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BIOPOLITICAL
VIEWS & NEWS

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ANNOUNCEMENTS

[New CGS Website](#)

This week, CGS unveiled a complete redesign of our website. We'd welcome your feedback!



[Join CGS as a Program Director on Genetic Justice](#)

CGS is currently hiring a senior-level Program Director on Genetic Justice to bring a social justice framework to current debates and policy considerations on human biotechnology developments, with a focus on human gene editing for reproduction. The Program Director will foster collaboration among individuals in multiple academic and professional fields as well as a range of social justice and non-profit organizations; raise awareness among the public and the media; and influence state, national and international policy.



[Save the Date: Webinar on Gene Editing and the Future of Reproductive Justice](#)

CGS will be co-sponsoring a webinar, "Gene Editing and the Future of Reproductive Justice," with Black Women for Wellness and Our Own Voice National Black Women's Reproductive Justice Agenda on June 13 at 10am PT / 1pm ET. Details coming soon.



[ICYMI: #CGSBioethics Captures Conversation on Disability Justice and Human Genetic Engineering](#)

On April 24, CGS co-hosted a webinar on disability justice and human genetic engineering alongside the [Paul K. Longmore Institute on Disability](#), the [Disability Visibility Project](#), and the [Disability Rights Education & Defense Fund](#). In addition to our dynamic speakers, participants were invited to live-tweet the conversation at #CGSBioethics, which has been captured on [Storify](#). A video of the webinar will be posted shortly on the CGS YouTube channel.



CGS COMMENTARY

[“Being Human in a Biotech Age” Film Series Tackles Biotechnology and Society](#)

by Jonathan Chernoguz

Being Human in a Biotech Age is in large part an effort to open conversations about how technological innovations impact society. We're pleased to continue to use film to provide opportunities for nuanced exploration of how advancements can be implemented without increasing social inequities and injustice.



[Why I'm speaking about human genetic engineering as a Black woman with disabilities](#)

by Anita Cameron, Guest Contributor

Anita Cameron, an activist, blogger, and panelist for the “Disability Justice & Human Genetic Engineering” webinar, writes about why it is important to incorporate discussions of human gene editing for reproduction into disability justice conversations today.



[23andWho? Questions Cloud Partial Relaunch](#)

by Pete Shanks

23andMe is getting a re-start of sorts after the FDA recently approved direct-to-consumer tests for disease risks. But have the questions that previously prevented the company's DTC tests been resolved or repackaged?



[The Fertility Industry is 3-person IVF's Ultimate Prize](#)

by Leah Lowthorp

Dr. John Zhang's controversial use of the 3-person IVF technique could initiate human experimentation that is dangerous not only for existing people, but also for future generations.



[Is Surrogacy Always a “Win-Win” Situation](#)

by Ayesha Chatterjee, Guest Contributor

A new anthology, Babies for Sale? Transnational Surrogacy, Human Rights and the Politics of Reproduction, features more than 30 activists and scholars from around the world, and offers the first genuinely international study of the impact of commercial surrogacy.



[Who Knew Synthetic Biology Was So Hard?](#)

by Pete Shanks

A company recently threw in the towel for generating a glowing plant because synthetic biology isn't as easy as the hype suggests.



CGS in the NEWS

[Should Californians give more money for stem cell research?](#)

[citing CGS' Marcy Darnovsky]

by Bradley J. Fikes, *San Diego Tribune*

In January, the biomedical news site *STAT* published a lengthy and critical analysis of CIRM's record in clinical trials, quoting critics who said Prop. 71's supporters "shamelessly oversold" the initiative as providing quick cures. "The airwaves were swamped with guys in white coats who were identified with their academic affiliation even though they were principals of private companies (some of which later got CIRM grants), and basically saying, 'We're going to have cures by Christmas,'" said Marcy Darnovsky, who directs the Berkeley-based Center for Genetics and Society.



[No, Companies Shouldn't Pay Women to Freeze Their Eggs](#)

[citing CGS' Marcy Darnovsky]

by Mary Ann Mason and Tom Ekman, *Wired*

Social freezing has now become one of the fastest-growing sectors of the fertility industry. Frozen eggs give hope to the swelling ranks of professional women who do not have time to have a baby.



[How to Understand The Resurgence of Eugenics](#)

[citing CGS]

by Sydney Perkowitz, *JStor Daily*

In a U.S. where medical care is not equally available to all, genetic enhancement will likely be too costly for all but the wealthy. As in *Gattaca*, buying enhancement will not be illegal, nor seen as unethical. But it would widen existing health and social inequalities, as expressed in the reactions to the "Human Genome Editing" report. Those who can afford it would choose mental and physical advantages for their offspring, perhaps including traits such as selfishness or "win at all costs" personalities that might benefit them but harm society. This would enhance a special group that would not need Francis Galton's selective breeding to make itself superior over time, leaving everyone else as the In-valids.



NEWS

Human Genetic Modification

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HUMAN GENETIC MODIFICATION

[CRISPR studies muddy results of older gene research](#)

by Heidi Ledford, *Nature*

Scientists face tough decisions when the latest gene-editing findings don't match up with the results of other techniques.

[Biotech firm pulls pioneering gene therapy due to no demand](#)

by Ben Hirschler, *Reuters*

The biotech company behind the Western world's first gene therapy and the most expensive prescription medicine in history is giving up on the product because of lack of demand. Only one patient has been treated commercially

since the drug was first approved in Europe nearly five years ago.

▶ [New policy to ban pregnancies with genetically modified embryos](#)

by The Yomiuri Shimbun, *The Japan News*

Aiming to meet the challenges posed by new technologies such as genome editing — a technology that efficiently alters genes — the government is considering limiting human embryo modification through genome editing to basic research, and prohibiting both the implantation of embryos with altered genes in a uterus and the live births of such embryos.

▶ [Mitochondrial replacement techniques, Mexico and the legal unknowns](#)

by César Palacios-González, *BioNews*

In addition to these two important points there is a third aspect that warrants attention, and that has been constantly under-reported: that of the legality of the procedure. This question is particularly vexatious given that part of the procedure happened in the US and another part in Mexico.

BIOETHICS

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▶ [Under Fire, National Academies Toughen Conflict-of-Interest Policies](#)

by Paul Basken, *Chronicle of Higher Education*

The 154-year-old scientific academy, chartered by Congress during the Lincoln administration, has long enjoyed a reputation as a top-quality producer of in-depth, impartial academic analyses on a range of national policy questions. But that reputation has been challenged by complaints about two reports — one on medical pain relief and another on genetically modified organisms — whose authors' ties to industry were not made clear.

▶ [Skepticism About Biotechnology Isn't Anti-Science](#)

by Tess Doezema, *Slate*

The way forward is not drawing battle lines between those who are “for” or “against” science and closing down regulatory processes to all but the narrowest risk-based considerations. Rather, we should be forming and expanding spaces for a wide range of participants in creatively considering how to solve society's biggest challenges. We need new ways of thinking and talking about technological promise and possibility in the world that we live in.

▶ [In Theory: Scientists may soon be able to engineer organs. What does religion have to say about that?](#)

by The Burbank Leader, *Los Angeles Times*

“Most people say that it is the intellect which makes a great scientist. They are wrong: it is character.” I think Albert Einstein's appraisal of what is required of those pursuing the outer limits of human knowledge holds true more than ever. As research takes us to intellectual heights that heretofore have been the realm of science fiction, our existing ethical, regulatory and legal systems are being outdistanced by new discoveries.

▶ [Should You Be Able to Patent an Organism?](#)

by Robert Hart, *Slate*

It is unclear which culture will come to rule synthetic biology. A more open-source approach, coupled with falling costs of DNA synthesis, will likely see the field opened up to more and more actors. An intellectual property-heavy approach will see synthetic biology follow a closed path like that of biotechnology.

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▶ [Gene Editing Might Change What Being Human Actually Means](#)

by Edd Gent, *Singularity Hub*

“The urgency to rebuild ourselves following disease and injury impels many patients to want therapies now, without a concern for how the technologies being used on our cells or bodies may affect human identity,” [four scientists] write [in *Science*].

ARTS & CULTURE

▶ [Who Owes the Henrietta Lacks Family](#)

by Hannah Giorgis, *The Ringer*

The Oprah-led HBO film is a moving portrayal of a black family's struggle for justice. But is being seen enough?

▶ [Oprah Winfrey on ‘The Immortal Life of Henrietta Lacks’](#)

by Salamishah Tillet, *New York Times*

I wanted to tell the story because I lived and worked in Baltimore as a young reporter for eight years, and I never in all those years of reporting, of being involved in the community, going to church every single Sunday at Bethel A.M.E., never once heard the name Henrietta Lacks. So I thought when I read the book, “Wow, if I don’t know this story, I’m sure that there are many many other people who also don’t know.”

▶ [Hey Instagram, Don’t Tell Me When to Freeze My Eggs](#)

by Liz Stinson, *Wired*

Instagram’s ads, uniformly square and often well designed, are better than most at capturing my attention. But this ad was different. Not for its appearance—it had the same millennial pink background and liberal use of emoji that many companies use to reach women of a certain age—but for what it was selling. The ad, for New York City fertility clinic Extend Fertility, featured a colorful illustration of a sperm wiggling its way into an ovum. Below it, the caption read: “When you freeze your eggs, you #freezetime. How often do you get to do that?”

GOVERNANCE

▶ [The U.S. Regulations for Biotechnology Are Woefully Out of Date](#)

by Brooke Borel, *Slate*

While the Penn State scientists used biotechnology to manipulate the mushroom’s genes, their work didn’t trigger government oversight, in part because current law doesn’t necessarily apply to food made with CRISPR. The case highlights a chronic challenge with biotechnology regulation: It can’t keep up with the fast pace of innovation. No surprise there: The relevant laws haven’t had a proper update in more than 30 years.

▶ [Can Parents Sue If Their Kid Is Born With The ‘Wrong’ DNA?](#)

by Kristen V. Brown, *Gizmodo*

In a fascinating legal case out of Singapore, the country’s Supreme Court ruled that this situation doesn’t just constitute medical malpractice. The fertility clinic, the court recently ruled, must pay the parents 30% of upkeep costs for the child for a loss of ‘genetic affinity.’ In other words, the clinic must pay the parents’ child support not only because they made a terrible medical mistake, but because the child didn’t wind up with the right genes.

▶ [Sessions orders Justice Dept. to end forensic science commission, suspend review policy](#)

by Spencer S. Hsu, *Washington Post*

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Attorney General Jeff Sessions will end a Justice Department partnership with independent scientists to raise forensic science standards and has suspended an expanded review of FBI testimony across several techniques that have come under question, saying a new strategy will be set by an in-house team of law enforcement advisers.

► [University of California appeals CRISPR patent setback](#)

by Sharon Begley, *STAT*

The University of California has filed an appeal to overturn a February decision by a US patent tribunal that dealt UC a setback in its efforts to win foundational patents on the genome-editing technology CRISPR-Cas9.

► [The March for Science...and Politics?](#)

by Anne Fausto-Sterling, *Gap Junction Science*

One side of an intra-science debate has charged the other with refusing to accept facts and data and thus with being anti-science and political. When launched at someone whose life's work has been dedicated to the advancement of scientific knowledge and love of rational thought, these are truly fighting words. But even while squabbling with each other, both sides are horrified at creationism, anti-vaxers, climate deniers, and tobacco, oil and gas companies which claim (using paid scientists!) that their products and activities are harmless. How do we identify and counter the real science deniers while at the same time accepting that political differences also and often legitimately shape the conclusions of scientists who are passionately committed to producing reliable results using the tools of objective investigation?

► [#MarginSci: The March for Science as a Microcosm of Liberal Racism](#)

by J. Ama Mantey, *The Root*

"The reason why this is important to talk about and deal with is because they want us—and by 'us' I mean folks from marginalized communities, scientists of color, queer scientists, and the rest of who've been relegated as not fully human or not existing," said Lee. "They're happy for us to physically be on the line. They're happy for us to literally show bodies to demonstrate this overwhelming support [for the M4S], but they will not defend our issues or us. So, it's like, 'No, no, you want us to show up, but you won't show up for me,' and that's a line in the sand [for me.]"

► [European Court Strikes Down Required Sterilization for Transgender People](#)

by Liam Stack, *New York Times*

Changing the name or gender on a government-issued document like a driver's license has long included a frightening step for transgender people in almost two dozen European countries: mandatory sterilization. But those days may be coming to an end. Gay and transgender activists in Europe have argued for years that the sterilization requirement was an institutionalized violation of human rights, and [in early April] the European Court of Human Rights agreed.

► [Lawsuit against stem cell clinic Stemgenex can move forward, judge rules](#)

by Michael Hiltzik, *Los Angeles Times*

Judge Antony J. Battaglia dismissed several claims brought by three former patients at the clinic, including an allegation that Stemgenex has misled patients because it has produced no evidence that its treatments have any scientific basis. He said it's unclear that the plaintiffs would be able to show that Stemgenex's representations about the effectiveness of its treatments are "actually false or misleading" because they haven't shown that the clinic's claims have "actually been disproved."

GENOMICS

▶ [The FDA's 23andMe decision will also change the rules for all at-home medical genetic testing](#)

by Dave Gershgorn, *Quartz*

Rather than having to prove the safety and validity of its entire testing process of analyzing a vial of spit every single time, companies only have to prove the method is accurate for each new disease.

▶ [ACMG Guidelines at Odds With FDA Green Light for 23andMe Health Risk Tests](#)

by Turna Ray, *GenomeWeb*

The top organization in the US responsible for developing genetic testing guidelines is not on board with the US Food and Drug Administration's decision last week to allow 23andMe to sell genetic health risk tests online directly to consumers.

▶ [Why Thousands of Women Might Be Getting Unnecessary Mastectomies](#)

by Tracy Middleton, *Women's Health Magazine*

Genetic testing, once the realm of science fiction, has come so far that millions of physicians, and their patients, use it to help inform complicated medical decisions. But a new study in the *Journal of Clinical Oncology* suggests that both patients and doctors need a better understanding of test results..

▶ [Genes for Racists?](#)

by Aaron Panofsky, *Cultural Anthropology*

White nationalist interpretations of [genetic ancestry testing] GAT are important because they reflect more than simple ignorance or misunderstanding of the science. Most population geneticists would be appalled at the use of their variation-based research to build typological theories of human classification. But these scientists have produced tools open to such interpretations.

▶ [Will Google's groundbreaking health study really do any good?](#)

by Jessica Hamzelou, *New Scientist*

People have been mapping human health by collecting data from volunteers for decades, but Google is billing its version as a step change. That's largely down to the addition of snazzy new technologies that Verily will use to track the study participants: with more frequent and reliable data, the company says it will be able to draw conclusions no one has. But is this simply a techno-fetishisation? And worse, could the vaunted technology even get in the way?

▶ [How safe is your DNA?](#)

by Anne Marie Green, *CBS News*

A new high-tech, controversial law enforcement procedure has some people worried it threatens the privacy of our DNA.

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ASSISTED REPRODUCTION

▶ [A Baby or Your Money Back: All About Fertility Clinic Package Deals](#)

by Ron Lieber, *New York Times*

Welcome to the fertility casino, which frequently presents the rarest of scenarios: A commercial entity offers a potentially money-losing proposition to customers in exchange for a generous supply of in vitro fertilization procedures. People pay tens of thousands of dollars for the privilege, and when they come out with a newborn in their arms they're often thrilled to be on the losing end financially.

▶ [Emergency Hysterectomy for Teenage Victim of Illegal Egg Harvest](#)

by Wang Lianzhang, *Sixth Tone*

A 17-year-old girl sold more than 20 of her eggs to black-market middlemen, and the illegal surgery nearly cost her her life. On [April 26], the two middlemen, surnamed Deng and Lai, were sentenced to 12 and 10 months in prison, respectively, and fined a total of 8,000 yuan (\$1,160).

VARIOUS

▶ [Why Silicon Valley Keeps Getting Biotechnology Wrong](#)

by Casey Johnston, *New York Magazine*

The “move fast and break things” mantra that has helped Silicon Valley disrupt countless industries over the last two decades is more dangerous when applied to medical science.

▶ [The next super weapon could be biological](#)

by Peter Apps, *Reuters*

With the threat of chemical weapons in Syria and nuclear arms in North Korea, the risk of biological weapons has largely dropped off the international agenda. But evolving technologies and genetic engineering may open the door to new dangers.

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