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November 2019

BioPolitical News&Views

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CGS IN THE NEWS

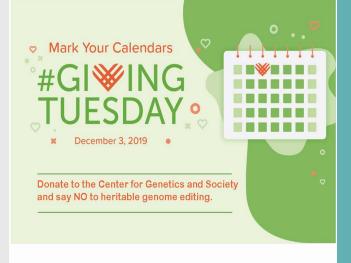
WHAT WE'RE READING

CENTER FOR

AND SOCIETY

GENETICS

SPOTLIGHT



Giving Tuesday is right around the corner. Is Center for Genetics and Society in your plans this year? <u>Your donation</u> supports the only independent nonprofit organization in the US bringing public attention to social justice concerns arising from human genome editing, abuse in the fertility industry, DNA profiling in law enforcement, and other genetic technologies poised to shape our world. Mark your calendar for December 3!

ANNOUNCEMENTS



Climate Crisis, Designer Babies, Our Common Future

CGS, along with the Haas Institute for a Fair and Inclusive Society and the UC Berkeley School of Public Health, hosted a discussion on October 18 between scholar john a. powell and climate change activist Bill McKibben. Participants described the evening as "inspirational," "thought-provoking," and "just what is needed at this point in time." If you missed it, don't worry: You can now <u>watch the video</u> on demand.

Genomics

CRISPR Consensus

On October 26, CGS Program Director on Genetic Justice Katie Hasson participated in a panel at the Innovative Genomics Institute meeting called "CRISPR Consensus," an open symposium on the role of public participation in germline editing decision making. Katie's remarks addressed the topic "Bringing in the Public: Platforms and Pathways for Public Engagement and Debate."

Anya: What Does It Mean to Be Human?

CGS Executive Director Marcy Darnovsky participated in an October 29 screening and panel discussion of the new "science + fiction" film *Anya*. Darnovsky, along with filmmaker Carylanna Taylor and colleagues from UC San Francisco and the Innovative Genomics Institute, explored the puzzles and ethical quandaries the movie poses.



Getting Serious about Social Implications

On November 6 in Washington, D.C., Marcy Darnovsky presented at a daylong meeting on "Ethical, Societal, and Policy Issues in Germline Gene Editing" convened by the American Society of Gene and Cell Therapy. Her presentation, "Heritable Genome Editing: Getting Serious About Social Implications" was part of a panel on "Viewpoints on the Path Forward."

COMMENTARY



Why Has Abuse in the IVF Industry Gone Ignored?

Pamela Mahoney Tsigdinos, *Biopolitical Times* | 10.15.2019 In a first-of-its-kind workshop, scholars, patients, and medical professionals came together to discuss the many forms of abuse patients suffer at the hands of the rapidly-expanding reproductive technology industry—and why it's so difficult to hold "big fertility" accountable.



Another \$5.5 Billion for the California Stem Cell Agency?

Pete Shanks, *Biopolitical Times* | 11.04.2019 As the California Institute for Regenerative Medicine gears up to ask taxpayers for billions of additional public dollars, critics point out that agency advocates have pinned their case on the dubiously rosy prospect of medical breakthroughs and cures, much as they did in 2004.

CGS IN THE NEWS



Controversial '3-Parent Baby' Fertility Technique Fails to Deliver for Older Women

Emily Mullin, *Medium One Zero* | 10.15.2019 Some fertility experts have pushed so-called mitochondrial replacement as a fertility booster for women over 37, but a new study offers no evidence to support this claim. CGS' Marcy Darnovsky notes that the mission creep surrounding '3-parent baby' techniques is a sign of what's in store if heritable gene editing is permitted.

WHAT WE'RE READING

 Assisted Reproduction
 Genomics

 Human Genetic Modification
 Science and Society
 Stem Cells

ASSISTED REPRODUCTION

Screening Embryos for IQ and Other Complex Traits is Premature, Study Concludes

Jocelyn Kaiser, Science | 10.24.2019

Most people agree that screening IVF embryos for desirable traits is a bad idea. A new study concluded that screening embryos for traits that are influenced by many genes would also be mostly inaccurate.

How Big Is the Fertility Services Sector?

Alison Motluk, Hey Reprotech! | 10.15.2019

Investors are paying close attention to the global fertility services market, which carries an estimated value of up to \$25 billion annually. These numbers are only expected to go up.

Why an IVF Bill Is the Next Fault Line for the French Republic

Camille Robcis, The Washington Post | 10.14.2019 The French National Assembly will soon vote on a bill that extends access to assisted reproductive technologies to single women and lesbian couples. The proposed change has sparked fierce debate among policymakers and the public.

Sperm Donor Sues Because His Medical School Misused His Sperm

Ellen Trachman, Above The Law | 10.09.2019

An Oregon doctor is suing Oregon Health and Science University for misusing sperm he donated while attending medical school. Despite promises that no more than five children would be created using his material, he has discovered 17 offspring so far, many of whom unknowingly live and attend school in the same communities.

GENOMICS

Controversial 'Gay Gene' App Provokes Fears of a Genetic Wild West

Amy Maxmen, Nature | 10.29.2019

The new "How Gay Are You?" app warns users that it does not "predict same-sex attraction," but it does "place them along a gradient of same-sex attraction" based on their uploaded genetic data. Scientists and genetic counselors say that the app and other unregulated tools like it can cause anxiety, unnecessary medical expenses, stigmatization and worse.

HUMAN GENETIC MODIFICATION

Ethical Red Flags Fly As Russian Biologist Pushes Boundaries Of Gene Editing

Andy Heil, Radio Free Europe | 10.26.2019

Almost a year after He Jiankui announced the birth of gene-edited twin girls, experts are grappling with how to respond to Denis Rebrikov and the ethics of his plan to start pregnancies with gene-edited embryos.

New 'Prime' Genome Editor Could Surpass CRISPR

Jon Cohen, Science | 10.21.2019

A refined version of CRISPR, referred to as "prime editing," appears to target genomes more precisely than CRISPR, a development that could open the door to expanded medical use in humans.

Russian 'CRISPR-Baby' Scientist has Started Editing Genes in Human Eggs with Goal of Altering Deaf Gene

David Cyranoski, Nature | 10.18.2019

Denis Rebrikov is in the news again, this time announcing an update to his plans to edit human eggs using CRISPR. Although he says he won't start pregnancies with edited embryos without authorization from Russian authorities, he is still conducting experiments that move toward his goal of editing a mutation that causes congenital deafness.

Calling Embryo Editing 'Premature,' Russian Authorities Seek to Ease Fears of a Scientist Going Rogue

Olga Dobrovidova, STAT | 10.16.2019

The Russian health ministry has issued a statement declaring its alignment with the World Health Organization's cautious stance on heritable genome editing. The statement represents a stumbling block for Denis Rebrikov, who has publicly declared his intention to create "CRISPR babies."

Using CRISPR to Edit Eggs, Sperm, or Embryos Does Not Save Lives

Tina Rulli, STAT | 10.15.2019

Supporters of CRISPR for heritable gene editing often insist it should only be used in cases of serious medical need. But does any application of this technology qualify as a medical need? Creating a person without a particular genetic disease who would otherwise not exist should not be considered the same thing as treating or curing existing diseases.

SCIENCE AND SOCIETY

Ethical Research — The Long and Bumpy Road from Shirked to Shared Sarah Franklin, *Nature* | 10.29.2019

It wasn't always the case, but the ethics of research is now everybody's business. Expert knowledge and reliable data are essential but never enough. Bioethics must rely less on specialized expertise and more on diversity and inclusivity to create humane and trustworthy governance of emerging technologies.

How Science Has Shifted Our Sense of Identity

Nathaniel Comfort, Nature | 10.08.2019

Scientism is the ideology that science is the only valid way to understand the world and solve social problems. In many cases, fetishizing science has limited our understanding of humanity, revealing less about who we are and more about what we're willing to believe.

STEM CELLS

Critics Unmoved by Economic Report; Still Say No More Billions for California's Stem Cell Agency

David Jensen, California Stem Cell Report | 10.10.2019

Despite the release of two reports claiming that CIRM has and will continue to boost California's economy, detractors in the legislative and policy arenas claim the Agency was a massive taxpayer investment that has failed to contribute anything substantial to the state, its citizens, or the field of regenerative medicine.

State Stem Cell Agency Hails Sales Tax Revenue, Job Growth as It Nears End of Life

Erin Allday, San Francisco Chronicle | 10.09.2019

Just ahead of filing paperwork for a \$5.5 billion ballot measure in 2020, the California Institute for Regenerative Medicine released a self-funded economic impact study that reported favorably on its contributions to the state's economy. Many readers, however, note that the economic gains CIRM claims credit for would likely have happened anyway.

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