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CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

September 9, 2016

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ANNOUNCEMENTS

[Gene editing for “better babies?” Preventing a eugenic future](#)

The prospect of using new gene editing tools for human reproduction is closer than it's ever been. Some proponents are actively downplaying its unacceptable safety risks to future children and generations, and dismissing its profound social hazards. If proposals for “human enhancement” hold sway, we will have crossed a threshold into an era of high-tech eugenics that is completely at odds with any vision of a just and equitable human future. We recently published new background materials to help you stay on top of the debate:

- [5 Reasons to Say No to Genetically Modified Humans](#) [PDF]
- [Human Gene Editing: A Timeline of CRISPR Cover Stories](#)
- [About Human Germline Gene Editing](#) (resource page)



[Two New Job Openings: Communications Coordinator and Campaign Director](#)

Come work with us! We're looking for people committed to social justice who would like to work toward ensuring that human biotechnologies are used for safe, effective, ethical, and affordable medical treatments – not to open the door to a eugenic future of increased inequality, discrimination, and conflict. More information [here](#).



[Welcome to New CGS Staff](#)

We are thrilled to welcome two new staff members. Seasonal Staff Assistant [Kayla Tolentino](#) joins us as a recent graduate of San Francisco State University, having majored in Community-Based Health Education and minored in both Political Science and Women's Health. Program Manager [Leah Lowthorp](#) joins us as a two-year fellow from the American Council for Learned Societies, with a dual PhD in Folklore and Anthropology from the University of Pennsylvania. Learn more about our Staff and Fellows [here](#).



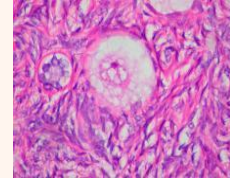
CGS COMMENTARY

[Victory: Eggs-for-Research Bill Dies in California Legislature](#)

by Emily Galpern, *Biopolitical Times* guest contributor

A bill that would have expanded the commercial markets for human eggs,

putting egg providers' health at risk, never made it to the Governor's desk.



[Will Genetic Engineering Really Change Everything Forever? \[Video Review\]](#)

by Elliot Hosman

The hype surrounding CRISPR gene editing and a future of designer babies is on playback with a popular new video. Is its optimism justified? And who decides what's inevitable?



[To Err is Biotechnological: Reflections on Pew's Human Enhancement Survey](#)

by Gina Maranto, *Biopolitical Times* guest contributor

Biotechnologies aimed at human enhancement come with a guaranteed set of deficits, inadequacies, inconveniences, and risks.



[5 Reasons Why We Need People with Disabilities in the CRISPR Debates](#)

by Emily Beitiks, *Biopolitical Times* guest contributor

"Why do I have to keep justifying my existence?" How gene editing policy discussions reproduce ableist assumptions and generate advocacy fatigue.



[Scandals Waiting to Happen: Institutional Conflicts of Interest at California Stem Cell Agency](#)

by Pete Shanks

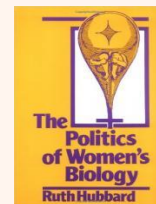
StemCells Inc., which has received tens of millions of dollars from the state-funded stem cell agency, paid its president a hefty sum when he joined its board a week after resigning his position.



[Remembering Ruth Hubbard](#)

by Marcy Darnovsky

Ruth Hubbard — biologist, feminist scholar, social justice advocate, and critic of what she termed "the gene myth" — has died.



[Questions about Deaths in Cancer Trials using Gene-Altered Cells](#)

by Katherine Drabiak, *Biopolitical Times* guest contributor

Excitement about immunotherapy and gene therapy approaches to cancer has eclipsed ethical questions about seven recent deaths in clinical trials.



CGS in the NEWS

[The Human Egg Business: More Media Coverage of California Cash-for-Eggs Legislation](#)

[citing CGS]

by David Jensen, *California Stem Cell Report*
AB 2531, backed by the fertility industry, would remove caps on payments for egg retrieval, thus inducing women to gamble with their health.



[Inside New York's Radical Egg-Freezing Clinic for Women](#)

[citing CGS' Marcy Darnovsky]

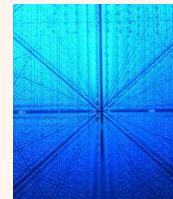
by Lizzie Crocker & Abby Haglage, *The Daily Beast*
Extend Fertility in Manhattan offers egg freezing at half market price. It's also the first standalone practice of its kind in the U.S.



[Public policy must address technology's impact](#)

[citing CGS' Marcy Darnovsky]

by John M. Hein, *The Sacramento Bee*
"We need to develop habits of mind, or habits of social interaction, that will allow for some very robust public participation on the use of these powerful technologies," says Marcy Darnovsky.



NEWS

[Forget Ideology, Liberal Democracy's Newest Threats Come From Technology and Bioscience](#)

by John Naughton, *The Guardian*
Homo Deus: A Brief History of Tomorrow, reviewed here, argues that "In the 21st century, those who ride the train of progress will acquire divine abilities of creation and destruction, while those left behind will face extinction."

[Humans of the Future Could Be Much Faster Than Usain Bolt or Michael Phelps](#)

South China Morning Post

We could be getting closer to the post-human era, where we modify our own genetics to the point that we're less recognisably "human" than ever before.

[In the Fight for Our Genes, Could We Lose What Makes Us Human?](#)

by Ziyaad Bhorat, *openDemocracy*

When genetics become the next currency for corporations and governments we risk the commercialization and politicization of who we are on a level far deeper than our skin.

[Staying Ahead of Technology's Curves](#)

by Doug Hill, *Boston Globe*

Embracing disruptive technologies without trying to anticipate and prepare for their potential consequences is now, more than ever, a bad idea.

[Silicon Valley was going to disrupt capitalism. Now it's just enhancing it](#)

by Evgeny Morozov, *The Guardian*

Tech giants thought they would beat old businesses but the guardians of capitalism are using data troves to become more, not less, resilient.

▶ [The surprisingly small benefit of some very \(expensive\) Big Ideas](#)

by Joe Gibes, *Bioethics @ TIU*

A new article in *JAMA* looks at the unfulfilled hype that has become entrenched in the fields of stem cells, genetics, and electronic health records.

▶ [Ruth Hubbard, 92, First Woman Tenured in Biology at Harvard](#)

by Bryan Marquard, *Boston Globe*

Ruth Hubbard shifted her focus from the laboratory to the petri dish of politics, becoming a prominent feminist critic of science.

▶ [Hacking life: Scientists 'recode' DNA in step toward lab-made organisms](#)

by Sharon Begley, *STAT*

It may not be long before scientists assemble genomes of higher organisms, as George Church proposed to do for the human genome.

▶ [US government may fund research to combine human cells and animal cells](#)

Associated Foreign Press

Stuart Newman asks: What if we have pigs with human brains and they are wondering why we are doing experiments on them? What about human bodies with animal brains? Could we harvest organs from them?

▶ [Experimental Cancer Therapy Holds Great Promise — But at Great Cost](#)

by Meghana Keshavana, *STAT*

Patients undergoing immunotherapy clinical trials with CAR-T cells are at risk for deadly cytokine release syndrome, but pharmaceutical companies are racing to get FDA approval.

▶ [What happens when anyone can edit genes at home? We're about to find out](#)

by Dyllan Furness, *Digital Trends*

Scientists express concern about the unintentional consequences of gene editing starter kits proliferating in biohacking communities.

▶ [Mind your genes! The dark legacy of eugenics lives on](#)

by Natasha Miller, *ABC [Australia]*

The misguided science of behavioral genetics and the social engineering potential of CRISPR show we have much to remember about the history of eugenics.

▶ [Diversity, disability and eugenics: An interview with Rob Sparrow](#)

by Xavier Symons, *BioEdge*

Philosophers and the medical profession have been way too swift to make judgments about other people's quality of life. We're not as far from the bad old eugenics as many think.

▶ [Scientists break 13-year silence to insist 'three-parent baby' technique is safe](#)

by Ian Johnston, *The Independent*

The researchers conclude the technique "can produce a viable pregnancy." But the pregnancy they established resulted in miscarriage.

▶ [The Perils of Planned Extinctions](#)

by Claire Hope Cummings, *Project Syndicate*

Instead of taking time to fully consider the ethical, ecological, and social issues of gene-drive technology, many are aggressively promoting its use in conservation.

▶ [Stem Cell Company Paid \\$443,500 to Former Head of State Agency That Funds Research](#)

by David Jensen, *The Sacramento Bee*

Conflict-of-interest allegations have dogged the agency since it was created in 2004 by California voters to use state bond proceeds to finance stem cell research.

▶ [Stem-Cell Treatments Become More Available, and Face More Scrutiny](#)

by Melinda Beck, *Wall Street Journal*

Critics say the clinics are peddling 21st century snake oil and want the FDA to crack down.

▶ [These New Stem Cell Treatments Are Expensive — and Unproven](#)

by Michael Hiltzik, *Los Angeles Times*

"Stem cells have become a medical buzzword," Paul Knoepfler notes. "I see a lot of businesses using direct marketing to patients to take advantage of that."

▶ [Will Embryonic Stem Cells Ever Cure Anything?](#)

by Aleszu Bajak, *MIT Technology Review*

The long, costly effort to cure diabetes with stem cells shows the difficulties and challenges of clinical translation.

▶ [Another Scathing Report Causes More Eminent Heads to Roll in the Macchiarini Scandal](#)

by Gretchen Vogel, *Science Magazine*

Fallout continues from a scandal involving patient deaths after a surgeon implanted artificial tracheae seeded with stem cells

▶ [Kuwait's new DNA collection law is scarier than we ever imagined](#)

by Daniel Rivero, *Fusion*

National security policies require residents, citizens, and visitors to submit DNA samples, shaping new definitions of the country's citizenship.

▶ [FBI's New DNA Process Produces More Matches in Suspect Database](#)

by Devlin Barrett, *Wall Street Journal*

In May, the Bureau reduced the number of genetic locations required for a potential match (from 10-13 to 8-9 loci), resulting in thousands of new "hits."

▶ [Gene Mapping May Not Be for Everyone](#)

by Karen Weintraub, *USA Today*

Genetic tests reveal variations in the genome that might not cause problems but could lead to unnecessary medical tests, anxiety and treatments.

▶ [Athletes are keeping their distance from a genetic test for concussion risks](#)

by Rebecca Robbin, *STAT*

Sports competitors, insurers, and researchers are cautious about the privacy and geneticization issues behind testing for "athletic" genes.

▶ [**The Human Genome Is Having Its Facebook Moment**](#)

by Whet Moser, *Chicago Magazine*

In less than a decade, as many people could have their genomes sequenced as use the social networking site (~1.7 billion monthly users).

▶ [**Do Olympians Have Better Genes Than You And Me?**](#)

by Christina Farr, *Fast Company*

Genetic tests aimed at discerning the genetic basis for athletic ability could be used coercively, and are undermined by important environmental factors.

▶ [**Why Gene Tests for Cancer Don't Offer More Answers**](#)

by Jessica Wapner, *Scientific American*

Genetic profiling of tumors has a long way to go. Many patients learn that their cancers have mutations for which no drug exists

▶ [**Illumina Would Like You to Sequence More DNA, Please**](#)

by Sarah Zhang, *WIRED*

The leader of the DNA sequencing market has a start-up accelerator program to find new applications for its technology.

▶ [**Ethical questions raised in search for Sardinian centenarians' secrets**](#)

by Stephanie Kirchgaessner, *The Guardian*

Samples from residents of Sardinia's "Blue Zone," who are famed for longevity, have been sold to a for-profit British research firm.

▶ [**In CRISPR Fight, Co-Inventor Says Broad Institute Misled Patent Office**](#)

by Antonio Regalado, *MIT Technology Review*

Is an email between competing researchers a smoking gun in the billion-dollar battle over patent rights for gene editing?

▶ [**CRISPR patent fight: The legal bills are soaring**](#)

by Sharon Begley, *STAT*

Editas has already spent \$10.9 million in 2016. Many in the CRISPR field wonder privately why the Broad Institute and UC Berkeley have not reached a settlement.

▶ [**The \\$100,000-Per-Year Pill: How US Health Agencies Choose Pharma Over Patients**](#)

by Fran Quigley, *Truthout*

Big Pharma wasn't always the beneficiary of US government-funded medicine breakthroughs. Then came the 1980s and the Bayh-Dole Act.

▶ [**How biotech executives profit from legal insider trades**](#)

by Damian Garde, *STAT*

Biotech bigwigs might be gaming an insider trading loophole to offset losses after failed clinical trials.

▶ [**New Surrogacy Bill Bars Married Couples with Kids, NRIs, Gays, Live-ins, Foreigners**](#)

by Express News Service, *The Indian Express*

The draft bill permits only "altruistic surrogacy" for childless couples who have been married for at least five years.

▶ [Why India's New Surrogacy Bill Is Bad For Women](#)

by Sharmila Rudrappa, *The Huffington Post*

In an attempt to regulate surrogacy, the bill has further deregulated the industry and opened the possibilities for deeper harms to working class women.

▶ [Surrogates are Workers, Not Wombs](#)

by Amrita Pande, *The Hindu*

Assumptions about women and reproduction derail effective worker protections in surrogacy regulation, as seen in India's draft legislation.

▶ [Surrogacy Still Big Business in Shanghai Despite National Ban](#)

by Alice Yan, *South China Morning Post*

Since China's one-child policy relaxed two years ago, the surrogacy industry has been expanding despite recent police raids.

▶ [Booming demand, state protections attract commercial surrogate birthing](#)

by Kathy Robertson, *Sacramento Bee*

California has more surrogacy regulation than most states. But the founder of an agency comments, "Anybody in the whole world – even a felon – can open an agency. There is no licensing, no background check."

▶ [Sperm Donor at Heart of Canadian Lawsuits Admits He Lied to Company Xytex, Police Say](#)

by Diana Mehta, *The Canadian Press*

Amidst pending lawsuits, Sperm Donor 9623 has turned himself in to the police for "falsifying paperwork."

▶ [Babies' Health Could Be Affected by Variation in IVF Nutrients](#)

by Jessica Hamzelou, *New Scientist*

Pharmaceutical companies keep the "recipe" of IVF culture media a secret, but research suggests long-term health effects for resulting children.

▶ [Two Women Pregnant after Having Ovarian Mitochondria Injected into Eggs](#)

The Japan Times

Some experts are calling for a careful response to the new procedure, as its safety and effects have not yet been scientifically verified.

▶ [Accessible Synthetic Biology Raises New Concerns for DIY Biological Warfare](#)

by Joseph Neighbor, *VICE Motherboard*

The monopoly on biology once held by governments and universities has been broken, posing significant challenges for the international community.

▶ [Finding Good Pain Treatment Is Hard. If You're Not White, It's Even Harder.](#)

by Abby Goodnough, *The New York Times*

Researchers have found evidence of racial bias and stereotyping in recognizing and treating pain among people of color, particularly black patients.

▶ [ExAC Project Pins Down Rare Gene Variants](#)

Nature Editorial

A new study found only 9 of 192 variants were actually linked to pathogenic disease despite ongoing use in diagnosis and treatment.

► [Many pediatric clinical trials go unpublished or unfinished](#)

by Ed Silverman, *STAT*

Of 559 clinical trials, 19% were discontinued. Of 455 completed trials, 30% never published results. Over 69,000 children participated.

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