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CENTER FOR GENETICS AND SOCIETY

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VIEWS & NEWS

March 9, 2019

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ANNOUNCEMENTS

[Dr. Katie Hasson Presents on the Dangers of "Bracketing the Social"](#)

On Tuesday, February 18, CGS' Katie Hasson addressed the Bioethics Group at UC San Francisco by invitation on the topic of why social scientists and members of the public must be involved in discussions and decisions related to the future of heritable genetic editing.



[CGS Welcomes New Communications Director](#)

CGS is pleased to welcome Adrienne van der Valk to our staff. Adrienne brings a background in journalism and political science to her role as communications director. Most recently she served as the deputy director for Teaching Tolerance, a project of the Southern Poverty Law Center, where she ran the editorial and marketing departments. Adrienne is passionate about social justice and excited to help CGS shape the national conversation about genetic and reproductive technologies. Welcome, Adrienne!



[Save the Date for "Fables and Futures"](#)

Mark your calendar for May 1, 2019. In partnership with the Paul K. Longmore Institute on Disability, the Health Equity Institute, and the San Francisco Public Library, CGS is co-hosting a reading and discussion with writer and disability rights activist George Estreich, author of the new book [Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves](#). The event will be held at the San Francisco Public Library and will also stream live. Be sure to open the April newsletter for more details!



CGS COMMENTARY

[Cash Problems at California's Stem Cell Program](#)

By Pete Shanks, *Biopolitical Times* | 03.05.2019

The California Institute for Regenerative Medicine is virtually out of money and hoping the state's voters will pass a \$10 billion ballot initiative, planned for the November 2020 election.



[DNA Testing of Present and Future Children](#)

By Pete Shanks, *Biopolitical Times* | 03.06.2019

Direct-to-consumer genetic testing companies are now marketing to parents—and to future parents who might want to select their children's traits.



[Are CRISPR Babies Healthy? Enhanced? Speculation Takes a Disturbing Turn](#)

By Katie Hasson, *Biopolitical Times* | 03.08.2019

We haven't learned anything new about the health of the gene-edited twins born last year, yet some scientists are nonetheless speculating that they'll be fine—or maybe even better than fine.



- TOP -

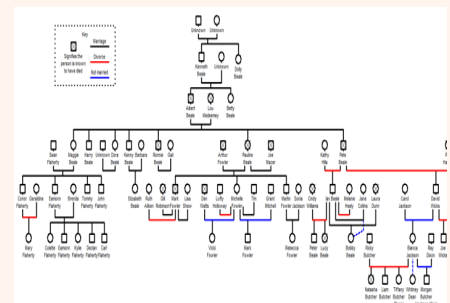
CGS in the NEWS

[Our Twisted DNA](#)

► [cites CGS' Marcy Darnovsky]

by Tim Flannery, *The New York Review of Books* | 03.07.2019

This review of Carl Zimmer's new book *She Has Her Mother's Laugh: The Powers, Perversions, and Potential of Heredity* ends with a cautionary note by CGS Executive Director Marcy Darnovsky about the prospect of an unregulated marketplace in reproductive gene editing. According to the reviewer, "Given the history of earlier misunderstandings of inheritance that Zimmer relates, it's a warning we better take seriously."



▶ [DNA Collection: The Next Big Thing in Privacy Litigation?](#)



Center for Genetics and Society v. Becerra, the lawsuit against the state of California, may be the tip of the iceberg when it comes to civil rights challenges to biometric data collection and retention practices by state and local governments.

NEWS

- Assisted Reproduction
- DNA Forensics
- Genetic Testing
- Human Gene Editing
- Precision Medicine
- Various

HUMAN GENE EDITING

▶ [We can edit the human genome, but should we?](#)

by Marc Montgomery, *Radio Canada International* | 02.13.2019
When it comes to deciding whether or how to proceed with editing the germlines of human embryos, Professor Françoise Baylis argues for a measured conversation with a diverse set of voices at the table.

▶ [China’s CRISPR twins might have had their brains inadvertently enhanced](#)

by Antonio Regalado, *MIT Technology Review* | 02.07.2019
When He Jiankui altered the germline of twin girls last November, he reportedly deleted a gene called CCR5. Now, scientists are saying this alteration not only affects HIV resistance but may also improve memory and the brain’s ability to make connections.

▶ [Why were scientists silent over gene-edited babies?](#)

by Natalie Kofler, *Nature* | 02.26.2019
Several high-profile U.S. scientists knew of He Jiankui’s plans to use CRISPR technology on embryos and bring them to term. Why didn’t these researchers recognize their obligation to speak up?

▶ [Chinese government funding may have been used for ‘CRISPR babies’ project, documents suggest](#)

by Jane Qiu, *STAT* | 02.25.2019
Three government institutions in China were listed as funders for He Jiankui’s reproductive gene editing experiments.

▶ [China tightens its regulation of some human gene editing, labeling it ‘high-risk’](#)

by Dennis Normile, *Science* | 01.28.2019
The Chinese government released draft regulations that would require national approval for clinical research involving human gene editing and other “high-risk biomedical technologies.” These regulations outline a range of legal penalties, including warnings, fines, a lifetime ban on participating in clinical research, and criminal charges.

▶ [Spain to reject registration of babies born to surrogate mothers in Ukraine](#)

by Marta Rodriguez Martinez and Rachael Kennedy, *Euro News* | 02.20.2019
In an attempt to crack down on international surrogacy, which is prohibited in Spain, the Spanish embassy in Ukraine announced that "no new registration records of children born through the surrogate pregnancy technique can be authorised."

▶ [The New, Invasive Ways Women Are Encouraged to Freeze Their Eggs](#)

by Amanda Mull, *The Atlantic* | 03.04.2019
Fertility-clinic start-ups are trying out cute Instagram ads and other social-media-friendly tactics to reach young anxious women.

▶ [Heartbreak, anxiety, lawsuits: The egg-freezing disaster a year later](#)

by Rich Gardella and Erika Edwards, *NBC News* | 03.04.2019
Thousands of frozen eggs and embryos have been lost after freezer tank failures in fertility centers across the country, bringing to light the under-regulation of the fertility industry in the U.S.

▶ [A Mother Learns the Identity of Her Child's Grandmother. A Sperm Bank Threatens to Sue.](#)

by Jacqueline Mroz, *The New York Times* | 02.16.2018
The fertility industry has long offered donors the option of anonymity. In the era of DNA ancestry testing, it's impossible to guarantee that a donor won't one day be contacted.

DNA FORENSICS

- News TOP -

▶ [China Uses DNA to Track Its People, With the Help of American Expertise](#)

by Sui-Lee Wee, *The New York Times* | 02.21.2019
American scientists and companies contributed genomic data, expertise, and laboratory equipment to a Chinese effort to track Uighurs, a predominantly Muslim ethnic group, using coerced DNA samples.

▶ [The NYPD's new DNA dragnet: The department is collecting and storing genetic information, with virtually no rules to curb their use](#)

by Allison Lewis, *Daily News* | 02.08.2019
DNA has unparalleled power to wrongly accuse. Genetic testing can now reveal a profile based on a few cells, and we shed hundreds of thousands of cells a day. Your DNA can show up in places you've never been.

▶ [Jerry Westrom Threw Away a Napkin Last Month. It Was Used to Charge Him in a 1993 Murder.](#)

by Sarah Mervosh, *The New York Times* | 02.17.2019
DNA ancestry databases have provided the keys to solving high-profile cold cases. They've also unlocked ethical concerns for individuals who intended to fill in their family trees, not implicate their relatives.

▶ [One Twin Committed the Crime — but Which One? A New DNA Test Can Finger the Culprit](#)

by Carl Zimmer, *The New York Times* | 03.01.2019
Advanced DNA sequencing can pinpoint genetic mutations that distinguish between identical twins, raising interest in law enforcement applications.

► [The NHS should run a mile from the genome sequencing goldrush](#)

by David King, *The Guardian* | 02.07.2019

A problematic proposal in the UK would allow individuals to pay the NHS for genomic sequencing. But as David King points out, “the predictive value of genomic sequence results for healthy people is extremely dubious.”

► [Precision medicine’s rosy predictions haven’t come true. We need fewer promises and more debate](#)

by Michael J. Joyner and Nigel Paneth, *Stat* | 02.07.2019

Scientists incorrectly predicted that mapping the human genome would result in revolutionary public health benefits. In light of precision medicine’s high costs and low returns, it’s time to reconsider the gene-centered paradigm.

GENETIC TESTING

► [In China, some parents seek an edge with genetic testing for tots](#)

by Michael Standaert, *MIT Technology Review* | 02.19.2019

Genetic talent tests claim to help parents determine where their child’s natural aptitudes lie. But the marketing of these test has swiftly outgrown scientific certainty of the results.

► [More than 26 million people have taken an at-home ancestry test](#)

by Antonio Regalado, *MIT Technology Review* | 02.11.2019

2018 was a record year for ancestry DNA test sales—and for the resulting privacy questions, legal challenges, and discovery of family secrets.

► [After you spit into a tube for a DNA test like 23andMe, experts say you shouldn’t assume your data will stay private forever](#)

by Erin Brodwin, *Business Insider* | 02.16.2019

Genetic data collected by DNA ancestry companies are only as safe as the most vulnerable points in their security protocols. This is bad news for consumers.

VARIOUS

► [Ten years after the ‘Berlin patient,’ doctors announce a second person has been effectively ‘cured’ of HIV](#)

by Kate Sheridan, *STAT* | 03.04.2019

For the second time, doctors appear to have put HIV into “sustained remission” with a bone marrow transplant from a donor with a naturally occurring variant of the CCR5 gene.

► [‘Miraculous’ stem cell therapy has sickened people in five states](#)

by William Wan and Laurie McGinley, *The Washington Post* | 02.27.2019

Over the past year, several patients have been hospitalized after being injected with cord blood stem cell products, but the for-profit stem cell market continues to grow.

► [DNA Gets a New — and Bigger — Genetic Alphabet](#)

by Carl Zimmer, *The New York Times* | 02.21.2019

Researchers have built a functioning DNA system with eight bases, rather than

the natural four, which raises questions about its potential applications, as well as about the nature of life elsewhere.

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