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News&Views

January 13, 2022

SPOTLIGHT

We're starting 2022 with profound gratitude for your generosity. We set an ambitious year-end fundraising goal – and you came through big time.

In 2021, we raised \$16,350 from 53 supporters and colleagues – over 50% more than any previous year! (If you'd like to add your contribution, we would be delighted.)

With big plans and an uncertain road ahead, your vote of confidence is especially meaningful. All of us at CGS are honored and bowled over by your support.



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Tomorrow! Jan. 14 ELSI Panel on Ensuring Equitable Use of New Genetic Technologies

CGS Senior Fellow and UC Berkeley Law professor Osagie Obasogie will moderate a discussion with Emily Klancher Merchant and Lisa Dive about new genetic technologies that have altered the landscape of human reproduction and how the study of eugenics can help us understand them. Registration and more information [here](#).

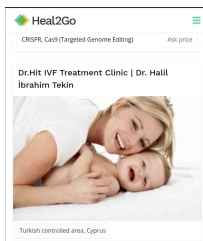
COMMENTARY

Tests Predicting Rare Disorders In Fetuses Are Usually Wrong

By SARAH KLIFF and AATISH BHATTIA

After a year of fertility treatments, Yael Geller was thrilled when she found out she was finally pregnant in November 2020. Following a normal ultrasound, she was confident enough to tell her 3-year-old son his "brother or sister" was in her belly. But a few weeks later, as she was driving her son home from school, her doctor's office called. A prenatal blood test indicated her fetus might be missing part of a

shows no signs of the condition screened positive for. Ms. Geller had been misled by a wondrous promise that Silicon Valley has made to expectant mothers: that a few vials of their blood, drawn in the first trimester, can allow companies to detect serious developmental problems in the DNA of the fetus with remarkable accuracy. In just over a decade, the tests have gone from laboratory experi-



What the Backlash against the NYT Investigation of Prenatal Testing Gets Wrong

Pete Shanks, *Biopolitical Times* | 01.13.2022

Criticism of the investigative reporting about cfDNA testing for rare conditions was at best overblown. The article raised important issues and demonstrated how commercial interests can lead to confusion. This may presage even more significant issues in an area that badly needs much more vigorous oversight.

A Further Note on the Upcoming Human Genome Editing Summit

Katie Hasson, *Biopolitical Times* | 01.13.2022

The Third International Summit on Human Genome Editing has been postponed to 2023. Hopefully, the organizers will use the extra year to expand inclusion of civil society and social justice voices. CGS is organizing to bring attention to social justice and human rights arguments for prohibiting human genome editing, at the Summit and beyond.

Remembering Marsha Saxton

Emily Galpern, *Biopolitical Times* | 01.13.2022

The Center for Genetics and Society mourns the loss of colleague Marsha Saxton, who died December 1, 2021. Marsha was a founding scholar of disability studies at the University of California, Berkeley and published numerous books and articles, including significant contributions to CGS' work.

Marketing GM Babies in Turkish Cyprus?

Pete Shanks, *Biopolitical Times* | 01.12.2022

A major concern for years has been "rogue fertility clinics" that could offer to create genetically modified babies. Eben Kirksey may have found some.

Some Notable 2021 Blog Posts

Biopolitical Times | 12.31.2021

Following an annual *Biopolitical Times* tradition, we present a selection of our favorite posts of the past year. These provide just a taste of what's available in our archive.



WHAT WE'RE READING

PRENATAL GENETIC TESTING | GENOME EDITING | ASSISTED REPRODUCTION |
EUGENICS | GENOMICS | STEM CELLS | AGRICULTURE

PRENATAL GENETIC TESTING

When They Warn of Rare Disorders, These Prenatal Tests Are Usually Wrong

[Sarah Kliff and Aatish Bhatia](#), *The New York Times* | 01.01.2022

Analysis of data from multiple studies showed that positive results on the five most common microdeletion tests are incorrect about 85 percent of the time. Some doctors may not understand how poorly the tests work. And some patients may still be inclined to believe the results, leading to unnecessary terminations. The F.D.A. does not regulate this type of test.

How Widespread Prenatal Testing for Microdeletions Can Hurt Patients and Why the Genetic Testing Industry Needs More Accountability

[Katie Stoll](#), *Gene Cuisine* | 01.04.2022

The results of the *New York Times* investigation into patients' experience with these screenings are disheartening, and unfortunately are also consistent with what we have seen through our work at Genetic Support Foundation. People deserve accurate and unbiased information about these tests before deciding whether to undergo them.

The Questions We Should Really Be Asking After Reading the NY Times Article About Prenatal cfDNA Screening For Microdeletions

[Robert Resta](#), *The DNA Exchange* | 01.08.2022

Criticism of the article glosses over hard but fundamental questions such as: Should we test for any condition prenatally? Realistically is there any purpose beyond selective termination? What criteria should be used? Who decides? What message does expanding genetic testing send to people with disabilities, their families, and their advocates?

GENOME EDITING

First sickle cell patient treated with CRISPR gene-editing still thriving

[Rob Stein](#), *NPR* | 12.31.2021

Victoria Gray has been doing so well for so long, over two years, that she's officially no longer in the landmark study she volunteered for. The plan was that her own bone marrow cells, edited and infused back, would produce a protein known as fetal hemoglobin, alleviating the symptoms of sickle cell. And it appears to have worked, for her and at least 22 of 45 patients.

ASSISTED REPRODUCTION

Whose baby is this? IVF mix-ups & other reasons to change the law

[Ellen Trachman](#), *TEDx Video* | 01.08.2022

What happens when people freeze embryos or gametes, but they get divorced or one dies? What if egg and sperm samples get mixed up? What if an embryo is implanted in the wrong woman? Attorney Ellen Trachman explains why our reproductive laws need to change – and how prospective parents can protect themselves and their families in the meantime.

A Popular Test Claims to Boost I.V.F. Success. The Science Is Unclear.

Amy Klein, *The New York Times* | 12.18.2021

Endometrial receptivity analysis takes a biopsy of the interior lining of the uterus, which is analyzed for more than 200 genes and purportedly used to predict the best time to implant an embryo. The test is not approved by the F.D.A., costs up to \$1,000, and according to recent research does not help.

Rushing Quebec's Bill 2 risks leaving many voices unheard

Alana Cattapan, Vanessa Gruben, Stefanie Carsley and Angela Cameron, *CTV News* | 12.14.2021

The bill reimagines Quebec's parentage laws, regulates surrogacy, and seeks to provide rights to information about their genetic origins for adoptees and children born from sperm and egg donation. It also introduces very controversial rules about identity documents for trans and non-binary individuals. This important legislation requires a robust participatory process.

EUGENICS

Does it really matter if you win or lose the genetic lottery?

Joseph L. Graves Jr., *The Lancet* | 01.01.2022

This review of *The Genetic Lottery: Why DNA Matters for Social Equality* by Kathryn Paige Harden concludes that the book fails to make a convincing case for advancing progressive social movements with genetic analysis rather than with universal health care, meaningful employment, and cleaning up the physical environment.

California Will Compensate Survivors of Eugenics' Forced Sterilizations

S.E. Williams, *Black Voice News* | 01.03.2022

Survivors can visit www.victims.ca.gov/fisc, call 800-777-9229, email fiscp@victims.ca.gov, or write to P.O. Box 591, Sacramento, CA 95812-0591 for a confidential application, accepted through Dec. 31, 2023. Compensation will not impact a survivor's Medicaid or Social Security status or benefits and will not be considered income for state tax purposes or for community property, child support, restitution or a money judgment.

GENOMICS

Sickle Cell Math Is Brutally Simple, but Not Widely Taught

Gina Kolata, *The New York Times* | 12.28.2021

An inexpensive blood test can warn couples if they face one in four odds of having a baby with the disease. No one ever told Lametra Scott and Rickey Buggs about it. Both carried the trait and their son has the disease. To help confront sickle cell's fraught history, Dr. Scott has founded a nonprofit, Breaking the Sickle Cell Cycle, to spread information and work for a cure.

Your DNA Test Could Send a Relative to Jail

Rafil Kroll-Zaidi, *The New York Times Magazine* | 12.27.2021

Solving crimes with the help of genomic databases is becoming mainstream — with some uncomfortable implications for privacy. Even genetic genealogy pioneer CeCe Moore concedes that the notion of individual "consent" doesn't address the problem, since revealing your DNA profile is a decision that affects everyone to whom you're biologically related.

STEM CELLS

Stem cell agency: Following the money — and its performance

David Jensen, *Capitol Weekly* | 12.17.2021

The California Institute for Regenerative Medicine will hand out \$519 million in awards in this fiscal

year. It plans to “establish a statewide manufacturing network” to accelerate the commercialization of research it has financed, while focusing on equity and inclusion. Success will require making good bets about the science and a generous dollop of luck.

AGRICULTURE

The USDA’s new labeling for genetically modified foods goes into effect Jan. 1. Here’s what you need to know.

Laura Reiley, *The Washington Post* | 01.01.2022

The agency’s new rules do away with terms like ‘GMOs’ and build in several loopholes. Andrew Kimbrell, executive director of the Center for Food Safety, estimates that consumers will “have to spend four times as much time in the supermarket reading labels” and become “USDA citizen investigators to make sure this law has some consequences.”

How Biotech Crops Can Crash — and Still Never Fail

Aniket Aga and Maywa Montenegro de Wit, *Scientific American* | 12.27.2021

The U.N. Food Systems Summit failed to recognize that a narrow focus on technology to address the complex structural problems of farming and food has an astonishingly poor track record. The global community must support agroecology focused on biodiversity and farmers’ knowledge within a framework of human rights, peasant rights, and food sovereignty.

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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