

May 16, 2023

SPOTLIGHT ////



First UK Babies Born after "Three-Person IVF": Why all the secrecy?
Pete Shanks, *Biopolitical Times* | 05.15.2023

The secretive way in which this controversial human experimentation has been conducted raises disturbing issues and many unanswered questions. It is past time for the details to be examined by experts and published for all to see.

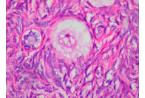
ANNOUNCEMENTS

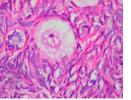
Ford Foundation

CGS receives grant from the Ford Foundation

The Center for Genetics and Society is delighted to announce a two-year core support grant from the Ford Foundation to fund our work challenging eugenics and fostering disability inclusion in society. The CGS team deeply appreciates this generous recognition of our efforts to bring disability rights and a range of social justice perspectives to the ongoing public and policy deliberations about emerging reproductive and genetic technologies.

COMMENTARY







Katie Hasson, Biopolitical Times | 05.16.2023

At a recent National Academies workshop on in vitro gametogenesis, experts from a range of fields commented on the fast-developing science and potential uses in assisted reproduction. Predictably, the overall tone was one of approval, despite the significant technical challenges and concerns about equity and social justice.

CGS provides comments to National Council on Disability about heritable gene editing

CGS Staff, Biopolitical Times | 05.15.2023

"When perspectives and concerns from disability communities and other social justice communities are not put at the center of public and policy discussions of germline editing, the conversations will continue to be shaped by false assumptions, ableism, and eugenic legacies."

CGS IN THE NEWS

Beyond IVF: Scientists debate ethics of human reproduction without egg and sperm

Karen Weintraub, USA Today | 04.23.2023

Although making artificial gametes—even a new person—from skin or blood cells would have grave social implications, some scientists are working to advance the technique. CGS' Katie Hasson observed, "The profit potential and the push to commercialize these technologies can be a big motivation."

WHAT WE'RE READING

GENE THERAPIES | HERITABLE GENOME EDITING | GENOMICS | EUGENICS ASSISTED REPRODUCTION | SURROGACY360 | VARIOUS

GENE THERAPIES

Gene therapy for muscular dystrophy stirs hopes and controversy

Rob Stein, NPR | 05.02.2023

A company that developed a gene therapy for Duchenne muscular dystrophy is asking the FDA for accelerated approval without direct evidence that it's actually helping to alleviate symptoms and prevent disease progression.

A new era for treating sickle cell disease could spark a health-care revolution

Carolyn Y. Johnson, The Washington Post | 04.28.2023

Long overlooked by the medical establishment, sickle cell patients are now at the center of gene therapy innovation. Researchers are testing CRISPR therapies on small numbers of patients in the hopes of receiving FDA approval.

The gene-therapy revolution risks stalling if we don't talk about drug pricing

Editorial, Nature | 04.25.2023

The promises of gene therapy are threatened by their high price tag. Patients can't afford them, and governments are reluctant to fund their development.

Delivering Revolutionary Cell/Gene Therapies to the Underserved, Creating More Accessibility

David Jensen, The California Stem Cell Report | 04.24.2023

Although California's stem cell agency aims to support development of affordable and accessible gene therapies, its funding requirements exclude most institutions in rural and remote areas, intensifying inequalities in access to costly therapies.

HERITABLE GENOME EDITING

The ethics, equity, and governance of human genome editing need greater consideration

Sarojini Nadimpally, The BMJ | 05.03.2023

Genome editing must be subject to public engagement and debate on its ramifications through an ongoing process of discussion, deliberation, and debate involving a diverse spectrum of people with definitive knowledge, perspective, communication, and power.

What Happened to Concerns About Human Enhancement?

R. Jean Cadigan, Margaret Waltz, Rebecca Walker, Rami Major and Incidental Enhancements Research Group, *The Hastings Center: Bioethics Forum* | 04.25.2023

Largely left off the program at the Third International Summit on Human Genome Editing, enhancement asserted itself as a concern, and rightly so: using CRISPR for enhancement raises grave concerns and deserves more scrutiny.

Gene Genies?

Jane Clinton, Camden New Journal | 04.13.23

The Francis Crick Institute's exhibition Cut + Paste examines genome editing, but makes no mention of Crick's embrace of eugenics.

Can gene editing kill deadly diseases?

Colin Baker, Al Jazeera | 04.11.2023

"Embryo editing is not just jumping into a swimming pool without knowing it has water," Fyodor Urnov said. "It's doing so blind-folded, head down, with nobody watching. The risks that are already known that we cannot mitigate are so severe that to even tempt human beings with this idea, it's unethical."

GENOMICS

Panel urges caution in tying sexual orientation, education levels to genes

Jocelyn Kaiser, Science | 04.25.2023

Genomics studies that attempt to make "group comparisons" based on genetic links to social outcomes such as income and education and to traits such as intelligence exacerbate the harmful—and incorrect—social narrative about differences between racial groups.

'It totally backfired': The pitfalls of Alzheimer's genetic testing

Julie Steenhuysen, Reuters | 04.22.2023

Genetic testing for the gene variant that increases Alzheimer's risk is becoming more common, but there are few support services to help people deal with the implications of the test results.

Widespread Newborn DNA Sequencing Will Worsen Risks to Genetic Privacy

Crystal Grant, *ACLU* | 04.19.2023

Despite police misuse of biological data from newborns in the U.S., researchers have proposed sequencing newborns' full genomes. More regulation is needed to protect the privacy of infants and their families.

EUGENICS

Hundreds of forced sterilization survivors are owed money from California. Only a handful have received it

Phil Barber, The Press Democrat | 05.03.2023

More than a year after the state approved reparations for survivors, the California Victim Compensation Board has approved just 80 applications, less than 20% of the number it had received. Some cite limited outreach to explain the low number of survivors who have applied for compensation.

Opponents need to stop equating abortion with eugenics

Carla Hall, Los Angeles Times | 05.01.2023

There is a long, horrible history of eugenics policies in the United States, but eugenics values are not what motivate the 21st century reproductive rights movement. In fact, abortion bans, like eugenics, rob women of their choice of whether to bear children, and disproportionately impact poor women, particularly women of color.

A Short History of Eugenics: From Plato to Nick Bostrom

Chris Wiggins and Émile P. Torres, Truthdig | 05.01.2023

Longtermism — an ideology promoted by tech billionaires like Elon Musk and increasingly embraced by influential figures within major governing bodies such as the United Nations — is another iteration of eugenics.

'Hipster eugenics': why is the media cosying up to people who want to build a super race?

Arwa Mahdawi, The Guardian | 04.21.2023

Self-proclaimed 'pro-natalists' don't go around saying that they only want white babies, but there's a thin line between their movement and the 'great replacement theory.' The loudest voices in the movement are clearly only pro people like themselves being born.

Eugenics after the Nazis? The Evolution of a Problematic Discipline

Christos Konstantopoulos, The Collector | 04.27.2023

Although the term eugenics is most closely associated with the Nazis, eugenics neither started nor ended with World War II. Rather, modern eugenics was gradually phased out and ingeniously reinvented, allowing it to survive past 1945 in new forms: forced sterilization, and now, gene editing.

Why Silicon Valley is bringing eugenics back

Paris Marx, Disconnect | 04.21.2023

Eugenics has a long history in Silicon Valley, and the triad of effective altruism, longtermism, and pronatalism is bringing it back. Elon Musk is arguably the most visible face of its resurgence.

ASSISTED REPRODUCTION

lan Sample, The Guardian | 05.09.2023

A Newcastle clinic has been approved to use the experimental IVF technique in 30 cases since 2019. The risky procedure has led to less than 5 successful births.

New Programs Allow Women To Freeze Their Eggs For Free—As Long As They Donate Half Of Them

Kristine Thomason, Women's Health | 04.27.2023

The money women receive for donating their eggs is framed as compensation for time and effort, but it often functions as "egg selling." While freeze-and-share programs sidestep cash questions, they introduce other ethical concerns.

Man Who Has Fathered Hundreds Is Barred From Donating Sperm

Claire Moses, The New York Times | 04.28.2023

A court in the Netherlands banned a man who fathered at least 550 children in the past 16 years and lied to prospective mothers and fertility clinics from donating more sperm.

America's first IVF baby is pitching a way to pick the DNA of your kids

Antonio Regalado, MIT Technology Review | 04.26.2023

A startup says it will assess embryos created in IVF clinics for their future chance of common diseases and then rank them, so parents can pick the one with the best future. Critics call it "consumer eugenics."

When Freezing Sperm Makes a Patriotic Statement

Emma Bubola, The New York Times | 04.18.2023

Ukrainian soldiers who want to give their wives a way to have children even if they die are freezing their sperm. Ukraine's Parliament is debating a bill that would let them do so at the state's expense.

SURROGACY 360



On Surrogacy, a Top Israeli Feminist Does the Nonfeminist Thing

Hagar Shezaf, *Haaretz* | 05.08.2023 Although advances make it possible for more people to have children via surrogacy, proper protections are needed to ensure

VARIOUS

Bringing back woolly mammoths and dodos is a bad idea

Dayton Martindale, Vox | 04.26.2023

De-extinction not only distracts from conservation priorities, but also harms individual animals: both the surrogate parents and newborn clones face risks of suffering and trauma. They are instruments in a research project of unclear benefit.

that surrogates are not exploited.

Duke Has Quietly Discontinued a Costly, Unproven Autism Treatment Anna Merlan, Vice | 04.17.2023

Duke University is discontinuing its controversial program that charges parents high fees to treat their autistic children with unproven stem cell and cord blood techniques. But a for-profit stem cell clinic with murky ties to Duke seems poised to take its place in offering the treatments.

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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