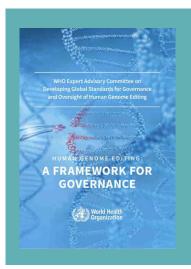


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July 22, 2021

SPOTLIGHT ///



New Recommendations on Human Genome Editing from WHO

CGS Press Statement | 07.12.2021

The World Health Organization reports recognize the need for global cooperation and meaningful public engagement. However, they fall short by not calling for a global ban on heritable genome editing. A global moratorium, at the very least, is needed for the public empowerment process the reports encourage, and to apply the principles of social justice and solidarity they invoke.

ANNOUNCEMENTS



New joint appointment at UC Berkeley for CGS Senior Fellow Osagie Obasogie

Congratulations to CGS Senior Fellow Osagie Obasogie, whose new faculty appointment at Berkeley Law makes him the only Professor on campus with a joint appointment at the School of Public Health and Law School. Osagie told the Berkeley Law newsletter that he is "especially enthused about bringing critical conversations around medicine, science, and technology to the law school." He noted, "Once we have a better understanding of how race and racism have shaped law and medicine, we can begin to have conversations about how to fix the inequities perpetuated by these institutions." We are delighted to be continuing CGS' long affiliation with Osagie as he embarks on this new chapter.

COMMENTARY



WHO Asserts Leadership on Human Genome Editing

Pete Shanks, Biopolitical Times | 07.21.2021

The significance of the reports begins with WHO's status as an agency of the United Nations that is stepping up to assert its moral leadership and making what appears to be a long-term commitment to an ongoing work program around gene editing and other emerging technologies.



Victory for Reproductive Justice in California: New Budget Includes Reparations for Survivors of Eugenic Sterilization

Emily Galpern, Biopolitical Times | 07.13.2021

The \$7.5 million program will provide up to \$25,000 per survivor and funds to raise awareness about this unjust history. California Latinas for Reproductive Justice, Disability Rights Education and Defense Fund, and California Coalition for Women Prisoners spearheaded the effort, which was actively supported by many social justice allies, including CGS's biopolitical network.

CGS IN THE NEWS



World Health Organization advisers urge global effort to regulate genome editing

Megan Molteni, STAT | 07.12.2021

A World Health Organization advisory committee urged a halt to any experiments that might lead to the births of gene-edited humans. The committee notes that heritable human genome editing technology is still too scientifically and ethically fraught for use, but suggests how governments might establish somatic gene editing as a tool for improving public health. [cites CGS on global laws]



Should we edit human embryos' genomes, and if so then how?

Dieter Egli, BioNews | 07.12.2021

As CGS' Marcy Darnovsky has noted, recent research has discovered that the use of CRISPR technology on early human embryos could lead to unintended damage. This researcher believes that continued basic research may solve these problems and lead to clinical use of such technology.

WHAT WE'RE READING

HERITABLE GENOME EDITING | GENE THERAPY | GENOMICS |
ASSISTED REPRODUCTION | EUGENICS | DISABILITY RIGHTS | GOVERNANCE | VARIOUS

HERITABLE GENOME EDITING

Human genome editing and moral leadership: findings of the WHO Expert Advisory Committee

Peter Mills, Nuffield Council on Bioethics | 07.14.2021

Perhaps the most important recommendations are the ones that enjoin the WHO Director General to bring the WHO's moral authority to bear in order to shore up a flaking international consensus and make

the case for more coordinated prospectus.

W.H.O. Experts Seek Limits on Human Gene-Editing Experiments

Gina Kolata, The New York Times | 07.12.2021

A committee of experts working with the World Health Organization called on the nations of the world to set stronger limits on powerful methods of human gene editing.

GENE THERAPY

Sickle cell disease and a pivotal moment to end health inequality

Ted W. Love, STAT | 07.15.2021

After decades of a dearth in investment and innovation in sickle cell disease, there are now promising treatment options and developments toward gene therapies. But there remain significant gaps in the care of those living with sickle cell disease. Health equality will be achieved only when they are treated with the same level of urgency as white people with rare diseases.

Equity and access need to be at the forefront of innovation in human genome editing

Jantina de Vries and Françoise Baylis, The Conversation | 07.12.2021

"As members of the WHO Expert Advisory [Committee], we appreciate the challenges in moving forward with human genome editing technology, given our commitment to ensure that this is not just personalized medicine for an elite few."

GENOMICS

A New Era of Designer Babies May Be Based on Overhyped Science

Laura Hercher, Scientific American | 07.12.2021

Orchid Biosciences aims to expand the market in screening tests for prospective parents and IVF embryos. Geneticists are skeptical, in large part because of the company's use of polygenic risk scores. With a marketing strategy that encourages routine use of IVF for those who can afford it, Orchid breaks new ground in introducing the first—but likely not the last—consumer-driven model of human reproduction.

What does the Chinese military want with your unborn baby's genetic data?

Arwa Mahdawi, The Guardian | 07.10.2021

"China is stealing your intimate data for evil purposes" is a popular genre in western journalism. But western companies are doing exactly the same thing. DNA is big business now and there is really no knowing who has your most intimate information, who they've sold it on to, and what those companies or governments are doing with it.

A secret algorithm is transforming DNA evidence. This defendant could be the first to scrutinize it.

Justin Jouvenal, The Boston Globe | 07.13.2021

Cybergenetics, the tool's maker, says the software code is a trade secret. Defendants argue that they have a constitutional right to examine the evidence against them for potential errors. This little-noticed Virginia case, and another in Pennsylvania, could become the first in the nation in which experts for defendants are allowed to peer inside.

ASSISTED REPRODUCTION

By creating mouse eggs entirely from scratch, researchers raise the prospect of a futuristic fertility treatment

Megan Molteni, STAT | 07.15.2021

Although it will not easily transfer to humans, the experiment could spark debate about how the

technology should be used. "The concern about this kind of research is that once you prove it's possible, the next question everybody asks is not 'should we use it?' Or 'do we have a need for it?' It's 'how are we going to use it?'," said bioethicist Megan Allyse.

Israel's high court opens the way for same-sex couples to have children via surrogacy

Claire Parker, The Washington Post | 07.11.2021

Restrictions on surrogacy for same-sex couples and single fathers in Israel must be lifted within six months.

Banning Abortion Doesn't Protect Women's Health

Michele Goodwin, The New York Times | 07.09.2021

The Supreme Court will review a Mississippi anti-abortion law, one of the most restrictive measures yet, and the gravest threat so far to Roe v. Wade. Implicit and explicit racial biases underpin coercive reproductive rights legislation, and Black women are disproportionately affected by these dangerous laws.

EUGENICS

California Approves Reparations for Survivors of Forced Sterilization

Mina Kim, KQED Forum | 07.21.2021

An hour-long discussion with Alexandra Minna Stern, author of, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America*; Gabriela Solano, victim of forced sterilization while incarcerated in a California prison; Stacy Cordova Diaz, great-niece of Mary Franco, who was sterilized in 1934 at the age of 13; and Cynthia Chandler, lawyer, whose work exposing sterilizations in California prisons is featured in the documentary "Belly of the Beast."

Survivors of California's forced sterilizations: 'It's like my life wasn't worth anything'

Erin McCormick, The Guardian | 07.19.21

"When people hear the term eugenics they often think of something that happened a long time ago," said Lorena García Zermeño, the policy and communications coordinator for the California Latinas for Reproductive Justice, a co-sponsor of the bill. "But the legacy of eugenics continues to this day."

Prince Harry, Meghan Markle Receive Environmental Award For Their Two-Children Limit

Evita Duffy, The Federalist | 07.12.2021

The UK-based charity Population Matters dubbed the estranged ex-royals "role models" for their "enlightened decision." However, the history of the population control movement is also deeply entwined in the classism and racism of the eugenics movement, and the couple have attracted criticism for their large mansion and use of private jets.

DISABILITY RIGHTS

Disabling Utopia to Save It

s. e. smith, The Nation | 07.14.2021

Utopian thinkers are especially prone to leaving out one group whose experiences and insights should enrich our dreams of the future: the disability community. For writers like H.G. Wells and Edward Bellamy, that absence was a desirable consequence of eugenics, a movement they enthusiastically supported. Science fiction also raises the prospect of using technologies like CRISPR to edit the human genome and thereby eliminate genetic disabilities.

GOVERNANCE

Pam Belluck, The New York Times | 07.14.2021

The Cleveland Clinic said that individual physicians could prescribe Aduhelm, but patients would have to go elsewhere to receive it. Mount Sinai's Health System in New York City has also decided not to administer Aduhelm.

'This is unprecedented': Several private insurers won't cover Biogen's Alzheimer's drug

Jonathan Saltzman, The Boston Globe | 07.13.2021

Six affiliates of Blue Cross and Blue Shield in Florida, New York, Michigan, North Carolina, and Pennsylvania will not cover the Cambridge biotech's drug, Aduhelm, because they consider it "investigational" or "experimental" or because "a clinical benefit has not been established."

The FDA Is Broken

Shannon Brownlee and Jeanne Lenzer, Washington Monthly | 07.10.2021

This is not the first time the FDA has given a drug the go ahead on the basis of a shaky surrogate endpoint. The Biden administration has an opportunity to remind FDA administrators of their primary responsibility — protecting the public from snake oil.

VARIOUS

Texas Senate Bill Drops Teaching Requirement That Ku Klux Klan Is 'Morally Wrong'

Mary Papenfuss, HuffPost | 07.19.221

The bill also eliminates requirements to include the writings of Martin Luther King Jr., United Farm Workers leader Cesar Chavez, and suffragist Susan B. Anthony. "How could a teacher possibly discuss slavery, the Holocaust, or the mass shootings at the Walmart in El Paso without giving deference to any one perspective?" asked state Sen. Judith Zaffirini.

Why Clinical Ethicists Are Not Activists

Carl Elliott, The Hastings Center Report | 07.13.2021

Asking the clinical ethicist to fix the problems of an academic health center is like asking the butler to fix the problems of the British monarchy. He is not there to rule, but to serve.

'The Man Who Hated Women' Is Mostly About the Women He Hated

Jennifer Szalai, The New York Times | 07.12.2021

Amy Sohn's new book looks back at the 19th-century moral crusader Anthony Comstock, chief architect of the Comstock Act of 1873, which made it a federal offense to mail "obscene" material. It features the women whose work he targeted, including the suffragist Victoria C. Woodhull, the anarchist Emma Goldman, and the birth control activist Margaret Sanger.

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