

To ensure delivery, please add info@geneticsandsociety.org to your address book or contacts.



CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

November 9, 2017

WEBSITE

BLOG

ABOUT US

PRESS ROOM

DONATE

SUBSCRIBE

Please also follow us on [Twitter](#), [Facebook](#), [YouTube](#), [Google+](#), [RSS](#) and on our [website](#) and [blog](#).

Announcements

Commentary

News

ANNOUNCEMENTS

[Talking Biopolitics with Shobita Parthasarathy and Tania Simoncelli](#)

The next event in CGS' *Talking Biopolitics* series will be on Thursday, November 16 at 10am PST / 1pm EST / 6pm GMT. University of Michigan Associate Professor [Shobita Parthasarathy](#) will discuss her latest book, *Patent Politics: Life Forms, Markets, and the Public Interest in the United States and Europe*, with [Tania Simoncelli](#), Director of Policy for Science at the Chan Zuckerberg Initiative. You can register for the event [here](#).



[CGS Debates Shoukhrat Mitalipov at Stanford](#)

Hosted by Stanford University's Debate Society, CGS Program Director Katie Hasson made the case against germline gene editing in a debate with Shoukhrat Mitalipov. In August, Mitalipov stirred controversy when he led a research team that was the first in the United States to edit a human embryo's DNA. More information to come.



[Why We Need a Black-Feminist Centered Bioethics in the Age of Gene Editing](#)

CGS Communications Coordinator Victoria Massie facilitated a workshop at the annual Black Women for Wellness Conference, "Power Manifesto," to discuss what kind of human future we want to write into our DNA—and who gets to decide.



[CGS Travels to Strasbourg](#)

CGS Program Manager Leah Lowthorp attended an [international conference](#) at the Council of Europe, marking the 20th anniversary of its Convention on Human Rights and Biomedicine (the Oviedo Convention). See her account [here](#).



[Folklore, Gene Editing, and the Twittersphere: #CRISPRfacts and #Gattaca](#)

At the [American Folklore Society Conference](#), CGS Program Manager Leah Lowthorp presented her paper, which calls on for attention to the folklore of science and technology as a way of understanding how the public is grappling with the quickly changing biotechnological world around us.



CGS COMMENTARY

[Revisiting Gattaca in the Era of Trump](#)

By Osagie Obasogie, *Scientific American*

What would it mean to embrace new gene-editing technologies such as CRISPR–Cas9 at the very moment white supremacy is, once again, on the rise?



[Written Evidence: UK Science and Technology Committee's Inquiry on Genomics and Genome Editing](#)

By Center for Genetics and Society, *National Health Service*

CGS submitted written evidence to the NHS inquiry on genomics and genome editing. We focused on the importance of maintaining the UK's existing prohibition on germline genome editing for reproduction or clinical applications, even as the NHS moves to integrate genomic medicine and somatic gene therapies.



[CGS at the Oviedo Convention's 20th Anniversary](#)

By Leah Lowthorp, *Biopolitical Times*

In the ongoing global conversation about human germline editing, the Oviedo Convention is a key policy touchstone. The recent 20th anniversary event makes clear that support for banning germline modification remains strong at the Council of Europe.



[In Support of Canadian Feminist Voices](#)

By Emily Galpern, *Biopolitical Times* Guest Contributor

Health Canada is engaged in a new deliberative process to create regulations for the provisions of the Assisted Human Reproduction Act that were required but never developed. Canadian feminists are concerned that scientists and clinicians will be the primary voices taken into account.



[One Small Step Toward Regulating Dubious Stem Cell Clinics](#)

By Pete Shanks, *Biopolitical Times*

California has enacted a law that begins to provide a framework for regulating stem cell clinics in the state. It's a start in the right direction, but it's only one small step.



NEWS

Assisted Reproduction

GENOMICS

Human Gene Editing

Stem Cells

Various

HUMAN GENE EDITING

► [Just Say No to Editing Human Embryos for Reproduction](#)

by Hille Haker, *Leaps Magazine*

To proceed ethically, I argue that the international community, through the United Nations and in line with the ban on human reproductive cloning, should explicitly ban embryo gene editing as a method of human reproduction.

► [Gene editing technology: Where should we draw the line?](#)

by Françoise Baylis, *Healthy Debate*

Respectful public engagement entails slow science, ethics literacy, and a commitment to the principles of responsibility, self-discipline, respect and cooperation.

► [Countering that Pro-Heritable Human CRISPR WSJ Piece](#)

by Paul Knoepfler, *The Niche*

There are no easy paths or fixes in this arena, but the scientific community needs to take stronger stands. In my view, now is not the time to proceed and that time, if it comes, is a long way off.

► [Bioethics Panels Open Door Slightly to Germline Gene Editing](#)

by Jeff Lyon, *JAMA*

Led by the American Society of Human Genetics, 11 organizations published a joint statement in August concentrating on the prospects for germline alteration, a no-fly zone among molecular biologists since the dawn of gene therapy in the 1980s.

▶ [**Nobel Winner Kazuo Ishiguro's 'Never Let Me Go' Predicted the Gene Editing Debate**](#)

by Ben Richmond, *Vice Motherboard*

Ishiguro's foray into science fiction does what the genre does best: It uncovers the implications beneath the advancement and asks contemporary society the human question.

▶ [**DNA surgery on embryos removes disease**](#)

by James Gallagher, *BBC*

The team at Sun Yat-sen University used a technique called base editing to correct a single error out of the three billion "letters" of our genetic code.

▶ [**'Chemical surgery' can correct genetic mutations behind many diseases—study**](#)

by Nicola Davis, *The Guardian*

Two new studies make scientists hopeful about new ways to understand and tackle certain genetic diseases.

▶ [**Modifying Your Own Genes Is Just An Injection Away—If You're Feeling Lucky**](#)

by Adele Peters, *Fast Company*

Anyone who chooses to inject themselves with modified DNA is taking a risk without enough data—or, arguably, any real data at all—about what might happen to make an informed decision. It probably goes without saying: Don't try this at home.

▶ [**An anarchist takes on the drug industry—by teaching patients to make their own meds**](#)

by Charles Piller, *STAT*

The company shies away from selling any products; it offers only free advice and encouragement, giving the FDA little reason to intervene.

▶ [**Anti-doping agency to ban all gene editing in sport from 2018**](#)

by Michael Le Page, *New Scientist*

The battle between sports cheats and testers is poised to enter a whole new arena. The World Anti-Doping Agency has extended its 2003 ban on 'gene doping' to include all forms of gene editing – but it is not clear the agency has the means to enforce this ban.

▶ [**Cascade of Costs Could Push New Gene Therapy Above \\$1 Million Per Patient**](#)

by Liz Szabo, *Kaiser Health News*

Taking the brakes off the immune system, can lead to life-threatening complications that require lengthy hospitalizations and expensive medications, which are prescribed in addition to conventional cancer therapy, rather than in place of it.

GENOMICS

- News TOP -

▶ [**My 'Orphan Disease' Has Given Me a New Family**](#)

by Rosemarie Garland-Thomson, *New York Times*

All those clichés of connectedness are now encoded in our genes. The human community is quite literally the human family.

▶ [**The Public's Distrust of Biotech Is Deepening. Commercialization May Be to Blame**](#)

by Jim Kozubek, *Undark*

A cutting-edge study foreshadows what genetic science might bestow to human health, but the public is rightfully wary.

▶ [Eugenics 2.0: We're at the Dawn of Choosing Embryos by Health, Height, and More](#)

by Antonio Regalado, *MIT Tech Review*

As machine learning unlocks predictions from DNA databases, scientists say parents could have choices never before possible.

▶ [Using DNA to Sketch What Victims Look Like; Some Call It Science Fiction](#)

by Ashley Southall, *New York Times*

Critics have raised concerns about the lack of peer-reviewed science behind the technology and the creeping expansion of how DNA is collected and used in criminal investigations, where it is susceptible to human bias, error and abuse.

▶ [Putting crime scene DNA analysis on trial](#)

by Lauren Kirschner, *ProPublica*

"The National Institute of Standards and Technology announced last week that it is launching a new study of certain types of DNA analysis used in criminal prosecutions...NIST will invite all public and private forensics labs in the U.S. to participate by testing the same set of complex DNA samples, and will compare the results, which will be published online next summer."

▶ [What DNA Testing Companies' Terrifying Privacy Policies Actually Mean](#)

by Kristen V. Brown, *Gizmodo*

If you do not read those documents—and many don't—you're missing the fine print that explains how your DNA can be used, misused, leaked, hacked, sold and commodified without your knowledge or deliberate consent.

▶ [3 Lessons From An Alarming Case Of Mistaken Cancer Gene Test Results And Surgery](#)

by Elaine Schattner, *Forbes*

This case should be a wake-up call about the quality of DNA testing and what variable guidance patients receive about their results. The implications are broad.

▶ [Navajo Nation reconsiders ban on genetic research](#)

by Sara Reardon, *Nature*

The policy that the Navajo Nation ultimately produces could serve as a template for other Native American groups considering how — or whether — to engage with genetic research, says a bioethicist at Vanderbilt University in Nashville, Tennessee.

▶ [A baby with a disease gene or no baby at all: Genetic testing of embryos creates an ethical morass](#)

by Andrew Joseph, *STAT*

People have access to more information about their own genes — or, in this case, about the genes of their potential offspring — than ever before. But having that information doesn't necessarily mean it can be used to inform real-life decisions.

ASSISTED REPRODUCTION

- News TOP -

▶ [First Report and Documentary on Surrogacy in Mexico](#)

by Grupo de Información en Reproducción

GIRE has released a report and documentary, *Deseos*, which grapples with the

politics of surrogacy through a human rights perspective.

▶ [**Anatomy of a Surrogacy**](#)

by Alison Motluk, *Hazlitt*

They wanted a baby, she wanted to carry it for them—for a fee. It's a common transaction but illegal in Canada, and the system here leaves both parties vulnerable.

▶ [**India outlawed commercial surrogacy—clinics are finding loopholes**](#)

by Sharmila Rudrappa, *The Conversation*

What impact are bans on commercial surrogacy having for women who work in the reproductive industry?

▶ [**She signed up to be a surrogate mother—and unwittingly gave her own child away**](#)

by Amy B. Wang, *Washington Post*

What followed was a lengthy, expensive legal battle. The San Diego surrogacy agency reportedly told Allen that the intended parents had relinquished the baby who was not their biological match—and also wanted up to \$22,000 in “compensation.”

▶ [**If a woman freezes her eggs, will her future babies be normal?**](#)

by Erin Blakemore, *Washington Post*

Because the technology is so new, there isn't a lot of data. There's no registry of births achieved using frozen eggs, and very few studies have focused on outcomes beyond pregnancy.

▶ [**Do celebrities have a responsibility to reveal their IVF?**](#)

by Zoe Williams, *The Guardian*

In Europe, 77% of IVF treatments fail – and doctors have suggested that famous people should be more honest about their fertility to combat the spread of misinformation.

▶ [**Chrissy Teigen, Gabrielle Union, and More Women Who Are Bravely Sharing Their Fertility Struggles**](#)

by *Vogue*

Tiegen's unapologetic take on the joys and pains of conception, pregnancy, and motherhood is sparking a wave of unguarded and heartfelt conversation.

▶ [**11th Circuit Denies Tax Deduction For Gay Man's Reproductive Expenses**](#)

by Peter J Reilly, *Forbes*

Kevin Newsom, President Trump's recent appointee to the Eleventh Circuit has managed to disappoint a major LGBT organization with his very first decision.

STEM CELLS

- News TOP -

▶ [**A Woman Went Blind After Stem Cells Were Injected in Her Eyes**](#)

by Sarah Zhang, *The Atlantic*

Cases of blindness now cropping up in the medical literature point to the potential dangers of letting hundreds of such clinics operate without oversight.

▶ [**California moves against unlicensed stem cell treatments—but is it doing enough?**](#)

by Michael Hiltzik, *Los Angeles Times*

What will make a difference in California may not be how the conversation starts, but where it leads.

▶ [Criticizing a Scientist's Work Isn't Bullying. It's Science](#)

by Simine Vazire, *Slate*

The *New York Times Magazine* story on Amy Cuddy brings up extremely important problems in science. But we cannot equate criticism with harassment.

▶ [Six Months Later, Controversy Still Plagues the March for Science](#)

by Ed Yong, *The Atlantic*

An open letter, signed by current and former members of the group, set off the latest round of complaints about its leadership.

▶ [Why We Loved "Orphan Black"](#)

by Elizabeth Preston, *Neo.Life*

A thriller about cloning, gene editing, and bioengineering is the perfect show for our times.

▶ [Protecting Against AI's Existential Threat](#)

by Ilya Sutskever and Dario Amodei, *Wall Street Journal*

We have a long way to go before powerful AI systems become a reality, which is exactly why we need to devote time and energy to AI safety now.

DONATE NOW
SECURE DONATIONS
BY GROUNDSPRING.org
