CENTER FOR GENETICS

BioPolitical News&Views

December 14, 2023

SPOTLIGHT



Scientists Still Can't Be Trusted on Gene Editing Pete Shanks, The Progressive Magazine | 12.04.2023

Five years on from the shocking discovery of He Jiankui's rogue gene editing experiment, some scientists continue to forge ahead with heritable genome editing. With more indications than ever that scientists can't be trusted on heritable gene editing, public discussion and calls for a moratorium or ban are increasingly urgent.

ANNOUNCEMENTS



Sharing our gratitude

We are so grateful for the overwhelming support our CGS community showed this Giving Tuesday. We raised nearly **\$6,000** to power the fight for genetic justice! Our end-of-year giving campaign is off to a great start. Can you help propel us into 2024 with a donation today?

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CGS IN THE NEWS

A look at the international race to create human eggs and sperm in the lab

Rob Stein, Regina G. Barber, Berly McCoy, *NPR* | 11.29.2023 "Combining [lab-made gametes] and genome editing and commercialization" is a "toxic stew" that would "create people...



supposedly biologically superior to others. We don't want to pave the road toward any kind of future that looks anything like that," said CGS' Marcy Darnovsky.

COMMENTARY



CRISPR therapies heading to the clinic

Katie Hasson, *Biopolitical Times* | 12.13.2023 Approval of the first CRISPR-based gene therapy in the US and UK shows the promise of gene editing to treat patients—and highlights big questions about safety, effectiveness, and access that remain.

WHAT WE'RE READING

GENE EDITING | EUGENICS ASSISTED REPRODUCTION | SURROGACY360 | VARIOUS

GENE EDITING

Gene therapy offered this 7-year-old freedom. The price: a grueling year

Brittany Trang, STAT | 12.13.2023

A newly developed gene therapy for beta thalassemia is described as a "one-time" infusion. The treatment process is arduous and lengthy, though, requiring months in the hospital, a course of chemotherapy, and isolation from others to let the immune system recover.

The ethical dilemma of gene editing: Our reporter took your questions

Carolyn Y. Johnson, The Washington Post | 12.12.2023

Linking to a CGS blog post by Pete Shanks, Johnson notes that "multiple rounds of international meetings have reaffirmed that gene editing is not ready to make heritable edits. Many countries have outlawed heritable gene editing."

New Sickle Cell Therapies Will Be Out of Reach Where They Are Needed Most

Rebecca Robbins and Stephanie Nolen, *The New York Times* | 12.08.2023 There is no clear path for African patients to get access to the treatments, which have multimilliondollar price tags and are highly complex to manufacture and deliver.

New gene therapies confront many sickle cell patients with an impossible choice: a cure or fertility

Megan Molteni, STAT | 12.06.2023

The recently approved CRISPR gene therapy that has been shown to cure sickle cell disease involves chemotherapy treatment, which comes with high risks of sterility for patients.

I received the new gene-editing drug for sickle cell disease. It changed my life.

Jimi Olaghere, *MIT Technology Review* | 12.04.2023

One participant in the clinical trial for the newly approved gene therapy said that his physical symptoms "disappeared overnight" and that he gained "the confidence that sickle cell disease won't take me away from my family, and a sense of control over my own destiny."

The first CRISPR cure might kick-start the next big patent battle

Antonio Regalado, MIT Technology Review | 12.01.2023

Vertex, the company that developed the newly approved therapy for sickle cell disease, doesn't own the US patent on editing human cells with CRISPR, and will likely face a lawsuit from the patent holders asking for royalties from the therapy and possibly damages.

The CRISPR Era Is Here

Sarah Zhang, The Atlantic | 11.27.2023

The approval of a CRISPR gene therapy for sickle cell disease is a landmark advance for gene therapies. However, the long-term durability and safety of gene editing are still unknown.

UK first to approve CRISPR treatment for diseases: what you need to know

Carissa Wong, Nature | 11.16.2023

In a world first, the UK medicines regulator approved a therapy that uses the CRISPR–Cas9 geneediting tool as a treatment. The therapy will treat the blood conditions sickle-cell disease and beta thalassaemia.

A Single Infusion of a Gene-Editing Treatment Lowered High Cholesterol

Emily Mullin, Wired | 11.14.2023

In an initial test on 10 people with an inherited condition that causes high LDL cholesterol, CRISPR editing in the liver reduced cholesterol. The overall safety of the treatment remains unknown.

EUGENICS

Would you do it if you could? Advanced DNA testing for embryos is here — and it's fraught.

Carey Goldberg, The Boston Globe | 12.07.2023

Nearly three quarters of respondents to a Harvard survey worry that the use of genetic screening for embryo selection could amount to eugenics, set up false expectations for a child, and exacerbate inequality.

New England Journal of Medicine reckons with its racist past and complicity in slavery

Usha Lee McFarling, STAT | 12.06.2023

In a series of essays, independent historians reflect on the role of the journal in perpetuating racist thinking in medicine that continues to this day.

Superintelligent AI — Transhumanism etc

Madhumita Murgia and John Thornhill, *Financial Times* | 12.05.2023 Some tech entrepreneurs and engineers attempting to advance artificial general intelligence adhere to transhumanist ideologies that rely on a eugenicist and racist foundation.

Pentagon Scientists Discuss Cybernetic 'Super Soldiers' That Feel Nothing While Killing In Dystopian Presentation

Matthew Gault, VICE | 12.01.2023

Pentagon officials at a military conference discussed future "super soldiers" enhanced with synthetic blood, night-vision eye drops, and pain-numbing stimulants. One speaker "hint[ed] that America's enemies were doing eugenics to create better pilots."

ASSISTED REPRODUCTION

'I couldn't believe this act of kindness': how Black women trying to get pregnant create their own healthcare networks

Cynthia R. Greenlee, The Guardian | 12.11.2023

Black women face higher rates of infertility and additional barriers to accessing reproductive technologies that could help them have children. Many turn to mutual aid groups to navigate these challenges.

Call to help UK IVF patients donate unused embryos after shortage hinders research

Hannah Devlin, The Guardian | 12.06.2023

Responding to the sharp decrease in IVF embryos donated for research over the past 15 years, some UK scientists are calling for a change in the law to make it easier for people undergoing IVF to donate unused embryos for research.

Why Anonymous Sperm Donation Is Over, and Why That Matters

Emily Bazelon, The New York Times Magazine | 12.03.2023

Some donor-conceived activists are advocating for government bans on anonymous gamete donation, but some LGTBQ parents worry that disclosure laws could undermine LGBTQ families, in part by opening the door to biological donors being recognized as parents.

SURROGACY360



Ministers approve plans to recognise international surrogacy for first time

The Irish Times | 12.12.2023

The Irish government passed legislation recognizing international surrogacy, both retrospectively and in the future. The law specifies a process intended parents must go through and a set of criteria for surrogacy arrangements. It also establishes a new regulatory agency.

VARIOUS

White House targets drug patents in latest effort to lower prices

Washington Post Staff, Washington Post | 12.07.2023 The White House has proposed a new plan to lower drug prices: if the federal government determines that a manufacturer has set the price of a drug too high, regulators could step in to license the drug to a competing manufacturer.

Data Breach at 23andMe Affects 6.9 Million Profiles, Company Says

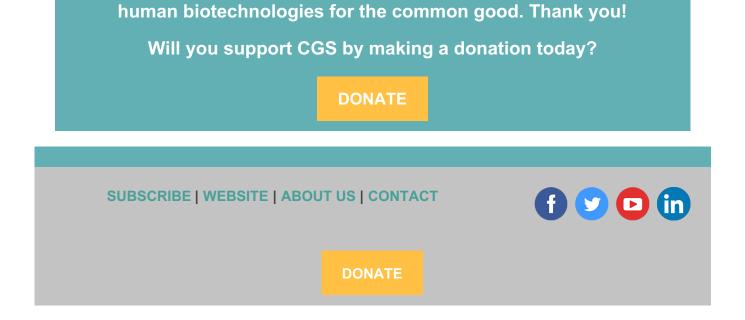
Rebecca Carballo, *The New York Times* | 12.04.2023 The genetic testing company 23andMe reported that hackers gained access to personal information and genetic relatedness data from 6.9 million profiles — about half of its customers.

Food and farming business experts: Food Standards Agency consultation on "precision-bred" GMOs is misleading and flawed

Staff, GMWatch | 11.21.2023

In a formal complaint to the UK's Food Standards Agency, a group of experts from business, farming, academia, science and civil society raised serious concerns about its public consultation process on genetically modified "precision bred" organisms.

If you've read this far, you clearly care about the fight to reclaim



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