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# CENTER FOR GENETICS AND SOCIETY

## BIOPOLITICAL VIEWS & NEWS

July 10, 2018

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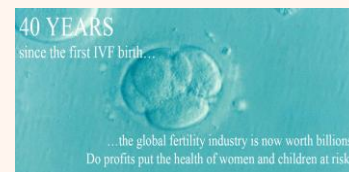
CGS in the News

News

## ANNOUNCEMENTS

### [40 Years of IVF: What's Been Overlooked?](#)

To mark the occasion of Louise Brown's 40th birthday, CGS and colleagues have prepared a two-page [fact sheet](#) on the multi-billion dollar IVF industry, highlighting high failure rates, understudied risks, lack of regulation and accountability, and social justice perspectives. Our partners on this project work on women's health and wellness, reproductive rights and justice, and disability rights; and/or represent organizations founded by current and former egg providers and IVF patients.



### [Upcoming Event, San Francisco: A Conversation on Biotech and Ethics](#)

Join CGS' Marcy Darnovsky and Osagie Obasogie for a discussion of biotechnology, bioethics, and beyond at the California Institute of Integral Studies in San Francisco on Thursday, July 19 at 7pm. Tickets and additional information available [here](#).



### [Welcome to CGS's New Summer Intern](#)

[Adam O'Regan](#) is an undergraduate at Stanford University where he is pursuing a dual degree in biology and anthropology. His academic interests lie at the intersection of science and society, and he is passionate about aligning science with the public good. In the past, Adam has conducted research in the field of environmental biology, volunteered for public service organizations both internationally and domestically, and worked as an editor for *Intersect*, the journal of science, technology, and society on Stanford's campus.



### [Center for Genetics and Society 2017 Annual Report](#)

In 2017, CGS escalated our efforts toward a world in which human biotechnologies promote social justice, the public interest, and the common good. There is no other organization like us in the United States. Check out our redesigned annual report [here](#).



## CGS COMMENTARY

### ["Flipping Out" Over Consent and Privacy: When Surrogacy Meets Reality Television](#)

By Alyssa Newman, Pop A.R.T. Guest Columnist

The woman contracting to be a surrogate wanted to "balance the playing field" for gay couples struggling to start families. But the fallout of their arrangement reveals the deep power inequities that underlie relationships between surrogates and commissioning parents.



Bravo reality TV star Jeff Lewis

### [Public and policy makers grow suspicious of genetic testing companies—for good reason](#)

By Adam O'Regan, *Biopolitical Times*

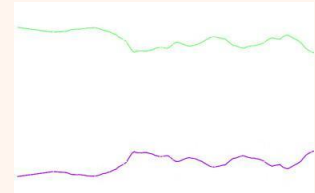
Who exactly does have access to consumers' DNA? That question has now become a topic of Congressional concern.



### [Polling News](#)

By Pete Shanks, *Biopolitical Times*

Gallup's annual Values and Beliefs survey includes questions about cloning, but not other pressing biotech issues.



### [Egg Selling in India](#)

By Diane Beeson, *Biopolitical Times* Guest Contributor

A two-part investigative series paints a picture that's very different than the fertility industry's romanticized promotion of egg retrieval for profit.



### [Review: \*The Gene Machine: How Genetic Technologies Are Changing the Way We Have Kids and the Kids We Have\*](#)

By Gina Maranto, *Biopolitical Times* Guest Contributor

The book leaves readers with a (not unfamiliar) nagging feeling that developments in assisted reproduction are outpacing individuals' and society's capacity to comprehend the full implications of the procedures on offer.



## CGS in the NEWS

### ▶ [Scientists Can Design 'Better' Babies. Should They?](#)

[Cites CGS' Marcy Darnovsky]

by Clyde Haberman, *The New York Times Retro Report*

At a time when manipulating the genomes of human embryos is becoming more mainstream, CGS' Darnovsky warns, "we have to ask where is the stopping point."



### ▶ [Using 23andMe to Reunite Families at the Border Comes With](#)

#### [Serious Privacy Risks](#)

[Cites CGS' Marcy Darnovsky]

by Tonya Riley, *Mother Jones*

DNA tests to reunite families at the border is not a quick fix, and not a wise one. It would be very dangerous to hand over private information of people who are already at risk in this country.



### ▶ [CRISPR Bioethics](#)

[Podcast with CGS' Katie Hasson]

by Kira Dineen, *DNA Today*

This podcast discussion peeks into the world projected by J.D. Lasica in his new genetics thriller novel, *Biohack*. Katie Hasson and Lasica discuss ethical issues surrounding CRISPR, and its implications for our future.

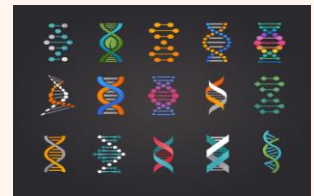


### ▶ [What happens to your DNA information after an ancestry test?](#)

[Cites CGS' Katie Hasson]

by Jesse Mulligan, *Radio NZ*

"It's time we had better regulations about who can access this information and how it can be used." CGS' Hasson exposes the potential downsides to sending in your saliva for commercial genetic analysis.



### ▶ [Does this dog look like a Saint Bernard? The questionable business of home DNA tests](#)

[Cites CGS' Marcy Darnovsky]

by David Lazarus, *The Los Angeles Times*

CGS' Darnovsky advises consumers to take personalized genetic tests with a grain of salt: "In fact, there are so many grains needed you are going to need a really big shaker."



### ▶ [5 biggest risks of sharing your DNA with consumer genetic-testing](#)

#### [companies](#)

[Cites CGS' Marcy Darnovsky]

by Eric Rosenbaum, *CNBC*

The privacy risks of direct-to-consumer genetic tests are coming more clearly into view.



### [Embryos Made From Genes of Three Biological Parents Fuel the Debate Over Designer Babies](#)

[Cites CGS' Marcy Darnovsky]

Kurt Pitzer, *People*

"It's irresponsible," CGS' Darnovsky tells *People*. "There are a lot of concerns that haven't been resolved by preclinical or animal work, so this is a kind of human experimentation."



### [Opinion: Three-Parent Embryos—A Slippery Slope?](#)

[Cites CGS' Marcy Darnovsky]

by John D. Loike and Alan Kadish, *The Scientist*

A clinic in Ukraine says it is using experimental mitochondrial manipulation techniques not to treat women at risk of transmitting disease to their children, but to treat infertility.



## NEWS

Assisted Reproduction

CRISPR

Eugenics

Genetic Testing

Genetic Testing at the Border

Various

## GENETIC TESTING AT THE BORDER

### [KQED: Leading Immigrant Aid Group Says No Thanks to 23andMe Offer to Help Reunite Detained Families](#)

by Gina Kolata and Heather Murphy, *The New York Times*

RAICES Communications Director Jennifer Falcon says the idea could cause more harm than good. "Essentially we're solving one violation of their civil rights basically with another."

### [CNN: DNA tests are in the works for separated migrant children and parents](#)

by Sarah Zhang, *The Atlantic*

Ignoring warnings from nonprofits, the Department of Health and Human Services has begun using genetic information in efforts to reunite immigrant families.

### [DNA testing could reunite families at the US border — and fuel surveillance](#)

by Russell Brandom and Rachel Becker, *The Verge*

Recent offers from commercial genetic testing companies risk significant ethical transgressions.

▶ [Genealogy site MyHeritage says 92 million user accounts compromised](#)

by Megan Thielking, *Stat News*

The recent security breach underscores growing concerns about the privacy of data submitted to genealogy platforms.

▶ [Genealogists Turn to Cousins' DNA and Family Trees to Crack Five More Cold Cases](#)

by Heather Murphy, *The New York Times*

More arrests have been made in cold cases that were tackled using a new approach that relies on an open-source ancestry site and genealogical techniques.

▶ [Lawmakers press genetic testing companies for details on their privacy policies](#)

by Megan Thielking, *Stat News*

Mounting concerns over how companies handle consumers' genetic data has caught the attention of policymakers, who want to shed light on the black box that is the direct-to-consumer DNA testing model.

▶ [Deleting Your Online DNA Data Is Brutally Difficult](#)

by Kristen V. Brown, *Bloomberg*

Consumers assume they retain control over their genetic information when they send it to commercial testing companies. But once you share your DNA online, you can't really ever unshare it.

▶ [DNA donors must demand stronger protection for genetic privacy](#)

by Mason Marks and Tiffany Li, *Stat News*

Public and private DNA databases may hold significant social benefits, but the lack of laws protecting those that share their DNA poses serious risks to public privacy.

▶ [After dog DNA debacle, Indigenous researcher says ancestry testing is 'stupid science'](#)

by CBC Canada, *CBC News*

"It's not that it's bad science but I don't think it should inform how we identify as Native people."

▶ [One of America's Biggest Genetic Testing Companies Refuses to Publicly Share Data That Could Save Countless Lives](#)

by Kat McGowan, *Mother Jones*

Many companies contribute genetic information to open databases. Myriad Genetics considers its trove of data to be a trade secret.

▶ [As more women turn to genetic testing for breast cancer, understanding risk is key](#)

by Katherine Drabiak, *Washington Post*

According to the FDA, most mutations that would increase an individual's risk are not detected by 23andMe's test.

▶ [The Online Gene Test Finds a Dangerous Mutation. It May Well Be Wrong.](#)

by Gina Kolata, *The New York Times*

Third-party analysis of raw DNA is not as rigorous as that done in a certified laboratory. But many consumers don't understand that their results are not conclusive.

▶ [Curious About Your Ancestry? Submit a DNA Swab, and a Big Grain of Salt](#)

by Maud Newton, *The New York Times*

"The tools currently available for exploring our histories are highly problematic. And yet, over millennia and over borders, the hunger to feel a connection to those who came before us, to those whose bodies brought forth ours, has persisted."

▶ [Results Of At-Home Genetic Tests For Health Can Be Hard To Interpret](#)

by Rob Stein, *NPR*

The tests have severe limitations and are not full-fledged genetic analyses. Their results can easily cause erroneous diagnoses.

## ASSISTED REPRODUCTION

- News TOP -

▶ [How IVF became a licence to print money](#)

by Fay Schopen, *The Guardian*

Private fertility clinics exploit desperate patients by selling add-ons such as acupuncture that likely have no effect on the outcome of IVF. Little is being done to regulate the industry.

▶ ['No other way to earn money': Why women from poor families become egg donors for infertile couples](#)

by Priyanka Vora, *Scroll.in*

Fertility clinics in India use networks of agents to recruit women willing to sell their eggs. The economic incentive outweighs the health risks for many women in need of income.

▶ [Swelling, bleeding and even death – women who donate their eggs face many medical risks](#)

by Priyanka Vora, *Scroll.in*

In India as elsewhere, egg donors are not adequately informed about the medical risks that hormone injections may bring.

▶ [Has the age of the anonymous sperm donor ended?](#)

by Elizabeth Payne, *Ottawa Citizen*

Donor anonymity has recently crumbled due to the rise of easy-to-access DNA testing.

## CRISPR

- News TOP -

▶ [As CRISPR–Cas adoption soars, summit calls for genome editing oversight](#)

by Eric Smalley, *Nature Biotechnology*

Reflections on two proposed initiatives: a global genome editing observatory, and the Association for Responsible Research and Innovation in Genome Editing.

▶ [China Is Genetically Engineering Monkeys With Brain Disorders](#)

by Sarah Zhang, *The Atlantic*

An MIT professor travels to macaque breeding facilities in China to experiment with new genetic-engineering technologies, in hopes of uncovering the secrets of conditions like autism.

▶ [A serious new hurdle for CRISPR: Edited cells might cause cancer, two studies find](#)

by Sharon Begley, *Stat News*

Two studies have found that editing cells with CRISPR may seed cancerous

tumors.

▶ [A Crispr Conundrum: How Cells Fend Off Gene Editing](#)

by Carl Zimmer, *The New York Times*

Scientists are working to untangle several issues in the CRISPR machinery. But scientists remain certain that unlocking CRISPR's secrets holds medical promise.

▶ [A CRISPR Pioneer on Gene Editing: 'We Shouldn't Screw It Up'](#)

by Sarah Zhang, *The Atlantic*

Feng Zhang says many problems still have to be solved before the technology can be used to treat human diseases.

▶ [Deleting a Species](#)

by Rowan Jacobson, *Pacific Standard*

We are on the brink of being able to genetically engineer an extinction. Should we?

## EUGENICS

- News TOP -

▶ [Behind the Criminal Immigration Law: Eugenics and White Supremacy](#)

by Ian MacDougall, *ProPublica*

The criminalization of undocumented entry into the United States was spearheaded in the 1920s by two men — one a committed eugenicist, the other "a proud and unreconstructed white supremacist."

▶ [Eugenics today: where eugenic sterilisation continues now](#)

by Robert A. Wilson, *Aeon*

Thought eugenics died with the Nazis? Think again: the eugenic programme of sterilising the 'unfit' continues even today.

▶ [How asylums became the crucible of genetics](#)

by David Dobbs, *Nature*

Gregor Mendel is usually named as the father of modern genetics, but it also draws from a much darker source: the statistical study of heredity in asylums for people with mental illnesses, argues the author of *Genetics in the Madhouse*.

## VARIOUS

- News TOP -

▶ [Report For Defense Department Ranks Top Threats From 'Synthetic Biology'](#)

by Nell Greenfieldboyce, *NPR*

Threats include creating viruses from scratch and increasing the lethality of them.

▶ [Exclusive: Neanderthal 'minibrains' grown in dish](#)

by Jon Cohen, *Science*

The scientists want to wire brain organoids to robots, hoping they will learn to control the robots' movement.

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