April 2020 GENETICS AND SOCIETY News&Views

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SPOTLIGHT

Our Work During the COVID-19 Crisis

Marcy Darnovsky, *Biopolitical Times* | 03.24.2020 Our focus these days—like yours, I imagine—is largely on the spread of COVID-19 and its dire consequences. But our work goes on, and we'll continue to share with you periodically in the weeks to come. This pandemic points to the relevance of concerns about social inequality: vulnerable groups are disproportionately experiencing risks and harms.

ANNOUNCEMENTS



Catch Up on Free CGS Resources

CGS Staff | 03.24.2020

If social distancing is giving you time to read, watch, and listen (certainly not the case for everyone), we've assembled some of our favorite free resources about the current debates and conversations on the social justice implications of human biotechnologies. We'd love to hear what you think.

Appreciations and Best Wishes to our Communications Director

CENTER FOR GENETICS AND SOCIETY

We bid a fond farewell to Communications Director Adrienne van der Valk, whose myriad contributions during her time at CGS helped us up our game in shaping public and policy conversations about the social justice implications of human genetics and assisted reproduction. We look forward to staying in touch with Adrienne as she launches her new venture, an independent design and communications company. Thank you, Adrienne!

COMMENTARY



Movie Review: Human Nature

Pete Shanks, *Biopolitical Times* | 04.02.2020

This documentary is really three movies in one: a useful explanation of the gene-editing tool CRISPR; the engrossing personal stories of two young people adjusting to life with a genetic disease; and an unfortunately one-sided discussion of the ethics of heritable human genome editing.



Heritable Human Genome Editing Is Not Inevitable

Donna Dickenson, Katie Hasson, Marcy Darnovsky, *Project Syndicate* | 03.17.2020 In recent years, the policy consensus barring genetic changes that would be passed down to a person's every descendant has been challenged. Though some scientists and bioethicists are now focused on creating a detailed roadmap for moving forward, there's a strong case to be made that the previous consensus was correct.



A Genetic Information Privacy Act in California

Pete Shanks, *Biopolitical Times* | 03.13.2020 State Senator Thomas Umberg has introduced a bill, SB 980, to offer new protections for users of direct-to-consumer genetic testing, part of a growing trend for states to regulate the industry.

CGS IN THE NEWS



Doha Debates turns spotlight on future of genetics

Gulf Times | 03.13.2020 The question of where the line should be drawn in human gene editing, and if it should be allowed to create "superhumans," was tackled by Doha Debates, and viewed by 4.9 million worldwide on Twitter. Katie Hasson debated with Julian Savulescu and Jamie Metzl, and won the popular vote. (Versions of this article were reprinted widely.)

WHAT WE'RE READING

Assisted Reproduction | Animal Technologies | Disability Rights | Genomics Society | Stem Cells | Surrogacy

GENOMICS

DNA tests grow more vital in hereditary breast cancer treatments. They also raise unanswerable questions.

Sarah Elizabeth Richards, Washington Post | 03.15.2020

Genetic counselors are often left with the job of trying to help patients cope with the emotional fallout: How should you react to knowing you have something lurking in your DNA that might make you sick later? In some cases, women have undergone potentially unnecessary surgeries to remove their breasts in response to a murky threat.

Polygenic Scores: It is time to get real when trying to predict educational performance

Cecile Janssens, eLife | 03.13.2020

A study of 3,500 children in the UK shows that data on socioeconomic background and previous educational achievements can better predict how students will perform at school than genetic data.

Curing HIV and sickle cell falls short if the most vulnerable populations are left out

Francis S. Collins, Fortune | 03.08.2020

The goal for both HIV and sickle cell disease is to develop a gene-based approach that can be given to a living person in one outpatient visit. The dream is to initiate African clinical trials in 10 years—using procedures that are not much more complicated than receiving a blood transfusion.

SURROGACY

New York State Legalizes Gestational Surrogacy

Matt Tracy, Gay City News | 04.02.2020

New York lawmakers approved a budget bill on April 2 that includes provisions legalizing compensated surrogacy in the state. The vote came after a protracted battle that involved divisions among progressives, feminists, and supporters of LGBTQ rights over safeguards for surrogates and egg providers, legal parentage at birth, and other issues.

How Coronavirus Is Affecting Surrogacy, Foster Care and Adoption

David Dodge, *The New York Times* | 04.01.2020 The pandemic is not just impacting parents and pregnant people — all prospective parents are facing new challenges.

Surrogacy: new parents stuck in US amid Covid-19 shutdown

Sirin Kale, The Guardian | 03.26.2020

A family lawyer and assisted reproduction specialist has been keeping an unofficial tally of the babies born via surrogate who are now trapped in the US, unable to reach the homes of their intended parents outside the country. According to her list there are 21; she also counts more than 100 babies in that situation who are expected to be born via surrogate in the coming months.

International surrogacy and COVID-19

Alison Motluk, HeyReprotech Newsletter | 03.23.2020

Among the many people caught up in the COVID-19 nightmare are those involved in international surrogacy arrangements: expecting parents trying to get in, new parents trying to get out and others stuck in quarantine, unable to see their newborn children.

Coronavirus travel ban is having a worrying impact on queer parents expecting children via surrogacy

Lily Wakefield, Pink News | 03.23.2020

The coronavirus pandemic is having a dramatic effect on LGBT+ parents who are expecting children via surrogacy, according to an open letter from the Network of European LGBTIQ Families Associations.

ASSISTED REPRODUCTION

Getting Pregnant Was a Challenge. Then the Coronavirus Happened.

Christina Caron, The New York Times | 03.22.2020

Women across the US are learning that their fertility procedures need to be postponed for an indefinite period of time.

How Tech Will Change Fertility

Claire Tomkins, Forbes | 03.09.2020

Fertility treatments still have a success rate of below 50% on average and only account for 2% of live births. So, the question remains: How will the industry scale?

DISABILITY RIGHTS

I'm disabled and need a ventilator to live. Am I expendable during this pandemic?

Alice Wong, VOX | 04.04.2020

As medical rationing becomes a reality, "quality of life" measures threaten disabled people like me. Eugenics isn't a relic from World War II; it's alive today, embedded in our culture, policies, and practices in the form of systemic medical racism, ageism, and ableism, among other biases.

Americans With Disabilities Are Terrified

Elaine Godfrey, *The Atlantic* | 04.03.2020 They fear they could be denied life-saving treatment if they end up in the hospital with COVID-19.

The Coronavirus Pandemic Is Settling Some Old Arguments About Ableism

Andrew Pulrang, Forbes | 03.30.2020

In a pandemic, the thin veil of racial, financial, and social privilege that shields some disabled people from the worst of ableism is snatched away. And for disabled people of color, disabled people who are poor, and disabled people marginalized in countless other ways even in the best of times, the threat is even worse.

People With Intellectual Disabilities May Be Denied Lifesaving Care Under These Plans as Coronavirus Spreads

Amy Silverman, Arizona Daily Star | 03.27.2020

"What we're seeing here is a clash between disability rights law and ruthless utilitarian logic," said Ari Ne'eman. "What this is really about at the end of the day is whether our civil rights laws still apply in a pandemic. I think that's a pretty core question as to who we are as a country."

SOCIETY

Potential Inequities in New Medical Technologies

Eric B. Kmiec and Jonathan Marron, *Scientific American* | 03.28.2020 Even if we solve the ethical questions about using breakthrough techniques such as CRISPR, will all patients have equal access?

What the Pandemic Is Telling Us About Science, Politics, and Values

Daniel Sarewitz, Slate | 03.24.2020

The novel coronavirus offers up a powerful and extremely clear lesson about the appropriate role of science in helping to guide us toward a better future.

Police May Not Need a Warrant to Rummage Through Your Trash, But Warrantless Collection of DNA Is Unconstitutional

Jennifer Lynch, Electronic Frontier Foundation | 03.11.2020

The Electronic Frontier Foundation has filed an amicus brief in a South Dakota case arguing that the Fourth Amendment prohibits the police from surreptitiously collecting our DNA without a warrant.

STEM CELLS

\$5 Million Allotted: California Stem Cell Agency Receives 19 Applications for Research Targeting Covid-19

David Jensen, California Stem Cell Report | 04.08.2020

Nineteen scientists seeking to crush the coronavirus submitted applications this week for research grants from the California stem cell agency, which has set aside \$5 million for the job.

Final Cyberspace Dash Underway for \$5.5 Billion California Stem Cell Initiative

David Jensen, *California Stem Cell Report* | 04.03.2020 The campaign says it needs 35,000 more signatures in the next eight days to be sure that the multi-billion-dollar ballot initiative is presented to voters next fall.

Unproven Stem Cell Therapy Gets OK for Testing in Coronavirus Patients

Katie Thomas, The New York Times | 04.02.2020

The treatment, which has been promoted by President Trump's personal lawyer Rudy Giuliani, will begin early-stage clinical trials.

ANIMAL TECHNOLOGIES

Mutants or miracles?

Michael Slezak and Penny Timm, ABC Australia | 03.14.2020

They were the genetically modified cows that would change the dairy industry forever. Then it all went wrong and the experiment ended up in an Australian paddock.

Can We Bring Back Mammoths From Extinction? Probably Not — Here's Why

Riley Black, Discover | 03.09.2020

Bringing the beasts back from the dead is a tempting prospect. But genetic evidence suggests we may not fully understand what makes a mammoth.

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