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APRIL 2019

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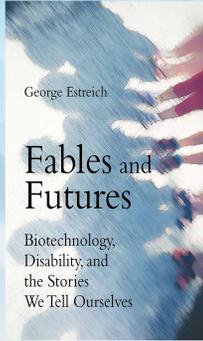
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SPOTLIGHT



George Estreich

Fables and Futures

Biotechnology, Disability, and the Stories We Tell Ourselves

A Reading and Discussion with George Estreich

author of *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*

MAY 1, 2019
6:00-7:30 P.M.
SAN FRANCISCO PUBLIC LIBRARY
Latino Hispanic Community Room
100 Larkin Street
San Francisco, CA

Reading and Discussion with George Estreich

Join us on May 1 for a reading and discussion with George Estreich, author of the new book *Fables and Futures*. Register today to attend this free event at the San Francisco Public Library or join us via live stream. Co-sponsored by the Paul K. Longmore Institute on Disability, the Health Equity Institute, and the San Francisco Public Library.

ANNOUNCEMENTS



A Dangerous Idea Film Screening and Discussion

Bay Area residents will have three opportunities in April to see the documentary *A Dangerous Idea: Eugenics, Genetics and the American Dream*, which explores the history of eugenic ideas in the United States and how they persist today. On [April 25](#), CGS Executive Director Marcy Darnovsky will join a panel discussion following a screening at the Delancey Street Theater in San Francisco. Additional screenings will be held [April 23](#) in Oakland and [April 24](#) in San Rafael. [Buy your tickets today!](#)



Teaching Technology in the Social Studies Classroom

CGS Executive Director Marcy Darnovsky, filmmaker Stephanie Welch (A Dangerous Idea), and author and educational consultant Milton Reynolds presented to high school and higher ed instructors at the California Council for the Social Studies on March 15. The session, titled “[Reckoning with Race as a Technology](#),” explored the question: What does the history of using “race” to normalize social hierarchies suggest about the challenges of emerging genetic technologies?



CGS Welcomes New Intern

CGS is pleased to welcome Kathrin Martin to our staff. Kathrin joins us from Geneva, Switzerland, where she recently graduated from the University of Geneva with a master’s degree in political science. She specializes in peace and conflict studies and is particularly interested in public policy, economic governance, and interest representation. Kathrin brings a keen interest in big data analysis to her work with CGS and, among other projects, will help CGS track how our issues are being discussed in international media. Welcome, Kathrin!

COMMENTARY



Pop ART: Would-be Parents as Prey

Kimberly Mutcherson, Guest Contributor, *Biopolitical Times* | 3.11.2019
Rampage, a movie about genetically modified animals gone berserk, provides a glimpse into why it’s dangerous to assume that technology developed with the best of intentions won’t someday become the stuff of nightmares.

nature

Proposed Moratorium on Heritable Genome Editing is a Welcome First Step

CGS Press Statement | 3.13.2019

What we hope this call will achieve, in line with the authors’ stated intent, is to ensure the conditions for fair, meaningful, broadly inclusive, and unrushed discussions of whether heritable genome editing should be permitted to proceed in countries where it is not already prohibited.



A Step in the Right Direction—But We Can’t Stop Here

CGS Editorial | 3.13.2019

The *Nature* commentary took an important first step, but it left out some critical perspectives. Given the stakes, these omissions matter when charting a path forward that must include diverse and underrepresented voices.

Did a Permissive Scientific Culture Encourage the ‘CRISPR babies’ experiment?

Donna Dickenson & Marcy Darnovsky, *Nature Biotechnology* | 3.15.2019
Shortcomings in the Nuffield Council report are examples of an



increasingly permissive climate among elite scientists that may well have emboldened He Jiankui.



One Week Later: Reactions to the Proposed Moratorium on Human Germline Editing

Katie Hasson, *Biopolitical Times* | 3.20.2019

Not long after the *Nature* commentary dropped, the World Health Organization panel appointed to establish standards for oversight of germline editing released their initial recommendations. This post summarizes those suggestions as well as reactions from several of CGS' associates and colleagues to the call for a moratorium.



Moratorium News Roundup: What Got Reported? What Didn't?

Pete Shanks, *Biopolitical Times* | 3.20.2019

What did journalists have to say about the *Nature* commentary? This roundup offers the highlights and some analysis of how the press reported on the conspicuous absence of some notable scientists from the list of signatories.



Three-person IVF: From Genetic Disease to Genetic Design

Ayesha Chatterjee, Guest Contributor, *Biopolitical Times* | 3.13.2019

It will not be surprising if we soon see the full weight of the fertility industry behind three-person IVF as standard care. For those of us trying to ensure human biotechnologies are used ethically, such a prospect is alarming.



Genetics and Privacy: Part 1

Pete Shanks, *Biopolitical Times* | 4.4.2019

The cumulative effect of blending DNA ancestry testing with criminal justice is that genetic privacy is under siege.

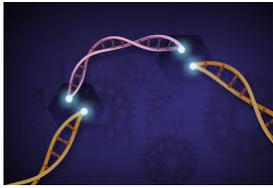


Genetics and Privacy: Part 2

Pete Shanks, *Biopolitical Times* | 4.4.2019

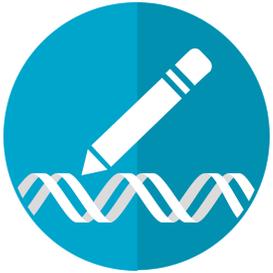
The DNA testing industry is attracting significant investment and contributing to the growth of genetic databases, which raise important privacy concerns.

CGS IN THE NEWS



Call For Global Moratorium On Creating Gene-Edited Babies **Rob Stein, *National Public Radio* | 03.13.2019**

“Allowing reproductive gene-editing would open the door to certain people whose parents were able to afford genetic upgrades being considered superior to everyone else. The last thing we want to do is build a future in which we’re creating classes of people who are considered genetic-haves and others who are have-nots,” said CGS Executive Director Marcy Darnovsky.



Scientists Call for a Moratorium on Editing Inherited Genes **Karen Weintraub, *Scientific American* | 03.13.2019**

CGS Executive Director Marcy Darnovsky says germ-line editing is “not safe, it’s not needed and it’s way too dangerous from a social point of view,” and that she “supports the goals of the coalition’s commentary, and hopes an open and fair global discussion will bring more people around to her point of view.”



Don’t Buy California’s Callous Attempt to Ignore People’s DNA Privacy Rights, EFF Tells Court **Karen Gullo, *Electronic Frontier Foundation* | 03.29.2019**

The State of California currently keeps on file the DNA profiles of thousands of individuals arrested for felonies — even if those individuals are never convicted of a crime. This practice violates the state constitution and is the basis of a lawsuit currently being brought by the Electronic Frontier Foundation, the Center for Genetics and Society, the Equal Justice Society, and an individual plaintiff, writer and editor Pete Shanks.

WHAT WE’RE READING

[Human Gene Editing](#) | [Assisted Reproduction](#) | [Various](#)

HUMAN GENE EDITING

What Is the World to Do About Gene Editing?

Stephen Buranyi, *New York Review of Books* | 03.21.2019

There has been a failure over the last decade of any center of power within the scientific community to develop a coherent moral and logistical framework for the future regulation of the technology. The situation practically guarantees that research will creep ever closer to the red line of human genome editing until inertia finally carries it over.

Adopt a Moratorium on Heritable Genome Editing

Eric Lander, Françoise Baylis, Feng Zhang, Emmanuelle Charpentier, Paul Berg et al., *Nature* | 03.13.2019

A group of eighteen scientists and bioethicists from seven countries call for a global moratorium on human germline editing and the establishment of an international governance framework.

Editing Genes Shouldn't Be Scary — Unless they Are the Ones that Get Passed Down to Future Generations

Eleanor Feingold, *The Conversation* | 03.15.2019

In gene editing, it matters enormously whether you are messing with a germline cell, and thus an entire future human being and all its future descendants, or just one particular organ.

CRISPR Gene Editing: Why We Need Slow Science

Landon J. Getz & Graham Dellaire, *The Conversation* | 03.15.2019

Slow CRISPR science would allow for proper consultation with appropriate stakeholders and the public before making the decision about whether to move forward.

WHO panel proposes new global registry for all CRISPR human experiments

Jon Cohen, *Science* | 03.19.2019

Falling short of calling for a moratorium, the panel of experts says any use of CRISPR technology in humans at this time would be “irresponsible,” and proposes a registry for gene editing experiments to be organized and enforced by funding agencies and journal editors.

Genome Engineers Made More Than 13,000 CRISPR Edits in a Single Cell

Antonio Regalado, *MIT Technology Review* | 03.26.2019

A team at Harvard claims they now have the ability to make thousands of genetic alterations to a single cell. This has huge implications and could lead to the “radical redesign” of entire species.

ASSISTED REPRODUCTION

The Fertility Doctor's Secret

Sarah Zhang, *The Atlantic* | 03.18.2019

Donald Cline opened his clinic when fertility treatments were still relatively new technology. Forty years later, some of his patients and their children have discovered that Cline cast himself not only in the role of doctor but of sperm donor —without consent or any sense of wrongdoing.

Malaysian Man Carrying Live Human Embryos Detained at Indian Airport

Anna Maria Romero, *The Independent* | 03.21.2019

Although surrogacy is illegal in both countries, it is believed couples in Malaysia may be sending their embryos to India to be implanted in gestational mothers with the help of fertility doctors working illegally.

VARIOUS

A Consumer DNA Testing Company's Alarming New Marketing Pivot

Elizabeth Joh, *Slate* | 03.29.2019

A new television ad for the consumer DNA database FamilyTreeDNA asks the public to share their DNA for the express purpose of helping to solve crimes.

Does the Rhetoric of Consumer Genetics Aim to Eliminate Disability Without Mentioning It?

George J. Annas, *Science* | 03.10.2019

In *Fables and Futures*, Estreich goes beyond the personal to describe the ways that genetic technologies and the stories told about them affect society and the ways we view disability.

Japan to Pay Compensation to People Sterilised Under Eugenics Law Modelled on

Nazi Programmes

Tom Barnes, *The Independent* | 03.16.2019

Payments will be given to survivors regardless of whether they gave consent. But critics note that the bill does not offer a formal apology from the Japanese state.

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