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CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL VIEWS & NEWS

March 9, 2017

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Announcements

Commentary

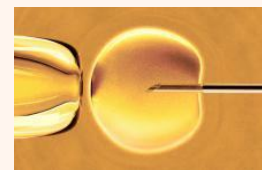
CGS in the News

News

ANNOUNCEMENTS

Critical Reactions to Report on Human Gene Editing

Media coverage of [Human Genome Editing: Science, Ethics, and Governance](#), released by the National Academy of Science and National Academy of Medicine on February 14, appropriately highlighted the report's recommendations to permit gene editing for human reproduction under certain circumstances. Critical comments by CGS and others were included in some 30 articles in newspapers, magazines, journals and websites including [The New York Times](#), [Washington Post](#), [Science](#), [Gizmodo](#), [The Scientist](#), and [Forbes](#). Many of these comments pointed to the report's radical departure from the concluding statement after the December 2015 [International Summit on Human Gene Editing](#), also organized by the National Academies, which stated that it would be irresponsible to proceed with human germline modification unless and until a "broad societal consensus" had been reached.



Included in this newsletter are CGS's press statement and blog post on the report, along with several representative news articles about it.

CGS COMMENTARY

The Center for Genetics and Society Comments On New Human Gene Editing Report

Press Statement

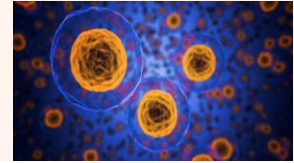
Permitting human germline editing for any reason would likely lead to its escape from regulatory limits, to its adoption for enhancement purposes, and to the emergence of a market-based eugenics that would exacerbate already existing discrimination, inequality, and conflict. We need not and should not risk these outcomes.



[Opening the Door to Genetically Engineered Future Generations: How the NAS Report Ignores Widespread International Agreement](#)

by Leah Lowthorp

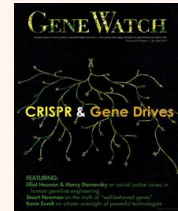
The report represents the first time that human germline modification has ever been given a green light, radically departing from a long-standing international consensus that interventions in the human germline should remain off limits.



[Social and Political Dangers of Human Germline Interventions](#)

by Marcy Darnovsky and Elliot Hosman, *GeneWatch*

We need not risk a never-ending repro-genetic upgrade cycle that threatens to split human society even more dramatically than our current tolerance for inequality already allows.



[Editing Humans](#)

by Marcy Darnovsky, *Bioscience Technology*

Children whose families could afford “genetic upgrades” would likely be perceived by parents and teachers as superior, with all-too-predictable results.



- TOP -

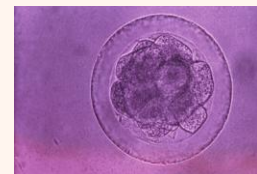
CGS in the NEWS

[Scientific panel says editing heritable human genes could be ok in the future](#)

[citing CGS' Marcy Darnovsky]

by Rob Stein, *NPR*

What used to be science fiction and far-off hypotheticals have now become urgent social justice questions,” says Marcy Darnovsky, who runs the Center for Genetics and Society, a genetic watchdog group. “But actually, right now, I think they’re urgent social justice questions.



[Egg Freezing for Millennials: The Latest Start-up Trend](#)

[citing CGS' Marcy Darnovsky]

by Angelina Chapin, *New York Magazine*

Medical companies are marketing prolonged fertility as freedom, creating the illusion that this procedure is a piece of cake.



[California's stem cell program ponders a future of challenges and old promises](#)

[citing CGS' Marcy Darnovsky]

by Michael Hiltzik, *Los Angeles Times*

It won't be long before CIRM must confront the question of whether to fold up shop when its well runs dry, seek outside funding from foundations and industry,



or appeal to voters for more public money.

NEWS

Gene Editing, CRISPR ETC.

Assisted Reproduction Technology

Genetic Testing

GMOs

Various

GENE EDITING, CRISPR ETC.

▶ [Human Germline Genome Editing: An 'Impressive' Sleight of Hand?](#)

by Françoise Baylis, *Impact Ethics*

While the authors of the 2017 report are moved by the desire of some to have genetically-related children, others are not similarly convinced that this should be an important consideration in decision-making about the permissibility of germline editing.

▶ [DIY Gene Editing: Fast, Cheap—and Worrisome](#)

by Amy Dockser Marcus, *The Wall Street Journal*

The Crispr technique lets amateurs enter a world that has been the exclusive domain of scientists.

▶ [The US is cracking down on rogue genetic engineers](#)

by Kristen V. Brown, *Gizmodo*

The FDA proposed a new rule that would require any genetically engineered animal go through a strict regulatory procedure.

▶ [Broad Institute prevails in heated dispute over CRISPR patents](#)

by Sharon Begley, *STAT*

Although today's molecular biologists, especially those doing genome editing, have a good idea of who made which seminal discoveries, the patent decision will likely shape how history views the CRISPR pioneers.

ASSISTED REPRODUCTION TECHNOLOGY

- News TOP -

▶ [Could we one day make babies from only skin cells?](#)

by Kelly Murray, *CNN*

"IVG takes us into uncharted territory, so it's hard to say legal issues that might come up," [Paul Knoepfler] said, adding that "even other more extreme technologies, such as cloning, of the reproductive kind are not technically prohibited in the US."

▶ [Surrogacy babies born in Cambodia stuck in limbo waiting for visas to leave for Australia](#)

by Lindsay Murdoch, *Sydney Morning Herald*

The Cambodian government is refusing to issue exit visas for all surrogacy cases where the newborn babies have a foreign passport, in a developing human crisis in the country.

▶ [Regulating the donor-conception industry in the US](#)

by Wendy Kramer, *BioNews*

As a response to the current lack of oversight, in January 2017 the Donor Sibling Registry submitted a [Citizen's Proposal](#) to the FDA.

GENETIC TESTING

- News TOP -

▶ [The Privacy Delusions of Genetic Testing](#)

by Peter Pitts, *Forbes*

Customers are wrong to think their information is safely locked away. It's not; it's getting sold far and wide. Many testing firms that generally don't sell patient information, such as Ambry and Invitae, give it away to public databases. Such transfers, as privacy consultant Bob Gellman puts it, leave a "big gap in protections."

▶ [It's easy money: Lab offers doctors up to \\$144,000 a year to push dubious genetic tests, employees say](#)

by Charles Piller, *STAT*

As a result of regulatory loopholes, Proove and others in this multi-billion dollar industry have grown rapidly by tapping into the public angst and touting personalized DNA-based tests backed by little or no credible scientific data.

▶ [The Next Pseudoscience Health Craze Is All About Genetics](#)

by Kristen V. Brown, *Gizmodo*

Scientists are skeptical that we've decrypted enough about the human genome to turn strings of As, Ts, Cs and Gs into useful personalized lifestyle advice.

▶ [SDPD Finds a Way Around State Law Limiting DNA Collection From Juveniles](#)

by Kelly Davis, *Voice of San Diego*

The ACLU has filed a lawsuit challenging the department's DNA collection policies, arguing that juveniles can't provide informed consent especially if being coerced by police, and questioning which juveniles are being targeted.

▶ [Conflicting views on a wider police use of DNA](#)

by Eli Rosenberg, *The New York Times*

Many see familial searching in police DNA databases as an invasion of privacy that draws an innocent group of people into criminal inquiries, and disproportionately impacts communities of color.

▶ [Secrets of life in a spoonful of blood](#)

by Claire Ainsworth, *Nature*

Researchers are pushing to sequence entire fetal genomes based on a blood draw from the mother early in pregnancy. But they are struggling to interpret the data this yields, and are facing knotty ethical quandaries. What, for example, should doctors do if they find a DNA sequence that sometimes causes disease — but not always?

GMOs

▶ [Next generation genetically modified foods need better regulation](#)

by Dana Perls, *STAT*

Researchers are tinkering with nature's DNA in new and potentially problematic ways and without clear regulatory guidance.

▶ [Just One Small Problem With This Major Report on GMO Safety](#)

by Tom Philpott, *Mother Jones*

Researchers allege undisclosed conflicts of interest on a National Academies of Sciences panel.

VARIOUS

- News TOP -

▶ [Henrietta Lacks' family wants compensation for her cells](#)

by Andrea K. McDaniels, *Baltimore Sun*

"My mother would be so proud that her cells saved lives," Lawrence Lacks said in a statement. "She'd be horrified that Johns Hopkins profited while her family to this day has no rights."

▶ [How mammoth cloning became fake news](#)

by John Hawks, *Medium*

"Science clickbait is fake news. Today I count 65 stories, mostly repeating the same stupid mistakes."

▶ [Eugenics and the outer limits of good breeding](#)

by Juliana Edelman, *The Irish Times*

We should not think that eugenics or eugenical ideas have disappeared. Indeed, in some ways they have taken more insidious and subtle forms and are now intermingled with ideas about race and xenophobia.

▶ [Is the 'Anthropocene' Epoch a Condemnation of Human Interference -- or a Call for More?](#)

by Wesley Yang, *New York Magazine*

Technologists have turned what began as a call for radical austerity into a renewed push for significant technological advances.

▶ [Trump's travel ban is already stopping scientific collaboration](#)

by Chelsea Whyte, *New Scientist*

The effects of the ban on the scientific community may be more far reaching than disrupting travel plans for individuals. "Freedom of communication is essential for science to function," says the CEO of the American Association for the Advancement of Science.

▶ [Trump's 2018 budget will squeeze civilian science agencies](#)

by David Malakoff, *Science*

The chunk of the federal budget that includes most of the U.S. government's spending on basic science may shrink by 10.5% in 2018.

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