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July 1, 2016

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ANNOUNCEMENTS

[CGS Welcomes Summer Staff](#)

We are very pleased to be working this summer with Hasmik Djoulakian and Stephanie Maroney. Hasmik, a CGS staff associate since mid-May, is a rising senior at Syracuse University who also organizes on campus and works for various social justice organizations in the Syracuse community. Stephanie, a UC Davis Mellon Public Scholar who will be joining us during July and August, is a doctoral candidate in Cultural Studies finishing a dissertation that examines how dietary advice and nutrition science are informed by emergent understandings of human biology.



[Fall Internships Available](#)

The Center for Genetics and Society is accepting applications for Fall internships. Please click [here](#) for the complete intern announcement.



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Please join the biopolitical conversations at [#TalkingBiopolitics](#) on Twitter, and on [Facebook](#). And for dozens of great videos, please subscribe to the [CGS YouTube Channel](#), where you can watch what you've missed and re-watch what you'd like to see again.



CGS COMMENTARY

[UK Researchers Now Say Three-Person Embryo Technique Doesn't Work; Propose New Method](#)

by Jessica Cussins, *Biopolitical Times* guest contributor

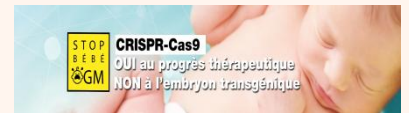
New research shows the mitochondrial manipulation technique recently legalized in the UK faces major unknowns.



[Hateful politics infiltrate human genome editing debate in France](#)

by Elliot Hosman

A new campaign calling for an international moratorium on CRISPR embryo experiments has been launched by a prominent anti-abortion and anti-LGBT group in France.



[The Disappointing NAS Gene Drive Report](#)

by Pete Shanks

The National Academies report on gene drive technology has not yet provoked the widespread debate it deserves.



[Unheard Publics in the Human Genome Editing Policy Debate](#)

by Elliot Hosman

The socially dangerous prospect of using genome editing tools for human reproduction underlies the need for caution in modifying embryos in basic research.



[On the 14-Day Rule and Other Limits](#)

by Pete Shanks

Speed limits are somewhat arbitrary but sensible; so is the 14-day rule for embryo research.



[Updates: The California Legislature and the Market in Human Eggs](#)

by Marcy Darnovsky

The fertility industry-sponsored bill is opposed by a range of women's health, reproductive justice, and public interest organizations.



[The "Outing" of Sperm Donor 9623](#)

by Hasmik Djoulakian

A lawsuit by families who used the sperm of a "schizophrenic felon" lands at the complicated intersection of fertility clinic negligence, genetic reductionism, disability, and eugenics.



CGS in the NEWS

▶ [Gene editing technique could transform future](#)

[citing CGS' Marcy Darnovsky]

by Fergus Walsh, *BBC News*

In a nightmare, "I realised with horror that it was Hitler and I was being expected to discuss this technology with him and he eagerly wanting to use it."

▶ [Senate eyes human egg business \[California\]](#)

[citing CGS' Marcy Darnovsky]

by David Jensen, *Capitol Weekly*

"Offering large sums of money encourages women in need to gamble with their health. Bioethicists call it 'undue inducement.'"

NEWS

▶ [They're going to CRISPR people. What could possibly go wrong?](#)

by Sharon Begley, *STAT*

Possible consequences range from off-target alterations to conflicts of interest in the clinical trial.

▶ [First Human Test of CRISPR Proposed](#)

by Antonio Regalado, *MIT Technology Review*

The proposed cancer treatment is an immune therapy in which a patient's own blood cells will be removed and genetically altered.

▶ [Promising gene therapies pose million-dollar conundrum](#)

by Erika Check Hayden, *Nature News*

Economists, investors and medical insurers can't figure out how to pay for gene therapy treatments.

▶ [Federal Oversight Group Has Complaints But Says Yes To CRISPR Trial](#)

by Alex Lash, *Xconomy*

Despite worries about conflict of interest, an NIH committee voted to let researchers move ahead with a clinical trial that could be the first use of CRISPR-Cas9 in a human treatment.

▶ [Gene-therapy trials must proceed with caution](#)

by Editorial, *Nature*

Past mistakes, which have ranged from harmful to deadly, must be prevented from recurring.

▶ [CRISPR Therapeutics adds \\$38M to Series B pot. but lags behind Parker](#)

by Ben Adams, *Fierce Biotech*

An NIH committee has backed a study funded by billionaire Sean Parker that will attempt to alter the T cells of 15 people with cancer.

▶ [Money Behind First CRISPR Test? It's from Internet Billionaire Sean Parker](#)

by Antonio Regalado, *MIT Technology Review*

Parker's foundation is unusual because it says it will control patents on research it funds and even bring treatments to market.

▶ [This scientist is trying to stop a lab-created global disaster](#)

by Kristen V. Brown, *Fusion*

"If we misuse our power, we lose the trust. That is the tightrope we walk," says Kevin Esvelt.

▶ [The National Academies' Gene Drive study has ignored important and obvious issues](#)

by Jim Thomas, *The Guardian*

Some important gaps in the study include an analysis of The report ducks questions about militarization, commercialization, and food security, but acknowledges there is "insufficient evidence to support the environmental release of gene drives."

▶ [Genetically engineered bugs to fight malaria and Zika? Not so fast, experts say](#)

by Joel Achenbach, *The Washington Post*

The use of "gene drive" technologies threaten incalculable harm to ecosystems worldwide.

▶ [Gene drive debate must include voices from Africa, elsewhere](#)

by Richard Nchabi Kamwi, *STAT*

The conversations have been missing the perspectives of representatives from malaria-affected countries, largely in South and Central America, Africa, and southern Asia.

▶ [A 'family spat' spills out in public, as scientists debate effort to build a human genome](#)

by Andrew Joseph, *STAT News*

Although it's not a goal of the project, brewing up a complete synthetic human genome could lead, in theory, to the formation of an actual person, sans parents.

▶ [Mitochondrial Replacement Hype Goes Nuclear Including by Wellcome Trust](#)

by Paul Knoepfler, *The Niche*

A new paper shows serious and difficult safety hurdles, but the UK media and some UK scientists are engaging in hype, claiming the exact opposite.

▶ ["Safe" call? My thoughts on the latest mitochondrial replacement paper](#)

by Ted Morrow, *Ted's Blog*

The reaction from many has been upbeat, but my reading of the paper is different. Despite all the warnings about mitonuclear mismatching, it is apparently glossed over by scientists and science communicators alike."

▶ [Better Mitochondrial Replacement: But Why?](#)

by Ricki Lewis, *PLOS*

As long as there are alternative ways to have healthy children, efforts to manipulate mitochondria, unless directed at developing a treatment for patients, should stop.

▶ [A Cautionary Tale of 'Stem Cell Tourism'](#)

by Gina Kolata, *The New York Times*

A patient who sought dubious stem cell therapies now has an aggressive tumor in his spine that doctors don't know how to treat.

▶ [Unproven Stem Cell Clinics Proliferate in the U.S.](#)

by Dina Fine Maron, *Scientific American*

570 websites advertise unproven therapies for sports injuries and conditions including autism, multiple sclerosis and Alzheimer's disease.

▶ [Stem Cell Scientist Suspected of Involuntary Manslaughter](#)

by Karl Ritter, *ABC News*

A disgraced stem cell scientist is facing preliminary charges of involuntary manslaughter in connection with two patients who died after windpipe transplants.

▶ [California stem-cell institute's political gamble](#)

by Paul Knoepfler, *San Francisco Chronicle*

Why is the state agency lobbying for a radical departure in how the U.S. Food and Drug Administration vets experimental stem-cell therapies?

▶ [How iPS cells changed the world](#)

by Megan Scudellari, *Nature*

Though therapies using induced pluripotent stem cells have proved challenging, iPS cells have become important for modelling and investigating human diseases, as well as for screening drugs.

▶ [Stem cell factory opens door for trials of personalized diabetes treatment](#)

by Andrew Joseph, *Stat News*

The proposed treatment for type 1 diabetes, based on induced pluripotent stem cells, could enter clinical trials in a few years.

▶ [Organ research scientists combine human stem cells and pig DNA](#)

by Kevin Rawlinson & Nicola Davis, *The Guardian*

Safety and ethical questions accompany efforts by researchers to grow human

organs for transplants inside pigs.

▶ [All about the base: New businesses eye the opportunities in managing genome data](#)

The Economist

Currently, one firm - Illumina - controls 70% of a market worth \$3.3 billion in 2015.

▶ [23andMe Sells Data for Drug Search](#)

by Antonio Regalado, *MIT Technology Review*

23andMe is monetizing DNA rather the way Facebook makes money from our "likes." What's more, it gets its customers to pay for the privilege.

▶ [Are DIY gene-testing kits a good idea?](#)

by Sharon Brennan, *The Guardian*

Over-the-counter genetic tests leave some people knowing they may develop a serious illness but unable to do anything about it.

▶ [A DNA Test Won't Explain Elizabeth Warren's Ancestry](#)

by Matt Miller, *Slate*

Could more data that would improve the precision of ancestry tests? Probably not — in fact, it might get more complicated.

▶ [Testing, testing: Prenatal genetic screening](#)

by Joe Gibes, *Trinity International University*

Confusion and uncertainty surround both the accuracy of prenatal genetic screening and people's understanding of what PGS is.

▶ [FDA chief aims to recruit 100 million Americans for precision medicine research](#)

by Meghana Keshavan, *STAT News*

President Obama's Precision Medicine Initiative set a goal of recruiting a million volunteers to hand over their genetic and health data. The new head of FDA thinks that's far too modest.

▶ [Biden unveils launch of major, open-access database to advance cancer research](#)

by Laurie McGinley, *The Washington Post*

The Vice President says the Genomic Data Commons will encourage collaboration among scientists, and will protect patient privacy.

▶ [The Supreme Court decision that's shaking up biotech](#)

by Damian Garde, *STAT*

A lower court's decision will stand: Sequenom can't patent its prenatal gene test because it is based on a natural biological process.

▶ [Should We Sequence the DNA of Every Cancer Patient?](#)

by Antonio Regalado, *MIT Technology Review*

Mayo Clinic will provide infrastructure to store, analyze, and A startup plans to give free genetic tests to 100,000 cancer patients in order to steer them to drug

companies.

▶ ['Silicon Valley arrogance'? Google misfires as it strives to turn Star Trek fiction into reality](#)

by Charles Piller, *STAT News*

Google has positioned itself to be a giant in life sciences, but its setbacks and prominent scientists' skepticism call into question this vision of the future of medicine.

▶ [Big Biotech is here — and it's starting to look a lot like Big Pharma](#)

by Meghana Keshavan, *STAT News*

The market characteristics and goals of biotech companies align increasingly with those of pharmaceutical companies.

▶ [Myriad Genetics Refuses To Accept That People Have A Right To Access Their Own DNA Sequences](#)

by Glyn Moody, *Tech Dirt*

Despite major court rulings against gene patents, Myriad still refuses to release information from its huge DNA database built over years of sequencing patients' BRCA genes.

▶ [Swiss back genetic testing of embryos \(again\)](#)

by Celia Luterbacher, *Swiss InfoNews*

Testing embryos can prevent transmission of serious genetic diseases, but also threatens discrimination against people with disabilities and a "slippery slope toward eugenics."

▶ [As surrogacy industry expands, legal and ethical issues mulled](#)

by Bun Sengkong & Will Jackson, *The Phnom Penh Post*

Surrogacy agencies in Cambodia and websites such as Gay with Kids facilitate cross-border surrogacy, although the Cambodian government remains unclear on surrogacy policies.

▶ [Book Review: Discounted Life - The Price of Global Surrogacy in India](#)

by Elo Luik, *BioNews*

Rudrappa locates surrogacy within the histories of politics and control as well as aspiration, nationalism and modernisation that the bodies of working-class Indian women have long been subjects of and subjected to.

▶ [Do women who donate their eggs run a health risk?](#)

by Sandra G. Boodman, *The Washington Post*

Health advocates say that donors are being falsely reassured that the process is safe, without being told that there is no definitive research.

▶ [The Politics of Women's Eggs](#)

by Diane Tober, *Undark*

A California bill would allow researchers to obtain eggs by paying women to provide them, though little research exists on the procedure's long-term health impacts.

▶ [Japanese city backs egg-freezing scheme to boost birthrate](#)

by Associated Press [Urayasu, Japan], *The Guardian*

The city of Urayasu is allocating £600,000 for a project in which women will receive a substantial discount to freeze their eggs.

▶ [Subsidised egg freezing isn't the answer to Japan's birth rate](#)

by Angel Petropoulos, *New Scientist*

The health risks of egg retrieval make Japan's publicly-funded egg freezing initiative a poor solution to the country's problem of population shrinkage.

▶ [Bill covering in vitro fertilization for injured veterans clears the House](#)

by Seattle Times Staff, *The Seattle Times*

Veterans Affairs is closer to paying for in vitro fertilization for injured soldiers seeking to have children.

▶ [DIY sperm test to hit the market this fall](#)

by Meghana Keshavan, *STAT News*

The semen centrifuge will calculate sperm count, but not sperm motility or other factors that affect fertility.

▶ [Eugenics victim still waiting for last payment](#)

by Tim Buckland, *Star News Online*

Human genome synthesis could redefine what now joins all of North Carolina's fund to compensate victims of its eugenic sterilization program is in limbo, with lawsuits pending.

▶ [House votes to expand compensation for eugenics victims](#)

by Colin Campbell, *The News & Observer*

The North Carolina House voted to expand a program to compensate people who were sterilized by the state government from 1929 to 1974.

▶ [Did Infamous Tuskegee Study Cause Lasting Mistrust of Doctors Among Blacks?](#)

by Aaron E. Carroll, *The New York Times*

The Tuskegee Study was a horrific instance of racism and injustice in medical research, but racism is a systemic condition of US health care, not an isolated event.

▶ [Workers May Soon Have To Share Health Data — Or Pay A Penalty](#)

by Stephanie M. Lee, *BuzzFeed News*

Ever thought about joining your work's wellness program? The consequences of opting out could soon get stiffer.

▶ [Start-ups selling new blood tests directly to consumers raise safety and accuracy concerns](#)

by Melody Petersen, *The Los Angeles Times*

Worried about the rising number of unproven lab tests, the FDA has proposed strengthening its rules so that it can regulate the riskiest of the lab-developed

tests.

▶ [Undertake a Clinical Trial at Your Own Risk](#)

by Steve Sternberg, *US News & World Report*

"Money should be set aside to care for people like me, if we're damaged in a clinical trial. We shouldn't be discarded."

▶ [DEA Wants Inside Your Medical Records to Fight the War on Drugs](#)

by Christopher Moraff, *The Daily Beast*

The agency wants access to millions of private health files without a warrant, including those of two transgender men who are taking testosterone.

▶ [Lab-grown mini-guts open door to personalised medicine](#)

by Tarek Bazley, *Al Jazeera*

Dutch researchers have used the organoid technology to choose medication tailored for individual patients.

▶ [Interview: "Democratic deliberation" and bioethics](#)

by Nelson Michael & Xavier Symons, *BioEdge*

A member of the Presidential Commission for the Study of Bioethical Issues discusses the state of US bioethics.

▶ [What does Brexit mean for bioethics?](#)

by Xavier Symons, *BioEdge*

Currently, one firm - Illumina - controls 70% of a market worth \$3.3 billion in 2015.

▶ [The Problem With Super-Muscly Pigs](#)

by Judith Benz-Schwarzburg & Arianna Ferrari, *Slate*

Technologies to genetically engineer sentient animals for meat production raise questions about the human-animal relationship.

▶ [Read Sonia Sotomayor's Atomic Bomb of a Dissent Slamming Racial Profiling and Mass Imprisonment](#)

by Mark Joseph Stern, *Slate*

Her dissent explains the extent to which police violate predominantly black and brown people's bodily integrity during "stop and frisk" procedures.

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