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CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

January 11, 2018

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Announcements

Commentary

CGS in the News

News

ANNOUNCEMENTS

[Thank you for your end-of-the-year support](#)

Your contributions make a genetically just future possible. Thank you for your help in reclaiming the biotech era for the common good—and in bringing that vision to the public, policy makers, and media.



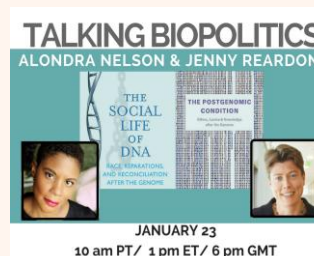
[Work with CGS: Summer 2018 internship applications open until January 16](#)

CGS is a host organization for the Reproductive Rights Activist Service Corps (RRASC), a program through which undergraduate students participate in 10-week paid internships. Learn more and apply [here](#).



[Join us January 23: Talking Biopolitics with Alondra Nelson and Jenny Reardon](#)

Don't miss out on our next [Talking Biopolitics webinar series](#) event! We're bringing together two leading scholars, Alondra Nelson and Jenny Reardon, to discuss their work on genomics and social justice. They will also answer your questions. Reserve your spot now, by [registering!](#)



[Save the dates: Two Bay Area GATTACA Screenings and Discussions](#)

We're taking a look back at *GATTACA*, a film that has shaped an entire generation's imagination of how to think about a future where fertility clinics market "genetic upgrades" so that affluent parents can pre-determine their children's traits. Mark your calendars for: March 6 at the David Brower Center in

Berkeley; and March 8 at the San Francisco Main Public Library. Stay tuned for more details!



[CGS Presents at the Association of American Law Schools' Annual Meeting](#)

On January 6, 2018, CGS Executive Director Marcy Darnovsky spoke on a panel titled "Legal Challenges of Editing the Genome: Coming to Terms with CRISPR Technology." To view the conference's full program, click [here](#).



CGS COMMENTARY

[What Just Happened? Looking Back at 2017's Human Germline Editing Developments](#)

By Katie Hasson and Leah Lowthorp, *Biopolitical Times*

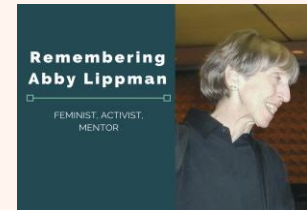
Last year, there were a number of important technical and political news stories on gene editing. Here are some of the most important, along with a brief glance into what to expect in 2018.



[Remembering Abby Lippman](#)

By Diane Beeson, Marcy Darnovsky, Stuart A. Newman, Marsha Saxton, Tina Stevens, Kayla Tolentino, *Biopolitical Times* Guest Contributors and CGS staff

Several long-time friends and colleagues share thoughts and memories of Abby's legacy after her death in December.



[A Dozen Excellent 2017 Blog Posts](#)

By Pete Shanks, *Biopolitical Times*

From critiquing media claims on the latest gene editing "breakthrough" to analyzing how TV shapes DNA forensics in the courtroom, here are some of our favorite *Biopolitical Times* blog posts.



[So You Got a DNA Test for Christmas. What Now?](#)

By Pete Shanks, *Biopolitical Times*

Personal DNA tests were a much-recommended gift this Christmas, in a triumph of marketing over explanation.



[New assisted reproduction regulations require feminist voices](#)

By Francine Coeytaux, Marcy Darnovsky, Susan Berke Fogel, and Emily Galpern,

International Journal of Feminist Approaches to Bioethics Blog

An urgent call for the development of policy in this field to include the viewpoints of feminist scholars and advocates who have worked to safeguard women's health and rights.



[- TOP -](#)

CGS in the NEWS

[Fertility Testing Is Big Business—But Is It Really Helping You Get Pregnant?](#)

► [cites CGS Fellow Gina Maranto]
by Elissa Strauss, *Glamour Magazine*

New evidence shows that the tests many companies use to determine a woman's chances of having a baby are based on bogus science.



[Fertility Testing Is Big Business—But Is It Really Helping You Get Pregnant?](#)

► [features CGS' Marcy Darnovsky]
by Elizabeth Cook, *KPIX 5*

"I think that's a world we don't want to live in," said Marcy Darnovsky, voicing concerns that gene editing technologies have the power to exacerbate already existing inequalities.



NEWS

[Assisted Reproduction](#)

[Biohacking and Gene Therapy](#)

[Gene Editing](#)

[Genetics Sequencing](#)

[Stem Cells](#)

[Various](#)

GENE EDITING

► [Genetic sequencing is the future of medicine](#)

by Craig Venter, *Washington Post*

The world agreed at the end of World War II to stop all direct human experimentation. Human germline editing would cross that boundary and take us back into random human genome editing, just to see what happens.

▶ [CRISPR gene editing moved into new territory in 2017](#)

by Tina Hesman Saey, *ScienceNews*

Researchers have been wielding CRISPR/Cas9 to make changes in animals' DNA. But its use in human embryos has more profound implications, researchers and ethicists say.

▶ [The Gene-Editing Conversation](#)

by Matthew C. Nisbet, *American Scientist*

Public dialogue about the new technology will require major investments from scientists, journalists, and philanthropists.

▶ [Designer Babies and Genetic Modification: Inequality on a Biological Scale](#)

by Nikhil Reddy, *Huffington Post*

Is there an ethical duty behind using genetic modification to ensure a child's success, or does such behavior engender a world in which imperfections are substandard, and inequality among humans becomes almost inherent and biological?

▶ [Meet the Woman Using CRISPR to Breed All-Male "Terminator Cattle"](#)

by Andrew Rosenblum, *MIT Technology Review*

Alison Van Eenennaam aims to create a bull that will father only male offspring: either normal bull calves or ones with two X chromosomes but also the male-making SRY. No females at all.

BIOHACKING AND GENE THERAPY

- News TOP -

▶ [Biohacker CRISPRs himself in attempt to get bigger muscles](#)

by *GMWatch*

The problem is that he is also putting at risk the wider society.

▶ [Is a 'Cure' for Blindness Worth \\$1 Million?](#)

by Sarah Zhang, *The Atlantic*

Some blind people are questioning how the first gene therapy to treat inherited blindness has been valued.

▶ [FDA approves first gene therapy for an inherited disease](#)

by Laurie McGinley, *Washington Post*

Spark Therapeutics' treatment for childhood-blindness, called Luxturna, is expected to be available in select centers this spring. Yet the products, should they reach patients, are likely to carry stratospheric prices.

▶ [Gene therapy for inherited blindness sets precedent: \\$850,000 price tag](#)

by Carolyn Y. Johnson, *Washington Post*

Both the Luxturna treatment and its price tag challenge almost all the norms in the current drug distribution and payment system.

▶ [With No Cure in Sight, CRISPR Could Offer Hope for Lou Gehrig's Disease](#)

by Kristen V. Brown, *Gizmodo*

A new study in mice offers a glimpse at how researchers might use gene therapy on motor neurons in the spinal cord responsible for ALS. Most cases are not inherited, but we know the exact gene responsible for causing its effects in a small percentage of them.

► [How the immune system could stymie some CRISPR gene therapies](#)

by Heidi Ledford, *Nature*

Researchers hoping to use a gene-editing technique to treat diseases may have to seek alternative enzymes.

► [Scientists Use Gene Editing To Prevent A Form Of Deafness In Mice](#)

by Rob Stein, *NPR*

While cautioning that much more research is needed, the scientists said they hope the technique might someday be used to prevent deafness in children born in families with a history of genetic hearing loss.

GENETIC SEQUENCING

- News TOP -

► [The Present and Future Asymmetry of Consumer Genetic Testing](#)

by Michael Schulson, *Undark*

The question looming over the genetic testing marketplace is whether consumer protections can keep up — and more pointedly, what fair, effective protections would even look like.

► [DNA Discrimination: Fixing the Fears of Genetic Testing](#)

by Olivia Nash, *Brown Political Review Magazine*

At a time when more protections against discrimination are needed, a bill like H.R. 1313 erodes the existing protections and obstructs the advancement of modern medicine; the focus of genetic policy reform should rest on increasing protection rights instead of eliminating what little privacy and safeguards are left under GINA.

► [Researchers Gather Health Data For 'All Of Us'](#)

by Richard Harris, *NPR*

The All of Us precision medicine initiative is the biggest push ever mounted to create a huge public pool of data that scientists—and anybody else who is interested—can mine for clues about health and disease.

► [Regeneron forms consortium to accelerate gene sequencing project](#)

by Bill Berkrot, *Reuters*

Six drug companies agreed to each invest \$10 million in the UK Biobank database, which will speed up the effort to complete exome sequencing of 500,000 participants by the end of 2019.

► [China launches world's largest human genome research project](#)

by Deng Xiaoci, *Global Times*

China has listed genomics as a key strategic field in its 13th Five-Year Plan (2016-20) for the country's economic and social development.

ASSISTED REPRODUCTION

- News TOP -

► [A Woman Gave Birth From an Embryo Frozen for 24 Years](#)

by Sarah Zhang, *The Atlantic*

Today, IVF and the cryopreservation of resulting embryos are so commonplace that it's easy to overlook how disruptive the process once seemed.

► [The cruel irony of IVF](#)

by Clare Goldwin, *Daily Mail*

Infertility is treated as a clinical problem. But what's not considered is the psychological trauma which starts the moment you discover you have a problem.

▶ [Tasmanian sperm and egg register recommended to secure children's rights](#)

by Henry Zwartz, *ABC News*

A central donor register is being recommended after a parliamentary committee heard of the "distress and anguish" that arises when children are unable to identify their biological parents.

▶ [Wombs-for-rent: China's underground surrogacy market is booming](#)

by Ruchira Sharma, *International Business Times*

According to a two-month investigation, women in rural villages are being lured away from their factory jobs to carry others' fertilised eggs to birth.

▶ [Majority of French now favor allowing surrogate motherhood: poll](#)

by Sarah White, *Reuters*

Until recently public opinion was against surrogacy, but the poll by Ifop found that 62 percent of French people support surrogacy.

▶ [When ignorance leaves pregnant surrogates on the wrong side of Cambodian law](#)

by Yon Sineat, Kong Meta and Erin Handley, *Phnom Penh Post*

The Ministry's "surrogacy amnesty" ended January 8, leaving intended parents, brokers and surrogates of babies born after that date to confront legal repercussions.

▶ [NHS must offer transgender men egg storage so they can be parents, says British Fertility Society guidance](#)

by Sarah Knapton, *The Telegraph*

The new guidance was drawn up by fertility experts who argue for 'equity' across the NHS, to allow transpeople to freeze eggs, embryos or ovarian tissue.

STEM CELLS

- News TOP -

▶ [New lawsuit against U.S. Stem Cell also alleges blindness](#)

by Paul Knoepfler, *The Niche*

As a stem cell researcher and someone who has followed the arena for a long time, it feels like substantial additional FDA action and clarity regarding for-profit stem cell clinics in America is urgently needed.

▶ [\\$5 Billion Bond Measure: California Stem Cell Agency Sets a Course to Secure Its Financial Future](#)

by David Jensen, *California Stem Cell Report*

The agency is funded by money that the state borrows -- bonds. The authority to issue those bonds is expiring, and the agency is down to its last \$269 million.

▶ [FDA Warns Stem Cell Supplier Over Unapproved Treatment](#)

by Michael Mezher, *Regulatory Affairs Professionals Society*

The FDA raised safety concerns over an unapproved product that goes beyond "minimal manipulation" and does not meet the regulation standards.

▶ [Stem cell clinics for heart failure: buyer be wary](#)

by Paul J. Hauptman, *STAT News*

You can walk into a stem cell business on Main Street and buy yourself an infusion with virtually no oversight from the medical community or state or

federal governments.

VARIOUS

[- News TOP -](#)

▶ [The invisible infertile: how cultural beliefs can shape statistics](#)

by Liberty Barnes and Jasmine Fledderjohann, *The Conversation*

Survey tools are not objective measures. The invisibility of marginalised groups in infertility tracking reflects broader social beliefs about who can and should reproduce.

▶ [The "Down Syndrome Abortion Ban" Uncovers A Difficult Truth About Pro-Choice Politics & Disability](#)

by Hillary Savoie, *Romper*

Genetic science is moving faster than our ability to fully comprehend the ethical, cultural, and social implications of said science.

▶ [Ancient Fables for the Neobiological Age](#)

by Brian Bergstein, *Neo.Life*

What *Frankenstein* and the golem tell us about the power and responsibility of science.

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