



March 15, 2022

SPOTLIGHT



CGS Presentations at Human Genome Editing Summit Events

CGS Associate Director Katie Hasson presented on heritable genome editing policy at The Royal Society event "Looking Ahead to the Third International Summit on Human Genome Editing." Watch Katie's presentation here and read CGS' recap of the full event here. The Stop Designer Babies mini-conference, "Why Your Movement Should Oppose Designer Babies," featured a presentation by CGS consultant Pete Shanks.

ANNOUNCEMENTS

Toward Abolition Medicine: Special issue of AMA Journal of Ethics

CGS Senior Fellow Osagie K. Obasogie edited the March 2022 special issue, which considers when and how abolitionist approaches should inform practice and policy in the health professions to promote good health outcomes for everyone, motivate equitable access to health services, and ensure the material conditions for individual and community health and safety. Read the issue **here**.



Virtual Conference Wrap-up: Looking Ahead to the Third Human Genome Editing Summit

Pete Shanks, Biopolitical Times | 03.15.2022

An overview of the three-day event that substituted for the Third International Summit on Human Genome Editing, which demonstrated a somewhat broader approach than did the first two Summits but still suffered from limited public engagement and a tendency to consider separately topics that are intrinsically intertwined.



Toward Abolitionist Approaches in Medicine

Osagie K. Obasogie, AMA Journal of Ethics | 03.01.2022 To the extent that medicine is often closely connected to sites of anti-Black racial oppression, what would an abolitionist approach to the profession look like?

WHAT WE'RE READING

ASSISTED REPRODUCTION | GENOME EDITING | GENOMICS | VARIOUS

ASSISTED REPRODUCTION

Collection of Articles on Surrogacy During the War in Ukraine

Surrogacy360 | 03.14.2022

The CGS resource Surrogacy360 presents a collection of recent articles that highlight a lesser-known aspect of the devastation caused by Russia's war on Ukraine: the impact on surrogacy-born babies, surrogates and their families, and intended parents from other countries. Underscoring surrogates' invisibility and unequal access to resources, these articles depict harrowing situations facing infants, surrogates, and intended parents.

In a Kyiv Basement, 19 Surrogate Babies Are Trapped by War but Kept Alive by Nannies

Andrew E. Kramer and Maria Varenikova, The New York Times | 03.12.2022

Babies born to surrogate mothers in Ukraine face threats to their safety and uncertain citizenship, with their biological parents still outside the country and unable to confirm their nationality. Surrogate mothers are trapped by fighting and face complex legal challenges for the babies they birth if they leave Ukraine.

Ukraine's Surrogacy Industry Has Put Women in Impossible Positions Alison Motluk, *The Atlantic* | 03.01.2022

Surrogates can't quit their jobs, even in wartime. The invasion of Ukraine has left surrogates in an impossible position, caught between fulfilling their responsibilities and doing what seems right for their families.

When an Ancestry Search Reveals Fertility Fraud

Jacqueline Mroz, The New York Times | 02.28.2022

Starting in the 1960s, three physicians in Rochester, N.Y., began secretly using their own sperm to impregnate their patients. Proposed legislation in New York would make this and other forms of "fertility fraud" a felony offense.

Major CRISPR patent decision won't end tangled dispute

Heidi Ledford, Nature | 03.09.2022

Despite the U.S. patent office's latest decision to award key patent rights to the Broad Institute, the dispute shows little sign of ending, and the intellectual property around CRISPR is growing more complex.

'It's a real-life Hunger Games': a lifesaving drug costs \$2m, but not every child can get it

Hannah Devlin, The Guardian | 03.05.2022

The gene therapy Zolgensma can stop the deadly childhood condition Spinal Muscular Atrophy in its tracks, but the drug's £1.2M price tag makes it inaccessible for families seeking the treatment.

Rediscovering a language of healing that doesn't require 'cure'

Lee D. Cooper, STAT News | 03.02.2022

Emphasizing future curative potential over present impact can turn health and disease into binary ideas rather than the spectrum they truly are. No one is fully healthy or fully diseased, and the language of biomedicine should aim for a humanizing nuance, not polarization.

First gene-editing treatment injected into the blood reduces toxic protein for up to 1 year

Jocelyn Kaiser, Science | 03.01.2022

The first team to disable a disease gene directly in a person through an infusion of CRISPR reported that levels of the toxic protein made by the gene dropped as much as 93% for up to 1 year.

UC Berkeley loses CRISPR gene editing patent case

Lisa M. Krieger, The Mercury News | 02.28.2022

The U.S. Patent and Trademark Office ruled that the patent for use of the genome-editing technology in humans belongs to the Broad Institute of Harvard and MIT, not UC Berkeley. Berkeley could lose \$100 million to \$10 billion in U.S. licensing revenues.

How to protect the first 'CRISPR babies' prompts ethical debate

Smriti Mallapaty, Nature | 02.25.2022

Two prominent bioethicists in China are calling on the government to set up a research center dedicated to ensuring the well-being of the first children born with edited genomes ahead of the possibly imminent release of He Jiankui from prison.

GENOMICS

Could drugs prevent Alzheimer's? These trials aim to find out

Alison Abbott, Nature | 03.09.2022

Several clinical trials are trying to understand whether antibodies that have been developed to target and clear amyloid- β proteins in the brain might treat the root cause of Alzheimer's before symptoms start. Researchers have recruited people with rare genetic predispositions for developing early-onset Alzheimer's to participate in long-running trials focused on prevention.

Bias and Inaccuracy in Marketing Noninvasive Prenatal Tests

The Hastings Center | 03.08.22

A new study finds that bias and inaccuracy are pervasive in the marketing of noninvasive prenatal tests. Regulation is needed to ensure that consumers can access material on these tests that is "accurate, trustworthy, and ethically responsible."

SFPD says use of rape victim's DNA in unrelated criminal investigation 'should not have happened'

J.R. Stone, ABC News | 03.03.2022

After it came to light that the San Francisco Police Department had used DNA from a sexual assault survivor to investigate other crimes, the department is looking at 17 cases to make sure that victims weren't identified as suspects with DNA from a rape kit. "Problems have been identified and policies put in place so it doesn't happen again," said SFPD Chief Scott.

Genomics' Ethical Gray Areas Are Harming the Developing World

Dyna Rochmyaningsih, Undark Magazine | 02.24.2022

If we want science to serve the whole of humanity, we need a strong set of universally binding rules on research ethics — rules that clearly give local authorities a voice on matters of research ethics in all studies involving human genetic sampling, not just those that are obviously medical in nature.

VARIOUS

California stem cell clinic to pay out \$3.65M settlement to former patients for ineffective treatments

Paul Schloesser, Endpoints News | 03.11.2022

Four years after the FDA admonished stem cell clinic StemGenex for making dubious claims about treating incurable diseases, and 3 years after the company first filed for bankruptcy, the clinic and its former CMO will pay \$3.65 million to former patients in a class action settlement.

US man who got the 1st pig heart transplant has died after 2 months

Lauren Neergaard and Carla K. Johnson, Associated Press | 03.09.2022

The first person to receive a heart transplant from a genetically modified pig has died, two months after he received the transplant. Doctors didn't give an exact cause of death, saying only that his condition had begun deteriorating several days earlier.

Bringing back the woolly mammoth and other extinct creatures may be impossible

Elizabeth Pennisi, Science | 03.09.2022

Research to sequence the full genome of the vanished Christmas Island rat "highlights the difficulties, maybe even the ridiculousness, of [de-extinction] efforts."

Gene-edited beef cattle receive regulatory clearance in U.S.

Candice Choi, Associated Press | 03.08.2022

U.S. regulators cleared the way for the sale of beef from CRISPR-edited cattle in coming years. The F.D.A. concluded that they do not raise any safety concerns and that meat from the animals or their offspring would not need to be labeled differently.

If you've read this far, you clearly care about the fight to reclaim human biotechnologies for the common good. Thank you!

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