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SPOTLIGHT

Deletions of Concern: Noninvasive Prenatal Screening and Disability, Part One

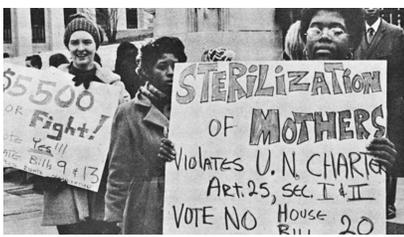
Award-winning author George Estreich returns to *Biopolitical Times* to reflect on prenatal tests and the assumptions that shape their use—along with the world in which people with disabilities, and the people who love them, have to live. What has changed in the years since the tests were introduced? Where are the silences in the conversation?

ANNOUNCEMENTS

“New Perspectives on Eugenics,” a Twitter conference

From January 31 to February 4, H-Eugenics is hosting “New Perspectives on Eugenics,” with presentations in the form of tweet threads and Q&A at scheduled times. On Friday, Feb. 4 at 11 am ET, CGS Associate Director Katie Hasson will present from the [@C_G_S Twitter account](#) on missing voices in the discussions about heritable genome editing. Learn more [here](#) and follow the conference hashtag #HNet_Eugenics2022.

COMMENTARY



Social Justice Coalition Key to Success in California's New Sterilization Compensation Program

Emily Galpern, *Biopolitical Times* | 01.26.22

The key to getting California's new \$7.5 million Forced or Involuntary Sterilization Compensation Program funded was the strength and breadth of the coalition of reproductive justice, disability rights, criminal justice, and allied organizations working for budget allocation.

WHAT WE'RE READING

GENOME EDITING | GENOMICS | ASSISTED REPRODUCTION
EUGENICS | XENOTRANSPLANTATION | VARIOUS

GENOME EDITING

On the road to treating mitochondrial disease

Danielle Gerhard, *Drug Discovery News* | 01.24.2022

Recent advancements in mitochondrial genome editing take scientists one step closer to developing viable treatments for mitochondrial diseases.

Going bald? Lab-grown hair cells could be on the way

Antonio Regalado, *MIT Technology Review* | 01.18.2022

Biotechnology startups are using cell reprogramming technology to transform ordinary cells into hair-forming cells. A stem cell technology to treat hair thinning and baldness could capture a lucrative market that currently has few effective treatments.

New infographic highlights ethical issues 'on the horizon' in biology and medicine

The Nuffield Council on Bioethics | 01.13.2022

An interactive infographic anticipates upcoming developments and debates in human genome editing, forensic DNA phenotyping, whole genome sequencing of embryos and fetuses, and genome editing in farm animals.

GENOMICS

Their DNA Hides a Warning, but They Don't Want to Know What It Says

Gina Kolata, *The New York Times* | 01.21.2022

Some researchers who sequence DNA believe they have an obligation to notify study participants with gene variants that increase the risk for certain medical conditions. Some research subjects feel they have a right not to know.

Voluntary workplace genomic testing: wellness benefit or Pandora's box?

Kunal Sanghavi, Betty Cohn, Anya E. R. Prince, et al., *npj Genomic Medicine* | 01.20.2022

Genetic testing is becoming a popular addition to workplace wellness programs. Proponents cite the potential to lower employer healthcare costs, but some critics are concerned about the potential for discrimination and abuse.

NHS pilots genetic testing to predict risk of heart disease

[Hannah Devlin](#), *The Guardian* | 01.17.2022

An NHS pilot program will combine non-genetic risk factors with a polygenic risk score to identify individuals at highest risk of a heart attack or stroke. Some geneticists are concerned that the tests could lead to "genetic fatalism," and that they could further healthcare inequalities because they are less accurate for those with minority ancestries.

ASSISTED REPRODUCTION

'Unproven and unethical': experts warn against genetic embryo tests

[Linda Geddes](#), *The Guardian* | 01.25.2022

Representatives from the European Society of Human Genetics have warned against the "unproven" and "unethical" use of polygenic risk scores to screen IVF embryos. They stressed that there is no evidence that the technique, currently being offered by U.S. companies, can predict the risk of developing complex diseases like schizophrenia, type 2 diabetes, or breast cancer.

Some egg donor agencies advertise \$275,000 paychecks on social media — but the rigorous process is a far cry from making a 'quick buck'

[Hannah Towey](#), *Business Insider* | 01.23.2022

Ads targeting young women emphasize how lucrative it can be, but these ads can be misleading. The process of egg donation involves a series of screening tests, hormone injections, surgery, and monitoring—and the long-term risks of egg donation are unknown.

Sperm donation is largely unregulated, but that could soon change as lawsuits multiply

[Naomi Cahn and Sonia Suter](#), *The Conversation* | 01.18.2022

Sperm banks in the United States have escaped federal regulation, but states including New York and Connecticut are working to fill the gaps by requiring sperm banks to collect and verify donor information.

EUGENICS

Disabled People Can Still Be Forcibly Sterilized in Over Half of the US

Rewire News | 01.25.2022

A report by the National Women's Law Center reveals that 31 states explicitly allow the forced sterilization of disabled people, and 17 states allow disabled children to be forcibly sterilized. The report advocates for laws that allow disabled people to make reproductive decisions themselves.

White nationalists are flocking to the US anti-abortion movement

[Moira Donegan](#), *The Guardian* | 01.24.2022

This year's March For Life rally in D.C. revealed a growing cohort of explicitly white supremacist groups within the anti-choice movement. This is part of a broader project to ensure white hegemony and women's subordination, a connection with roots in the early twentieth-century eugenics movement.

The legacy of eugenics at U.Va

Jack Morgan, *The Cavalier Daily* | 01.17.2022

In the first half of the twentieth century, eugenic science was a required course in the University of Virginia's biology department. Now, the university is contending with its historical embrace of eugenics, from the University's founder Thomas Jefferson to former president Edwin Alderman, who recruited scientists from across the country to establish a hub for eugenic science.

XENOTRANSPLANTATION

Kidneys From a Genetically Altered Pig Are Implanted in a Brain-Dead Patient

Roni Caryn Rabin, *The New York Times* | 01.20.2022

Surgeons announced that they had successfully transplanted kidneys from a genetically modified pig into a 57-year-old brain-dead man. The lead surgeon hopes that pig kidney transplants will help address the kidney shortage crisis.

Xenotransplantation: Three Areas of Concern

L. Syd M. Johnson, *The Hastings Center Bioethics Forum* | 01.19.2022

Although xenotransplantation is a promising solution to organ shortages, we should be concerned about several issues with this emerging field: the potential to spread pathogens, exploitation of human research participants, and animal welfare.

Here are some questions about the pig heart transplant that people actually should be asking

Arthur Caplan, Laura Kimberly, Brendan Parent, and Tamar Schiff, *The Washington Post* | 01.14.2022

What data suggested that it would now be safe enough to try a pig heart in a living human? Why was this patient chosen and what was he told? What support will he receive to manage life post-transplant? Who else signed off on the transplant?

VARIOUS

A \$3bn bet on finding the fountain of youth

The Economist | 01.22.2022

Altos Labs, an anti-aging research company, has plenty of funding (\$3 billion), but no clear product. Altos founders have gathered a team of experts that is heavy on Nobel Laureates (including CRISPR co-discoverer Jennifer Doudna), with the hope that their collaboration will eventually produce viable commercial possibilities.

What's Wrong with the FDA?

Shannon Brownlee and Jeanne Lenzer, *Washington Monthly* | 01.20.2022

The FDA's 2021 approval of the proven-to-be-ineffective Alzheimer's drug Aduhelm points to deeper problems with the agency. Cozy relationships with the companies it regulates and dependence on industry funding weaken its regulatory power. Robert Califf, the FDA's new commissioner, has numerous ties with the pharmaceutical industry.

Rejuvenation by controlled reprogramming is the latest gambit in anti-aging

Michael Eisenstein, *Nature Biotechnology* | 01.19.2022

Partial reprogramming of somatic cells reconfigures gene expression networks in mice, thus reversing age-related cellular features. Altos Labs is one of many start-ups aiming to develop this research.

Deregulating GMOs in the UK

GMWatch | 01.19.2022

A new report finds that the UK's Department for Environment, Food and Rural Affairs failed to adequately consider public opinion in its public consultation. The government proceeded with deregulation of genetic editing, despite the majority of respondents expressing a preference for continued regulation.

Artificial intelligence can discriminate on the basis of race and gender, and also age

Charlene Chu, Kathleen Leslie, Rune Nyrup, and Shehroz Khan, *The Conversation* | 01.18.2022

Artificial intelligence systems exhibit biases based not only on race and gender, but also on age. Researchers and developers should acknowledge risk of ageism and develop safeguards against it.

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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