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CENTER FOR GENETICS AND SOCIETY

BioPolitical News&Views

June 20, 2023

SPOTLIGHT

Journalistic Hype of Investigator Hype?

Pete Shanks, *Biopolitical Times* | 06.19.2023

Media coverage of a research team's announcement regarding their development of human embryo-like models through reprogramming embryonic stem cells frames the advance as "groundbreaking," but other scientists are more skeptical.

ANNOUNCEMENTS

Welcome, Ananya, and thanks, Coby!

CGS would like to welcome our incoming summer intern, Ananya Roy! Ananya is a 2023 **Collective Rising Intern** and currently studying Sociology and Women, Gender, and Sexuality Studies at the University at Albany. We also extend our appreciation to outgoing intern, Coby Havazelet, for all of his work this spring!

ELSI Friday Forum: Population Descriptors in Genomic Research: Applying the NASEM Recommendations

July 14, 2023 at 12:00 pm ET

In a conversation moderated by CGS Advisory Board member Dorothy Roberts, authors of the recent National Academies report on the use of racial categories in genomics research will discuss: What are population descriptors? How can their selection entrench typological thinking and undermine scientific rigor? How can we better align the appropriate use of population descriptors with genomic research objectives? Register **here**.

CGS IN THE NEWS

Derrière l'intelligence artificielle, le retour d'utopies technologiques

Alexandre Piquard, *Le Monde* | 06.13.2023

Tech sector leaders including Sam Altman and Elon Musk are adopting Promethean—even messianic—tones, and promoting ideas inspired by transhumanism and long-termism, which many consider dangerous. Marcy Darnovsky notes that ideas about transhumanism and "tailor-made" babies with selected genes resonate both among Republicans and Democrats.

COMMENTARY

Lab-made gametes in the clinic: Who would benefit? Who should decide?

Alana Cattapan, Guest Contributor, *Biopolitical Times* | 06.19.2023

Concerns about reproductive autonomy, justice, and our responsibilities to future generations ought to be at the forefront of any discussion of reproductive technologies, including in vitro gametogenesis.

CGS collaborates with advocates and scholars on genetic justice

CGS Staff, *Biopolitical Times* | 06.14.2023

From the gene editing summit to our recent webinar, CGS has been even busier than usual in the first half of 2023. We are delighted to announce that our efforts have been recognized by the Ford Foundation with a grant supporting our work challenging eugenics and fostering disability inclusion in society.

WHAT WE'RE READING

HERITABLE GENE EDITING | ARTIFICIAL GAMETES AND EMBRYOS | GENE THERAPIES GENOMICS | EUGENICS | ASSISTED REPRODUCTION | SURROGACY360 | VARIOUS

HERITABLE GENE EDITING

His baby gene editing shocked ethicists. Now he's in the lab again

John Ruwitch, *NPR* | 06.08.2023

Disgraced researcher He Jiankui is attempting to rehabilitate his reputation, setting up a new lab to develop gene therapies for Duchenne muscular dystrophy. Critics are concerned, given his past gene-editing transgressions and lack of medical expertise.

Why we can almost guarantee that genetic enhancement will never be

fairly distributed

Sinead Prince, *Journal of Medical Ethics Blog* | 06.06.2023
Even if genetic enhancements were effective and could be distributed equally, disparities would persist. In fact, inequalities would be exacerbated by improving the genes of those already privileged with positive environments.

The best books on genetic engineering (including CRISPR) and designer babies

Françoise Baylis, *Shepherd* | 06.02.2023
Bioethicist Françoise Baylis shares her picks for the best books exploring the ethical and societal implications of using CRISPR in human reproduction.

The Disability Rights Critique of Technologies that Eliminate Human Genetic Variation

Rosemarie Garland-Thomson, *ELSIhub* | 04.12.2023
Increasingly routine practices of prenatal genetic testing and selective reproduction, along with advances in human gene editing, raise questions about whether and how these techniques discriminate against people with disabilities.

ARTIFICIAL GAMETES AND EMBRYOS

Most advanced synthetic human embryos yet spark controversy

Philip Ball, *Nature* | 06.16.2023
Two teams of scientists have announced that they have grown embryo-like structures, made entirely from human stem cells, that are more advanced than any previous efforts. They raise ethical and legal questions about the status of such ‘embryo models’ and how they should be regulated.

Synthetic human embryos created in groundbreaking advance

Hannah Devlin, *The Guardian* | 06.14.2023
Scientists have created synthetic, early-stage human embryos using stem cells instead of gametes. Although there is no near-term prospect of the synthetic embryos being used clinically, the work raises serious ethical and legal issues.

‘Embryo Models’ Challenge Legal, Ethical and Biological Concepts

Philip Ball, *Quanta Magazine* | 06.13.2023
Advances in the creation of early-stage synthetic embryos generate new potential uses that would bring many new ethical and legal questions, which current regulations do not address.

Alliance for Humane Biotechnology White Paper: Opposing Laboratory Manufacture of Children from Gamete-like Cells

Alliance for Humane Biotechnology | 06.07.2023
This white paper critiques the April 2023 US National Academies of Sciences workshop on in vitro gametogenesis and concludes that IVG should be opposed.

Creating a sperm or egg from any cell? Reproduction revolution on the horizon

Rob Stein, *NPR* | 05.27.2023
At a workshop organized by the US National Academies of Sciences, dozens of scientists, bioethicists, doctors, and others discussed the latest scientific advances in lab-created gametes, and explored the technology’s potentially far-reaching thicket of social, ethical, moral, legal and regulatory ramifications.

GENE THERAPIES

The quest for the era of personalised medicine

David Cox, *BBC* | 06.04.2023

In theory, personalized gene therapies should be more effective and have fewer side effects. In practice, personalized medicine can be erratic and expensive, and often there are simpler solutions.

High on Selling Hope, Less So on Production of Revolutionary Therapies

David Jensen, *California Stem Cell Report* | 06.04.2023

Developing cutting-edge therapies is an enormously expensive task: the $12 billion CA stem cell and gene therapy program has yet to finance an approved stem cell or gene therapy treatment during its 18 years of work, despite the expenditure of $3.5 billion from CA taxpayers.

'It's a vote for hope': first gene therapy for muscular dystrophy nears approval, but will it work?

Sara Reardon, *Nature* | 06.02.2023

Later this month, the FDA will decide whether to grant fast-track approval to the first gene therapy for Duchenne muscular dystrophy, which would allow the drug to reach the market before large clinical trials are completed.

Rich Horgan spearheaded a gene therapy for his brother. The trial ended in tragedy, but the work continues for more patients

Ryan Cross and Jared Whitlock, *Endpoints News* | 05.23.2023

After his brother Terry Horgan's death, Rich Horgan intends to continue developing custom gene therapies that could benefit other people with rare diseases.

Gene Therapy in the Womb Is Inching Closer to Reality

Max G. Levy, *Wired* | 05.22.2023

Researchers are testing new techniques for delivering gene therapies in utero on lab animals. One delivery technique shows that these therapies, when injected, could risk accidental germline edits.

The FDA just approved rub-on gene therapy that helps "butterfly" children

Antonio Regalado, *MIT Technology Review* | 05.19.2023

The FDA approved a new gene therapy ointment that provides a missing gene to skin cells so they can make collagen. It is the first gene therapy for sale that is applied to the outside of a patient's body and the first intended to be used on the same person repeatedly.

GENOMICS

Cells, Not DNA, Are The Master Architects Of Life

Alfonso Martinez Arias, *Noema* | 05.30.2023

A shift in our understanding of how we are made and who we are is underway: Genes, rather than determining every detail of biology, are integrated into the activity of cells.

Sought Out by Science, and Then Forgotten

Jennie Erin Smith, *The New York Times* | 05.23.2023

Four decades ago, medical researchers reached out to ailing families in Colombia because they hold clues to genetic modifiers of, and potential treatments for, Huntington's disease. Yet they remain cut off from experimental treatments, genetic counseling, and often basic medical care.

Benchtop DNA printers are coming soon—and biosecurity experts are worried

Robert F. Service, *Science* | 05.11.2023

Advances in DNA synthesis technology will offer any lab the chance to buy a benchtop DNA printer that can make DNA on demand, heightening concerns that malign actors could synthesize DNA to make a powerful toxin or pathogen.

EUGENICS

A major group of family genealogists apologizes for past racism

Sydney Trent, *The Washington Post* | 05.31.2023

One of the nation's oldest and largest genealogical societies apologized for its history of racism, which includes a eugenicist founder, Joseph Gaston Baillie Bulloch, and early resistance to integration.

Eugenics influenced the formulation of the European Convention on Human Rights

Torsten Hjelmar, *The European Times* | 05.27.2023

The concept of 'unsound mind' has its roots in eugenic thinking and has supported discrimination against people with disabilities. Marius Turda argues that "it is therefore highly problematic to continue to use this expression in the Convention on Human Rights."

What Can Feminists Make of the Eugenicist History of Abortion?

Erika Rodriguez, *Minnesota Women's Press* | 05.24.2023

Rather than using the history of abortion and eugenics as a justification for restricting abortion, we should interrogate the lingering ties between abortion and eugenics and ask ourselves: How can reproductive justice also be disability justice?

ASSISTED REPRODUCTION

Israel to transfer all IVF to public hospitals after Assuta scandals

Judy Siegel-Itzkovich, *Jerusalem Post* | 05.22.2023

Israel's Health Ministry wants to transfer responsibility for IVF from private hospitals to public hospitals after multiple mix-ups at Assuta Medical Center in Tel Aviv.

England's first not-for-profit fertility clinic closes within a year of opening

Helen Pidd, *The Guardian* | 05.21.2023

England's first not-for-profit fertility clinic, which promised to offer IVF at cost price and to only perform evidence-based procedures rather than unproven "add-ons" promoted by some private clinics, has shut within a year of opening.

SURROGACY360

Georgia to ban surrogacy for foreigners

Nini Gabritchidze, *Eurasianet* | 06.13.2023

The country of Georgia, which recently became an international surrogacy hub, moved to ban surrogacy for foreigners. The Prime Minister cited safety concerns for surrogates and children and trafficking risks, and expressed sentiments discriminatory toward same-sex couples.

Ukraine Considers Surrogacy Regulations In

Wartime

Ellen Trachman, *Above the Law* | 05.31.2023
In April 2023, the Ukrainian parliament considered and ultimately rejected legislation that would have paused surrogacy arrangements with foreign intended parents during wartime.

VARIOUS

The Who, Where, and How of Regulating AI

Eliza Strickland, *IEEE Spectrum* | 06.15.2023
The rapid development of artificial intelligence has brought new efforts in the European Union, the U.S., Canada, Brazil, and China to regulate it.

Transhumanism and Neuralink: the dawn of digitally enhanced humans

Neil C. Hughes, *Cybernews* | 06.10.2023
Elon Musk's Neuralink has FDA approval to initiate a clinical trial of its brain implant technology, an exciting development for transhumanists—but an alarming one for those concerned about the implant's many potential pitfalls.

Inside the quest to engineer climate-saving "super trees"

Boyce Upholt, *MIT Technology Review* | 06.08.2023
A Silicon Valley startup is using genetic modification to increase the carbon uptake of trees, but questions remain: how will these trees affect the rest of the forest? How far will their genes spread? And how good are they at pulling carbon from the atmosphere?

AI in medicine needs to be carefully deployed to counter bias – and not entrench it

Ryan Levi and Dan Gorenstein, *NPR* | 06.06.2023
New AI health tools are being used to help clinicians diagnose breast cancer, read X-rays, and predict which patients need more care, but they risk perpetuating long-standing racial inequities in how care is delivered.

New AI tool searches genetic haystacks to find disease-causing variants

Mark Johnson, *The Washington Post* | 06.01.2023
Scientists have developed an AI tool that sifts through millions of differences in a person's genetic blueprint to detect those that threaten health.

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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