

November 16, 2023

SPOTLIGHT



Support genetic justice on Giving Tuesday, November 28!

Your <u>contribution</u> fuels <u>our efforts</u> to secure a just and inclusive future where human biotechnologies serve the common good. The Center for Genetics and Society is the leading US nonprofit confronting the cutting-edge challenges of human genetics and assisted reproduction. Your support for genetic justice is essential, and it is deeply appreciated. Please <u>donate</u> today!

CGS IN THE NEWS



Ces Américains en croisade pour faire le plus d'enfants possible, et sauver l'humanité

[These Americans are on a crusade to have as many children as possible – and to save humanity]

Raphaëlle Besse Desmoulières, Le Monde | 10.29.2023

Explaining the link between embryo selection and eugenics, CGS' Katie Hasson commented, "To the extent that it's trying to improve the population or eliminate certain traits through reproduction, it is entirely consistent with eugenics."



What If Men Could Make Their Own Egg Cells?

Amy Dockser Marcus, The Wall Street Journal | 10.27.2023 Companies trying to create human eggs from skin cells in the lab see the technique as a potential profit-maker, but ethical concerns and skepticism about feasibility remain. CGS' Katie Hasson notes the challenges of determining whether lab-created eggs would be safe enough to create babies. "The only way now to know...[would be] to make an embryo and see how it develops," she says.

COMMENTARY



Justice for Henrietta Lacks

Isabelle Bartram, Guest Contributor, *Biopolitical Times* | 11.14.2023 The Lacks family's efforts for financial justice could be a model for other cases where tissues from patients were commercialized without their consent. In addition, it may bring to an end the questionable research practices that dehumanize the person behind the tissue sample.



Al and Human Gene Editing: Techno-Pessimism and Techno-Scams

Pete Shanks, Biopolitical Times | 11.13.2023

Despite evidence of ineffectiveness and potential threats to a just and equitable future, some continue to misplace hope for social improvement in AI and "techno-eugenic" embryo selection techniques.

WHAT WE'RE READING

GENE EDITING | GENOMICS | EUGENICS ASSISTED REPRODUCTION | SURROGACY360 | VARIOUS

GENE EDITING

Base editing, a new form of gene therapy, sharply lowers bad cholesterol in clinical trial

Jocelyn Kaiser, Science | 11.12.2023

Infusions of a base editor that disables a liver protein slashed "bad" cholesterol levels in three people prone to dangerously high levels.

Exploring danger, possibilities of genetic editing

Quinton Amundson, The Catholic Register | 11.10.2023

Beyond therapeutic uses of CRISPR lie thorny questions about its potential misuse. When it comes to germline gene editing, "Our knowledge is far too limited to start messing with a system that is so complex that we don't know of all the possible outcomes."

What if a CRISPR cure isn't such an easy choice?

Ned Pagliarulo and Shaun Lucas, BioPharma Dive | 11.08.2023

Exa-cel, a gene therapy for sickle cell disease, appears to work exceptionally well. Its benefits may not be accessible by all, or even most, of the thousands of people in the U.S. and the millions of people in the world who have severe sickle cell disease.

US FDA's Confidence In Gene Editing Safety Growing Enough That Regulatory Bar May Be Lowered

Derrick Gingery, Pink Sheet | 11.01.2023

The FDA appears to have grown more comfortable with experimental gene editing techniques, shifting its regulatory approach and lowering the high bar it set for safety standards.

Panel Says That Innovative Sickle Cell Cure Is Safe Enough for Patients

Gina Kolata, The New York Times | 10.31.2023

A panel of experts said exa-cel, a CRISPR-based treatment for sickle cell disease, was safe enough for clinical use, setting the stage for likely federal approval. It would be the first approved treatment

for a genetic disease using CRISPR.

Second Maryland Man to Receive an Altered Pig's Heart Has Died

Roni Caryn Rabin, The New York Times | 10.31.2023

The second man who received a transplanted heart from a genetically modified pig died six weeks after receiving the pig organ.

Can gene editing drive out HIV and hepatitis viruses from inside cells?

Cormac Sheridan, Nature Biotechnology | 10.30.2023

Researchers are developing CRISPR gene therapies that could cure HIV and hepatitis, but extensive clinical trials are needed to test whether the techniques are safe and effective.

Engineering CRISPR Cures: An Interview with Fyodor Urnov

Jonathan D. Grinstein, *Genetic Engineering & Biotechnology News* | 10.27.2023 Fyodor Urnov aims to expand the use of CRISPR to develop gene therapies for rare diseases. His startup is also working on another technique, epigenetic editing, which targets the proteins that encase genes rather than the genes themselves.

GENOMICS

New Jersey Keeps Newborn DNA for 23 Years. Parents Are Suing

Emily Mullin, Wired | 11.08.2023

All US states take pinpricks of blood from newborns to test for diseases, but New Jersey stores them for decades and may allow them to be used in police investigations. Parents are suing the state over its storage practices.

From a Fledgling Genetic Science, A Murky Market for Predictions

Ashley Smart, *Undark* | 10.27 2023

Start-ups with Silicon Valley backing aim to profit off new kinds of consumer genetic testing, moving beyond genetic prediction of disease risk to providing polygenic scores, including for complex traits laden with social stigmas. These companies, which have thus far escaped regulatory oversight, rely on specious claims linking genetics to complex traits and reinforce damaging cultural myths that disvalue diversity and disability.

Giant sloths and woolly mammoths: Mining past creatures' DNA for future antibiotics

Jason Mast, *STAT* | 10.25.2023

Researchers are using robots to resurrect snippets of DNA from Neanderthals, giant sloths, and woolly mammoths. They're hoping to find antimicrobial sequences that could help develop new drugs to treat infections in humans.

EUGENICS

Medical education must include the field's Nazi past, expert panel urges Gretchen Vogel, Science | 11.10.2023

All health care students worldwide should learn the history of Nazi crimes in medicine during the Holocaust, according to a *Lancet* report. These include the use of concentration camp prisoners in heinous medical experiments, widespread forced sterilizations, and "euthanasia" programs that murdered more than 200,000 people deemed mentally unfit, including children.

The Lancet Commission on medicine, Nazism, and the Holocaust: historical evidence, implications for today, teaching for tomorrow

Herwig Czech et al., The Lancet | 11.08.2023

Health science curricula rarely cover the horrific crimes of the Holocaust. Learning how healthcare

providers participated in this genocide can be part of an effort to integrate a commitment to universal human rights into medicine.

Fraud, Lies, Exploitation and Eugenic Fantasies

Émile P. Torres, Truthdig | 11.09.2023

The effective altruist movement has been caught up in a whirlwind of scandals and embarrassing stumbles that reveal the cult-like practices of the movement and underscore its reliance on eugenic ideas.

Few Survivors Have Been Paid as California Sterilization Reparation Program Winds Down

Garnet Henderson, Rewire News Group | 11.06.2023

The state's program to compensate victims of forced sterilization has denied three times as many applicants as have been approved.

ASSISTED REPRODUCTION

Colorado Donor-Conceived Person Protection Law Opens Public Comments On Proposed Rules

Ellen Trachman, Above the Law | 10.31.2023

As Colorado prepares regulations aimed at protecting donor-conceived persons, it has invited stakeholders to submit comments, either in scheduled live Zoom sessions or in writing.

Infertility gets a new, expanded definition to address 'the reality of all' seeking care, medical group says

Jacqueline Howard, CNN | 10.23.2023

The American Society for Reproductive Medicine Practice Committee has proposed an expanded definition of infertility to include anyone needing medical interventions "in order to achieve a successful pregnancy either as an individual or with a partner."

SURROGACY360



Proposed changes to surrogacy law 'will not be taken forward at the moment'
Aine Fox, *The Independent* | 11.10.2023

A UK health minister says that a major overhaul to surrogacy regulations, proposed by the Law Commission, will not be adopted at this time.

VARIOUS

First live birth of a chimeric monkey is a technical feat, but pushes ethical boundaries

Helen Floersh, Fierce Biotech | 11.10.2023

Researchers in China used stem cells to facilitate the first live birth of a chimeric monkey, but the one "success" survived for only 10 days. The ethics of developing human-monkey chimeras and the potential for animal suffering make the research ethically complex.

The Gates Foundation's new Al initiative: attempting to leapfrog global health

inequalities?

Jonathan Shaffer, Arsenii Alenichev, and Marlyn C. Faure, BMJ Global Health | 11.03.2023 The Gates Foundation is launching Al large language models in low- and middle-income countries in an effort to improve livelihoods, but the unfettered imposition of these tools into already fragile and fragmented healthcare delivery systems risks doing far more harm than good.

California becomes first state to ban use of 'excited delirium' as cause of death Sam Levin and Maanvi Singh, The Guardian | 10.10.2023

Used disproportionately to explain the deaths of Black and Latinx people in police custody, "excited delirium" has "an ignoble history linked to racism and fraudulent forensic science," commented CGS fellow Osagie Obasogie. California is the first state to ban its use as a cause of death.

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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