

Dear *Biopolitical Times* readers,

This month's newsletter is coming to you at a time of great uncertainty and challenge due to the COVID-19 outbreak. We send it along with our support for all of you, and our particular thoughts for those immediately affected and most vulnerable.

The Center for Genetics and Society team

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March 2020



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SPOTLIGHT



Katie Hasson Debates in Doha

On March 11, CGS' Program Director for Genetic Justice Katie Hasson participated in a 2020 Doha Debate titled "Future of Genetics—Should We Create Superhumans?" that drew 4.9 million Twitter viewers. Appearing onstage with Ghida Fakhry, Julian Savulescu, and Jamie Metzl, Katie addressed questions about "the long-term challenges and opportunities CRISPR presents," and highlighted the social justice and human rights implications of heritable genome editing. Watch the debate [here!](#)

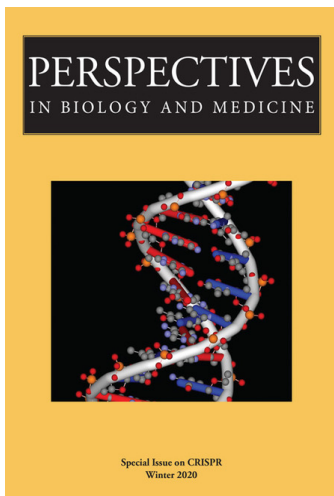
ANNOUNCEMENTS



Marcy Darnovsky Gives TEDx Talk

CGS Executive Director Marcy Darnovsky delivered a TEDx Talk at Laguna Blanca School in Santa Barbara titled “Use Gene Editing to Treat Patients, Not Design Babies.” Beginning with an explanation of where the debate stands now, she laid out the case against heritable genome editing, citing social justice and equity concerns that are often obscured in scientific discussions about the technology. You can watch Marcy’s talk [here](#).

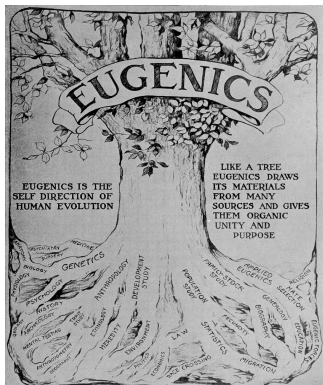
COMMENTARY



'Perspectives' on Heritable Human Genome Editing

Pete Shanks, *Biopolitical Times* | 03.06.2020

Perspectives in Biology and Medicine recently published a special issue on CRISPR. The contributors represent an unusually wide variety of backgrounds and perspectives, and include CGS’ Marcy Darnovsky and Katie Hasson. The journal’s goal is to publish “essays that place important biological or medical subjects in broader scientific, social, or humanistic contexts,” which is exactly what this issue offers for the gene-editing debate.



The Anglo-American Threat of a Eugenics Revival

Pete Shanks, *Biopolitical Times* | 02.21.2020

The resignation of a junior advisor to British Prime Minister Boris Johnson for advocating eugenics sparked discussion on both sides of the Atlantic and highlighted the worrying trend that eugenics may be becoming normalized again. Given this trend, it is vitally important to denounce and oppose both the revival of old-school eugenic attitudes and the introduction of new high-tech and consumer-driven varieties of eugenics.



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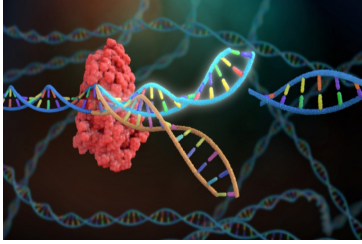
Society for International Development

Genetic Justice: Identity and Equality in the Biotech Age (full access)

Katie Hasson and Marcy Darnovsky, *Development* | 01.14.2020

In the context of growing nationalism, popularizing the idea that “nationality” and “roots” are determined by genetics is a dangerous practice. As CGS’ Katie Hasson and Marcy Darnovsky argue, genetic ancestry testing not only reinforces the belief that race is a biological category, it opens the door for misuse of genetic data, and may even help pave the way for higher social tolerance for human germline modification.

CGS IN THE NEWS



Professor Calls for Caution Around Gene Editing in Human Embryos

Jim Barlow, *Around the O* | 03.03.2020

University of Oregon professor Leah Lowthorp is one of the authors of “The Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction.” A cultural anthropologist and former CGS staff member, Lowthorp explores the online folklore of human genetic and assisted reproductive technologies, including the relationship between the hyperbole and public skepticism of scientific claims related to CRISPR technology.



Designer Babies: Rogue Science or Future Option?

Dolli Player and Alicia Matsuura, *The Daily Universe* | 02.18.2020

The ability to modify the human germline was once a distant prospect but, with the discovery of CRISPR - CAS9, scientists no longer question whether they can but whether they should. CGS Executive Director Marcy Darnovsky points out that, were this technology made available, wealthy parents would use germline editing to “get a leg up for their kid by dropping an extra \$100,000 at a fertility clinic,” thereby exacerbating social inequalities.

WHAT WE'RE READING

[Assisted Reproduction](#) | [Gene Therapy](#) | [Genomics](#) | [Society](#) | [Synthetic Biology](#)

ASSISTED REPRODUCTION

For a Change of Heart, Would-Be Egg Donors Face Threats and Bills

Alison Motluk, *UNDARK* | 02.24.2020

From charging “recovery fees” to forging egg donors’ signatures on legal documents to harassment, some fertility clinics have gone to extreme measures to coerce women into egg provision even after they decide against it.

Egg-Freezing: What's the Success Rate?

BBC News | 02.17.2020

Egg-freezing is marketed more widely than ever, but reported rates of pregnancy and birth from frozen-eggs vary significantly depending on the source, with some estimates as low as 1 percent. Why?

OHSS, the IVF Side-Effect Making Women's Fertility Journeys 'Agony'

Sophie Wilkinson, *The Huffington Post UK* | 02.08.2020

The in-vitro fertilization industry is booming, but few patients are aware that the hormone treatments they must undergo can cause life-threatening health problems like Ovarian Hyper-Stimulation Syndrome and even compromise the integrity of harvested eggs.

Eugenic Sperm

Karen Weingarten, *Nursing Clio* | 02.24.2020

The history of reproductive technologies is rooted in eugenic practices in ways that have become invisible today.

GENE THERAPY

Doctors Try 1st CRISPR Editing in the Body for Blindness

[The Associated Press](#), *The New York Times* | 03.04.2020

Doctors at the Casey Eye Institute at Oregon Health & Science University in Portland say they have used CRISPR for the first time to “operate” on the genes of a patient with an inherited form of blindness.

GENOMICS

You Can Learn a Lot About Yourself From a DNA Test. Here's What Your Genes Cannot Tell You

[Libby Copeland](#), *TIME* | 03.02.2020

Most direct-to-consumer DNA-testing companies focus on answering questions about ancestry and health. However, an emerging consumer genomics market caters to lifestyle and fitness concerns.

How to Build a Genome

[Michael Eisenstein](#), *Nature* | 02.24.2020

While it is certainly not cheap or easy, building genomes “from the ground up” for organisms like bacteria and yeast is now possible, given enough time and resources.

Stalked by the Fear That Dementia Is Stalking You

[Judith Graham](#), *The New York Times* | 02.20.2020

For people who have lost family members to dementia, fear of what lurks in their genes can preoccupy daily life. Some wonder if they should get tested for the APOE4 gene, although many doctors advise against it.

N.Y.P.D. to Remove DNA Profiles of Non-Criminals From Database

[Edgar Sandoval](#), *The New York Times* | 02.20.2020

For years, New York City has added to a local database of DNA, collecting samples not just from people convicted of crimes, but from people arrested or questioned, including minors. Now, under community pressure, they’re changing their practices.

When Your Ancestry Test Entangles Others

[Amy Dockser Marcus](#), *Wall Street Journal* | 02.14.2020

The unfiltered nature of DNA testing raises numerous questions about how to balance access to information with safeguards for privacy.

Who’s Looking at Your DNA Data? California Lawmaker Introduces Genetic Privacy Bill

[Andrew Sheeler](#), *The Sacramento Bee* | 02.12.2020

A proposed California law would prohibit DNA testing companies like Ancestry and 23andMe from sharing customer DNA information with outside parties without their consent.

California Senator Proposes Tighter Regulations on Direct-to-Consumer Genetics Testing Companies

[Jonathan Shieber](#), *TechCrunch* | 02.11.2020

Santa Ana’s Democratic Senator Thomas Umberg has introduced legislation that builds on the California Consumer Privacy Act to regulate the ways genetic testing companies can use the data they collect.

Why Sequencing the Human Genome Failed to Produce Big Breakthroughs in Disease

[Ari Berkowitz](#), *The Conversation* | 02.11.2020

It is now 2020 and no one carries a genome card. Physicians typically do not examine your DNA to diagnose or treat you. Why not?

SOCIETY

Want to Do Better Science? Admit You're Not Objective

[Angela Saini](#), *Nature* | 03.09.2020

Viewing science in isolation from the past and politics makes it easier for dangerous and discredited ideas to make their way back into the mainstream.

Should 'Broken' Genes Be Fixed? My Daughter Changed the Way I Think About that Question

[Ethan J. Weiss](#), *STAT* | 02.21.2020

The role of technology in medicine and family formation poses tough questions for families who have thriving children who also happen to have genetics disorders like albinism.

SYNTHETIC BIOLOGY

Crispr'd Cells Show Promise in First US Human Safety Trial

[Megan Molteni](#), *WIRED* | 02.06.2020

The results of a small clinical trial indicate that cells altered with CRISPR and injected into human cancer patients caused no ill effects three years later.

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