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BIOPOLITICAL VIEWS & NEWS

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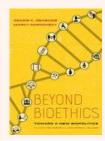
Eugenics reparations bill proposed in California legislature

A new California bill, <u>SB 1190</u>, would compensate people who were involuntarily sterilized under the state's eugenics laws, which were on the books until 1979. SB 1190 is authored by state Senator Nancy Skinner; organizational co-sponsors are <u>California Latinas for Reproductive Justice (CLRJ)</u> and <u>Disability Rights</u> <u>Education and Defense Fund (DREDF)</u>. Read more about the bill on <u>our blog</u>, <u>Biopolitical Times</u>.



Beyond Bioethics anthology now available!

Beyond Bioethics: Toward a New Biopolitics has been officially launched. Edited by Osagie Obasogie (UC Berkeley Professor of Bioethics and CGS Senior Fellow) and Marcy Darnovsky (CGS Executive Director), this anthology brings together the work of several dozen cutting-edge scholars and advocates, all of them committed to a new perspective on human biotechnologies that is grounded in social justice and public interest values. With a Foreword by Troy Duster and Afterword by Patricia J. Williams; available for purchase at University of California Press and Amazon.



The 2018 CGS Fellows Program

We are delighted to announce that CGS's 2018 Fellows are Lisa Ikemoto, Gina Maranto, and Brendan Parent. The CGS Fellows Program helps bring the work and perspectives of its experts to broad audiences in order to deepen public awareness and understanding of the social implications of human biotechnologies. We are honored to host these exceptional and committed scholars as Fellows, and look forward to our collaborations with them.



Gattaca events a success! Thank you for attending.

On March 6 in Berkeley and March 8 in San Francisco, CGS co-sponsored two screenings of the film *Gattaca*, each followed by a panel discussion with scholars and activists. Check out video of both panels on our <u>website</u> and <u>Youtube</u>. An

upcoming episode of podcast Life of the Law will feature the events.



Farewell and warm wishes

We bid a fond farewell to staff associate Kayla Tolentino, who joined CGS in the summer of 2016. We will deeply miss Kayla's keen insights, hard work, and unfailing helpfulness. We wish her the very best in her new role.



CGS presentations

The World Forum on Science and Democracy brings together "representatives of civil society engaged in the democratization of the production of scientific and technological knowledge." On March 14, David King of Human Genetics Alert (UK) and Marcy Darnovsky spoke via video to its fifth annual meeting, held in Bahia, Brazil, about "The Threat of GM Babies." On March 22, Osagie Obasogie and Marcy Darnovsky opened the second annual BioLaw Lapalooza conference, sponsored by the Stanford Center for Law and the Biosciences, with a presentation about <u>Beyond Bioethics: Toward a New Biopolitics</u>. On March 21, Leah Lowthorp spoke with students at the Stamford American International School in Singapore to answer questions about genetic modification in humans.



CGS COMMENTARY

<u>Germline Modification and Policymaking: The Relationship between</u> <u>Mitochondrial Replacement and Gene Editing</u>

By Jessica Cussins and Leah Lowthorp, The New Bioethics

The UK approval process for "mitochondrial replacement" has been cited as a model for future policymaking on human germline editing. CGS staffer Leah Lowthorp and consultant Jessica Cussins show the serious flaws in this approach.

The New Bioethics

How Not to Talk about Race and Genetics

By Jonathan Kahn, Alondra Nelson, Joseph Graves, Marcy Darnovsky, Osagie Obasogie, et. al., *Buzzfeed*

Race has long been a potent way of defining differences between human beings. But science and the categories it constructs do not operate in a political vacuum, notes this open letter produced by a group of 67 scientists and researchers.



Race, Genetics and a Controversy

By Alan Goodman, Marcy Darnovsky, et. al., *New York Times*This letter was co-produced by 33 scholars with backgrounds in anthropology, sociology, African-American studies, public health and law, among other disciplines.



Gattaca at 20: Looking Back, Looking Ahead...

By Katie Hasson, Biopolitical Times

What can we learn from Gattaca, twenty years after its release? And how close is our present-day reality coming to its dystopian vision? CGS recently cosponsored two <u>public events</u> in the Bay Area, where all-star panels of scholars and activists explored these questions. You can also read more about the disability justice-focused discussion at SF Public Library on the Paul K. Longmore Institute's blog, <u>Disability Remix</u>.



Assessing Public Opinion on Genetic Technologies

By Pete Shanks, Biopolitical Times

New articles about rethinking public engagement were published shortly after the UK Royal Society reported on a public dialogue about genetic technologies.



A Bill to Compensate Survivors of Eugenic Sterilization in California

By Emily Galpern, *Biopolitical Times* Guest Contributor
California finally has the opportunity to right a wrong that has long gone
unaddressed: introduced this legislative session, <u>SB 1190</u> would compensate
people who were involuntarily sterilized under eugenics laws that were on the
state's books for almost three-quarters of the twentieth century.



AncestryDNA Markets Genetic "Greatness" during the Olympics

By Leah Lowthorp, Biopolitical Times

Please don't heed AncestryDNA's call to discover your hidden genetic "greatness." This is a socially divisive, genetically essentialist marketing ploy that tries to make you believe that your greatness lies not in who you are, but in your biology.



What if we told you we could back up your mind?

By Pete Shanks, Biopolitical Times

Nectome is selling the idea of preserving your brain for future resuscitation in the course of a pre-arranged death.



CGS in the NEWS

Fertility clinic failures raise question of regulation in industry

[cites CGS' Marcy Darnovsky]

by Ginger Christ, The Plain Dealer

After two recent failures of cryotanks storing eggs and embryos, a number of agencies and organizations are investigating fertility clinics in Cleveland and San Francisco. A lack of federal oversight of the industry leaves it unclear what exactly, if anything, will come out of those investigations.



The Business of Making a Baby

[cites CGS' Marcy Darnovsky]

by Lindsey J. Smith, San Francisco Magazine

A new company says it's offering women fertility testing—and financing egg freezing and future IVF—as a way to improve access to reproductive technologies. But the combination of aggressive marketing and near-meaningless test results seems designed to cultivate panic.



Will California's \$3 billion in stem cell spending pay off? First royalty check arrives

[cites CGS' Marcy Darnovsky]

by David Jensen, The Sacramento Bee

California just received its first royalty payment from the state's stem cell agency. But is it anything other than theater, meant to assuage and allure voters in the run-up to a 2020 ballot measure that will ask for an additional \$5 billion in public money?



No Self-Editing: Biohacker Josiah Zayner Can't Stop Living Out Loud

[cites CGS' Marcy Darnovsky]

by Alex Lash, Xconomy

Biohackers like Josiah Zayner, who wants to live in a world where drunk people CRISPR themselves instead of getting tattoos, must look critically at their role as banner-holders for a new generation.



NEWS

Animal Technologies

Assisted Reproduction

Gene Editing

Gene Editing and Public Engagement

Genetic Testing

Precision Medicine

Race and Genetics

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GENE EDITING AND PUBLIC ENGAGEMENT

A global observatory for gene editing

by Sheila Jasanoff and J. Benjamin Hurlbut, *Nature* Scientists and policymakers have called for widespread public discussion of the possible effects of human gene editing, but efforts so far have fallen short of the global, cosmopolitan conversation that is needed.

Rethink public engagement for gene editing

by Simon Burall, Nature

The serious social and moral implications of human gene editing call for new kinds of public engagement that will require significant investments of time and money.

Interested in responsible gene editing? Join the (new) club

by Martin Enserink, Science

Organizers launched the new Association for Responsible Research and Innovation in Genome Editing (ARRIGE), an international effort to discuss and provide guidance on the ethical use of genome editing, at a kick-off meeting in Paris.

RACE AND GENETICS

- News TOP -

► The Unwelcome Revival of Race Science

by Gavin Evans, The Guardian

Although race science has been repeatedly debunked by scholarly research, in recent years the idea that certain races are inherently more intelligent than others has made a comeback. It's being promoted by a small group of anthropologists, IQ researchers, psychologists, and pundits.

▶ Is direct-to-consumer genetic testing reifying race?

by Timothy Caulfield, Policy Options

The marketing of ancestry testing reinforces dangerous ideas about race.

ASSISTED REPRODUCTION

- News TOP -

Patients mobilize after malfunctions at fertility clinics damage thousands of eggs, embryos

by Amy Goldstein and Ariana Eunjung Cha, *Washington Post* The impulse of couples to translate their anger or grief into legal action represents a new consumer activism in a proliferating realm of medical technology that remains unevenly regulated.

Beware Of IVF In Arizona. If Proposed Legislation Passes, Strangers Could End Up Having Your Genetic Children

by Ellen Trachman, Above The Law

Proposed legislation in Arizona would award the stored frozen embryos of a divorced couple to the person who wants to use them for reproduction, even over an ex-spouse's objections.

IVF to fix male infertility 'infringes human rights of women' argue scientists

by Sarah Knapton, The Telegraph

Scientists warn that using ICSI and IVF to "bypass" male infertility subjects healthy female partners to invasive procedures and infringes "the basic human rights and dignity of women."

GENE EDITING

- News TOP -

► How Editing RNA—Not DNA—Could Cure Disease in the Future

by Kristen V. Brown, Gizmodo

Due to its ephemeral nature, RNA could be a safer target for CRISPR editing than DNA.

CRISPR 'gone wild' has made stocks swoon, but studies show how to limit off-target editing

by Sharon Begley, Stat News

Scientists around the world are working to increase CRISPR specificity, as regulators struggle to decide exactly how much off-target binding should be acceptable.

▶ Britons in favour of editing genes to correct inherited diseases

by Ian Sample, The Guardian

A British Royal Society report on public dialogue about gene editing technologies showed some support for editing human embryos, alongside concerns about designer babies and "cosmetic" organisms such as micro-pigs or fluorescent fish.

GENETIC TESTING

- News TOP -

FDA Approved Breast Cancer DNA Test by 23andMe May do More Harm than Good

by Joyce Bichler, Breast Cancer Action

The Deputy Director of Breast Cancer Action explains the potential harmful effects of 23andMe's direct-to-consumer genetic testing for BRCA variants.

Staying ahead of the double helix

by Sujatha Byravan, The Hindu

India must legislate against genetic discrimination, before health insurance companies begin to require genetic testing and base premiums upon the results.

▶ DNA tests for IQ are coming, but it might not be smart to take one

by Antonio Regalado, MIT Technology Review

Massive troves of genetic data have allowed scientists to associate IQ test scores with genetic variation, creating polygenic scores claimed to predict intelligence. Companies are already marketing genetic IQ assessments. What happens if these scores are used to pick the smartest embryo from an IVF dish, predict children's intelligence, or guide education?

PRECISION MEDICINE

- News TOP -

▶ Dubai Plans to DNA Test all 3 Million of its Residents

by Kristen V. Brown, Gizmodo

The city of Dubai plans to sequence the DNA of its 3 million residents. The aim is to create artificial intelligence capable of analyzing the data and potentially predicting diseases before they occur.

► The Struggle to Build a Massive 'Biobank' of Patient Data

by Gina Kolata, The New York Times

The NIH will soon start recruiting individuals for the All of Us program, with the goal of collecting health information and sequencing the genomes of a representative sample of one million people in the United States. But this expensive effort faces many challenges—and a lot of skepticism.

ANIMAL TECHNOLOGIES

- News TOP -

► You Love Dogs? Then Don't Clone Them

by Jessica Pierce, The New York Times

Barbra Streisand's "personal" decision to clone her dog has larger ramifications, such as concerns about the welfare of the animals involved in cloning research and the millions of dogs already languishing in shelters.

Farmland gene editors want cows without horns, pigs without tails, and business without regulations

by Antonio Regalado, MIT Technology Review

"Barnyard entrepreneurs" hope the US Food and Drug Administration will change regulations that currently treat gene edits to animals like drugs requiring substantial safety tests before a modified organism is given the green light for consumption.

VARIOUS - News TOP -

How human embryonic stem cells sparked a revolution

by David Cyranoski, Nature

After 20 years of hope, promise, and controversy, human embryonic stem cells are reshaping biological concepts and starting to move into the clinic.

May the odds be ever in your favour? The politics of prognosis

by Joel Michael Reynolds, Aeon Ideas

Probability, far from being neutral, can directly contribute to injustice. Invoking probabilities can create a fatal cycle that can shape what medical treatment is offered and even change how people value children's lives.

California Supreme Court Upholds the State's Problematic Arrestee DNA Collection Law

by Jennifer Lynch, Electronic Frontier Foundation

The California Supreme Court upheld a state law mandating DNA collection from all arrestees, even if they are never charged with or convicted of a crime. The law threatens the privacy of tens of thousands of innocent Californians every year.

