

Victoria Turner, *Synapse* | 11.08.2019

The new film *Anya* addresses the complexities of human genome editing and the forces that compel our decisions about assisted reproduction. Following a recent screening and discussion, CGS' Marcy Darnovsky and other panel members observed that, while billed as science fiction, the dilemmas posed in *Anya* are not far outside the realm of possibility.

## WHAT WE'RE READING

[Animals](#) | [Assisted Reproduction](#) | [Gene Therapy](#) | [Genetic Selection](#)  
[Genomics](#) | [Human Genetic Modification](#) | [Science and Society](#)

### ANIMALS

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#### Wiping Out the Daughters: Burkina Faso's Controversial Mosquito Experiment

Hide Boersma and Joost Bastmeijer, *The Guardian* | 11.18.2019

The controversial use of gene drive technology is moving to Burkina Faso, which will see the release of genetically modified mosquitoes. By limiting the birth of females, scientists hope to drastically limit the spread of malaria, which kills 400,000 people worldwide each year.

### ASSISTED REPRODUCTION

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#### From Assisted Hatching to Embryo Glue, Most IVF 'Add-ons' Rest on Shaky Science, Studies Find

Sharon Begley, *STAT* | 11.05.2019

Two new studies published in the journal *Fertility and Sterility* found that some fertility procedures, which come with hefty price tags, offer negligible benefits. In some cases, they decreased the chances of IVF success.

### GENE THERAPY

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#### Scientists Dodge FDA to Offer a \$1 Million Anti-Aging Treatment in Colombia

Emily Mullin, *Medium One Zero* | 12.05.2019

A Kansas-based company is offering a gene therapy it says can reverse aging by up to 20 years, and it's taking the clinical trial to a small clinic in South America. Scientists and ethicists are sounding the alarm about the medically questionable trial, the ethics of the pricetag, and the location.

## GENETIC SELECTION

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### **The World's First Gattaca Baby Tests Are Finally Here**

[Antonio Regalado](#), *MIT Technology Review* | 11.08.2019

The biotech company Genomic Prediction will soon offer embryo report cards designed to help parents choose the healthiest and “best” option for implantation. The test includes not only indicators for common health problems, but markers related to intelligence and height.

## GENOMICS

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### **Crack Down on Genomic Surveillance**

[Yves Moreau](#), *Nature* | 12.03.2019

DNA databases that could be used for state-level surveillance are steadily growing. Without stringent safeguards, the use of these data can all too easily creep from legitimate law-enforcement efforts to human rights abuses.

### **Consumer DNA Testing May Be the Biggest Health Scam of the Decade**

[Ed Cara](#), *Gizmodo* | 11.20.2019

The US Food and Drug Administration and Government Accountability Office began broadcasting warnings about direct-to-consumer DNA testing a decade ago. Despite legal and public relations set-backs, the industry has flourished, putting tens of millions of people at risk for misunderstanding their medical futures and losing their genetic privacy.

### **Your DNA Profile is Private? A Florida Judge Just Said Otherwise**

[Kashmir Hill and Heather Murphy](#), *The New York Times* | 11.07.2019

A Florida detective recently obtained a warrant to search a DNA database of nearly one million users—a first in the US criminal justice system. Legal experts say the development could have profound implications for genetic privacy.

### **Sequencing the Genome of Every UK Baby Would Be an Ethical Minefield**

[Clare Wilson](#), *New Scientist* | 11.07.2019

Many doctors are deeply concerned about the ethics of a new National Health Service plan to conduct genetic testing on every baby born in the UK. The plan poses questions about genetic privacy, bodily autonomy, and the value of testing babies for conditions that manifest later in life.

### **The DNA Database Used to Find the Golden State Killer is a National Security Leak Waiting to Happen**

[Antonio Regalado](#), *MIT Technology Review* | 10.30.2019

GEDmatch is a private, volunteer-run DNA ancestry database used by law enforcement and genealogy enthusiasts. It's also easy to breach, according to three scholars who designed and implemented a successful

data harvesting attack.

## HUMAN GENETIC MODIFICATION

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### **China's CRISPR Babies: Read Exclusive Excerpts from the Unseen Original Research**

[Antonio Regalado](#), *MIT Technology Review* | 12.03.2019

He Jiankui and his colleagues documented the now-infamous CRISPR-babies experiment in an academic manuscript that has never been published. Top scientists who reviewed the manuscript note there are many reasons to criticize it beyond the obvious ethics breaches.

### **Gene Editing Might Alter Our DNA. It Might Destroy Our Humanity, Too.**

[Mark Buchanan](#), *Bloomberg* | 11.25.2019

The medical risks of heritable genome editing are numerous and extreme, but the most frightening thing about the use of this technology is its irreversible societal effects—on parents' relationships with their children, on income inequality, and on our collective beliefs about what it means to be human.

### **Human Germline Editing Needs One Message**

[Nature Editorial Board](#), *Nature* | 11.20.2019

Currently, there are two different international commissions on the clinical use of heritable genome editing. The existence of two panels—neither of which includes adequate representation from the disability rights community—is a bureaucratic hindrance to comprehensive, inclusive deliberation.

### **Netflix's "Unnatural Selection" Ducks the Big Questions About Gene Editing**

[Jonathan R. Latham](#), *Salon* | 11.10.2019

The four-episode series takes an uneven and at times convoluted look at topics such as gene drives, gene therapy, and biohacking without adequately framing the larger social and ethical questions surrounding gene editing technologies.

### **NIH Director Backs Moratorium for Heritable Genome Editing**

[Kevin Davies](#), *Genetic Engineering & Biotechnology News* | 11.08.2019

Speaking at a Policy Summit hosted by the American Society of Gene and Cell Therapy, Francis Collins offered his full support for an international moratorium on the first anniversary of the birth of the CRISPR babies in China.

## SCIENCE AND SOCIETY

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### **Can Biology Class Reduce Racism?**

[Amy Harmon](#), *The New York Times* | 12.07.2019

Teachers in Colorado have volunteered to use an experimental curriculum that inserts the topics of race and ancestry into lessons about Gregor Mendel and the basic function of DNA.

## China Uses DNA to Map Faces, With Help From the West

[Sui-Lee Wee & Paul Mozur](#), *The New York Times* | 12.03.2019

Scientists in China, the US, and elsewhere are trying to use DNA samples to create images of people's faces. The technology could be used to justify and intensify racial profiling in China and other state discrimination against Uighurs.

## A New Treatment Promises to Make Little People Taller. Is it an Insult to 'Dwarf Pride'?

[Damian Garde](#), *STAT* | 11.18.2019

The treatment for people with achondroplasia, a form of dwarfism, is controversial in part because it measures success in terms of added height, overlooking the fact that, in the eyes of many people with dwarfism, small stature is not a medical issue that needs to be corrected.

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