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GENETICS

BioPolitical News&Views

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SPOTLIGHT ///



Translating Genes into $\text{Health} \mathbb{B} - \text{Or}$ Dollars?

Pete Shanks and Emily Galpern, *Biopolitical Times* | 10.15.2021

The new carrier screening guidelines are riddled with problems, including potential conflicts of interest.

COMMENTARY



Will Biden's FDA Chief be Tied to Biotech and Big Pharma?

Marcy Darnovsky, *Biopolitical Times* | 10.14.2021 President Biden has not yet nominated a permanent head of the FDA. Among those in the running for the position are several individuals with close ties to the pharmaceutical and biotechnology industries.

CGS IN THE NEWS



On ranking embryos best to worst

CGS' Katie Hasson spoke about polygenic embryo screening with reporter Alison Motluk for her newsletter **HeyReprotech** (**story** for subscribers only). Katie points out that parental decisions are made in the context of social biases that "push decisions in particular directions... [T]he cumulative effect, over time, could really be damaging."

WHAT WE'RE READING

HUMAN GENOME EDITING | ASSISTED REPRODUCTION | EUGENICS | GENETIC TESTING | HENRIETTA LACKS | STEM CELLS | VARIOUS

HUMAN GENOME EDITING

Heritable human genome editing: Who decides? Science or society?

Françoise Baylis, Journal of Medical Ethics Blog | 10.11.2021

It is for civil society – not the scientific community – to set the research parameters for heritable human genome editing using governance mechanisms that take into consideration a range of societal values and priorities.

ASSISTED REPRODUCTION

'Lies and trauma': donor-conceived adults are still haunted by their origins

Gary Nunn, The Guardian | 10.09.2021

A new generation of donor-conceived adults in Australia is coming of age in the wake of regulatory and technological changes that have forced a once secretive industry to open its books. But those born before these changes continue to experience harm from prior policies and secrecy.

Regulating Assisted Reproduction

Sandy Hausman, WTVF Radio IQ | 10.06.2021

Virginia was the birthplace of the first American IVF baby, but the state is lagging when it comes to regulating fertility clinics. Virginia clinics are not required to warn their patients about the risks of assisted reproduction or keep detailed records of sperm and egg donation. National laws are needed that ensure uniform standards and protections for those who get care at fertility clinics.

EUGENICS

California state park with ties to racist past will now be called by Indigenous name

Lila Seidman, Los Angeles Times | 10.04.2021

By a 5-0 vote, the California State Park and Recreation Commission stripped the Patrick's Point State Park moniker and restored its Indigenous Yurok name, Sue-meg. The park is now named for a striking rock formation that lies off the coast near the site of a former Yurok village that served as

an important trade and cultural hub.

Britney's conservatorship is one example of how the legacy of eugenics in the US continues to affect the lives of disabled women

Michaela Kathleen Curran, The Conversation | 10.01.2021

Spears' story, especially her anguish over the loss of her reproductive agency, is shared by disabled women across the country. Recognizing the reproductive rights of disabled women is about promoting reproductive justice for all women.

GENOMICS

Genomes Show the History and Travels of Indigenous Peoples

Keolu Fox, Scientific American | 10.13.2021

Genetics gives us insights into the impact of both Indigenous peoples' proud history of migration and the shameful legacy of colonialism. Once used to make claims about Indigenous peoples' inferiority, today the science of the genome can be part of an Indigenous future we can all believe in.

Will Sociogenomics Reduce Social Inequality?

Erik Parens, Bioethics Forum | 09.30.2021

The arguments in Kathryn Paige Harden's new book do not justify her enthusiasm about, and her hopes for, the transformative left-leaning political potential of sociogenomics.

GENETIC TESTING

Genetic discrimination: The next great health battle likely to wash up on NZ shores

Chelsea Daniels, NewstalkZB | 10.06.2021

Growing concern in New Zealand about genetic discrimination has led to calls for Government intervention. Currently, life and health insurance companies are allowed to use genetic data in determining coverage and premiums for applicants.

At-home genetic testing for cancer and other disease risk is booming: Should you try it?

A. Pawlowski, Today | 10.04.2021

Genetic testing kits are convenient and fairly inexpensive, but there's a lot to think about before taking a test. Experts worry about whether the tests return valid results and whether people understand how much they can reveal.

The ethical landscape(s) of non-invasive prenatal testing in England, France and Germany: findings from a comparative literature review

Adeline Perrot and Ruth Horn, European Journal of Human Genetics | 10.04.2021 An international comparison illuminates ethical questions about NIPT and prenatal genome testing generally. For each country, principles and values such as reproductive autonomy, human dignity, disability rights, and the duty of care of health professionals are evaluated and compared.

HENRIETTA LACKS

WHO honors Henrietta Lacks, woman whose cells served science

Jamey Keaten, Associated Press | 10.13.2021

The World Health Organization honored the late Henrietta Lacks with the Director-General's Award, presented by Tedros Adhanom Ghebreyesus at a ceremony in Geneva. "Henrietta Lacks was exploited. She is one of many women of color whose bodies have been misused by science," he said.

Family of Henrietta Lacks files suit against biotech company for using famous 'HeLa' cells without permission

Meredith Cohn and Hallie Miller, The Baltimore Sun | 10.04.2021

Family members of Henrietta Lacks have filed a lawsuit against the U.S. biotech giant Thermo Fisher Scientific accusing the company of "unjust enrichment" for making and selling products that relied on cells taken from her without her consent decades earlier.

STEM CELLS

California's Multi-Billion Dollar Plan for Spending on Cell and Gene Therapy Is Nearing Completion

David Jensen, The California Stem Cell Report | 10.11.2021

The 35 directors of the \$12 billion California stem cell agency are scheduled to meet next week to discuss matters ranging from weakening conflict of interest rules to how they will spend several billion dollars over five years. This meeting is effectively the last opportunity for researchers and the public to comment directly to the board.

A Controversial Autism Treatment Is About to Become a Very Big Business

Anna Merlan, Vice | 10.06.2021

Duke University and a private company have been selling access to unproven cord blood treatments for autism. Now, they're planning something much bigger.

VARIOUS

Francis Collins, Who Guided N.I.H. Through Covid-19 Crisis, Is Exiting

Noah Weiland and Gina Kolata, *The New York Times* | 10.05.2021 The agency's director for more than three decades and three presidents said he will leave by the end of the year. He is planning to shift his focus back to the lab, and said that he hoped his replacement would be a woman.

The chimaera challenge

Liam Drew, Nature | 09.29.2021

Researchers seeking to develop a new supply of transplantable organs are creating pig-human chimaeras, mouse-human chimaeras, and even monkey-human embryos. Despite calls for open dialogue and public engagement, decisions about such experiments are made case-by-case by local institutional review boards.

Don't Count On Woolly Mammoths To Save The Planet

Frederick Hewett, WBUR | 09.27.2021

A start-up is creating buzz for its plan to bring back the extinct creatures. But the company's disingenuous posturing distracts from the deadly serious issue of climate change.

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