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BIOPOLITICAL VIEWS & NEWS

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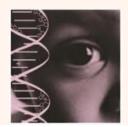
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ANNOUNCEMENTS

California Senate Considers Expanding the Market in Women's Eggs

The California Senate will vote soon on a fertility industry-sponsored bill that would overturn existing safeguards for women who provide eggs for research. The bill, AB 2531, would incentivize procedures that expose women to substantial short-term and unknown long-term health risks. It is opposed by women's health, reproductive rights and justice, and public interest organizations, including the Center for Genetics and Society.



<u>National Academies' Human Gene Editing Initiative: Public Meeting on Race, Religion</u>

Should CRISPR gene editing tools be used in human embryos prior to birth to re-engineer genes? The question is being addressed by the Human Gene Editing Initiative of the US National Academies. On July 12, the Initiative held the fourth meeting of its Consensus Study committee, which focused on "race and genetics in US history, and the intersection of moral views and public policy." Speakers on the agenda included Alondra Nelson, Keith Wailoo, NIH director Francis Collins, and Ronald Cole-Turner. We livetweeted the event using #GeneEditStudy and collected our favorites here.



Fall Internships Available

The Center for Genetics and Society is accepting applications for Fall internships. Please click here for the complete intern announcement.



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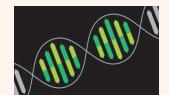
CGS COMMENTARY

Pro and Con: Should Gene Editing Be Performed on Human Embryos?

by Marcy Darnovsky, National Geographic

John Harris: "Research on Gene Editing in Humans Must Continue."

Marcy Darnovsky: "Do Not Open the Door to Editing Genes in Future Humans"



<u>The Case Against Public Investment in Reproductive Genetic</u> **Modification**

by Jessica Cussins, *Biopolitical Times* guest contributor Philosopher Tina Rulli argues that three-person IVF is not a "life-saving medical therapy."



Editorial Precision? Snapshot of CRISPR germline in the news

by Hasmik Djoulakian

Five questions about how the media talks about germline editing.



Frozen Eggs and Heated Debates

by Angel Petropanagos, *Biopolitical Times* guest contributor What's missing and what's misrepresented in public debates about social egg freezing?



The Direct-to-Consumer Stem Cell Industry in the US

by Pete Shanks

There are more stem-cell clinics than anyone suspected, and it's not clear that they are operating with proper supervision.



Puffing Cryonics in New Scientist?

by Pete Shanks

New Scientist is a popular science magazine that sometimes prioritizes popularity over science.



Two Decades After Dolly

by Pete Shanks

20 years after the first cloned mammal was born, the US still does not have legal prohibitions on cloned people, or on heritable human genetic modification.



CGS in the NEWS

Should we pay women to donate their eggs for research? No, and

here's why.

[citing CGS' Marcy Darnovsky, fellow Lisa Ikemoto]

by Michael Hiltzik, The Los Angeles Times

The risks of egg retrieval, particularly long-term risks, are not yet understood due to a lack of studies.

Bill to expand market in women's egg donations would undermine

safeguards

[citing CGS]

by Deborah Ortiz, Sacramento Bee

Let's not repeal a law that safeguards the health of women. We can support biomedical research without putting women's health at risk.

Sustainable Week: Fixing Our Broken Moral Compass

[citing CGS' Elliot Hosman]

by Chuck Stern, BTRtoday

Who decides what is good and bad, what is that person or entity's agenda?

What Ever Happened to Cloning?

[citing CGS' Marcy Darnovsky]

by Kimberly Leonard, US News & World Report

Twenty years since Dolly, the field of cloning remains highly inefficient for animals and too unethical to attempt with humans.

NEWS

No One Should Edit The Genes Of Embryos To Make Babies, NIH Chief Says

by Nidhi Subbaraman, BuzzFeed

Opponents of germline gene editing have strong concerns about both the safety and social consequences of altering reproductive cells.

► Considering Gene Editing

by Jef Akst, The Scientist

"Given the world as we know it, germline genetic enhancement could exacerbate the already obscene gap between the 'haves' and the 'have nots."

Do CRISPR enthusiasts have their head in the sand about the safety of gene editing?

by Sharon Begley, STAT

Off-target effects and other concerns around genome editing should be taken more seriously.

Human Enhancement Freaks People Out, Study Finds; Designer Babies Might 'Meddle With Nature'

by Ed Cara, Medical Daily

Survey reveals more wariness than excitement for genetic technologies that would 'enhance' people.

▶ We're on the cusp of a gene editing revolution, are we ready?

by Editorial, New Scientist

Fast-moving genetic technologies may be on the road to outpacing public acceptance and debate.

In Juno patient deaths, echoes seen of earlier failed company

by Sharon Begley, STAT

"Both companies...had only a superficial, almost cartoonish, understanding of how [the experimental therapy] works at the cellular level. And now three people are dead."

► FDA Lets Cancer Trial Resume after 3 Patient Deaths

by Damian Garde, STAT

After only two days, the FDA accepted Juno Therapeutics' reason for the deaths and allowed the trial to continue.

Why gene-therapy drugs are so expensive

by N.L., The Economist

British pharmaceutical company GSK announced it will charge US\$665,000 for a gene therapy for ADA-SCID (aka "bubble boy disease").

► NY Times: Fresh and Major Attention to Immunotherapy and Cancer

by David Jensen, California Stem Cell Report

The New York Times unveiled a dramatic special report on gene therapy and immunotherapy to treat cancer.

▶ Peter Thiel Is Very, Very Interested in Young People's Blood

by Jeff Bercovici, Inc.

The controversial venture capitalist believes transfusions may hold the key to his dream of living forever.

Can this woman cure ageing with gene therapy?

by Dara Mohammadi & Nicola Davis, The Guardian

Elizabeth Parrish has tried out her company's anti-aging gene therapy, but the biology of aging may be more complicated than we understand.

► Gene Editing: The Dual-use Conundrum

by Janet Phelan, New Eastern Outlook

The office of the Director of National Intelligence declined to comment further on the inclusion of gene editing as a potential "weapon of mass destruction."

Fresh concerns raised over controversial 'three parent baby' therapy which aims to eliminate inherited disease

The Irish Examiner

Research has shown adverse effects on metabolism and lifespan, among other concerns.

First he pioneered a new way of making life. Now he wants to try it in people

by Karen Weintraub, STAT

"If someone were to proceed with [three-person IVF] now, my own view is that's probably irresponsible."

▶ It's been 20 years since Dolly. Where's my clone?

by Sharon Begley, STAT

Cloning some animals is much harder than cloning others.

► Resumed stem cell study

by Editorial, The Korea Times

Cloning-based stem cell research in Korea is set to resume, and will use nearly 600 human eggs.

NIH Plans To Lift Ban On Research Funds For Part-Human, Part-Animal Embryos

by Rob Stein, NPR

The agency is proposing to permit scientists to get federal money to make human-animal chimeric embryos under carefully monitored conditions. (Public comment until September 4.)

Stem Cell Therapies Are Still Mostly Theory, Yet Clinics Are Flourishing

by Gina Kolata, The New York Times

570 clinics in the United States are offering untested stem cell therapies.

Hwang Woo-suk's stem cell aspirations fail again

by Chung Hyun-chae, The Korea Times

A Korean agency has rejected the registration of disgraced scientist Hwang

Woo-suk's stem cell line, citing a lack of evidence that it was created through somatic cloning.

<u>'False Hopes, Sizable Profits' -- The Nation's Largely Unregulated</u> Stem Cell Clinics

by David Jensen, California Stem Cell Report

"The clinics use hope as a marketing tool. A weapon," writes Paul Knoepfler.

▶ FDA should stand firm on stem-cell treatments

by Editorial Board. Nature

Regulation of stem cell treatments is critical, given that many of the treatments don't even work.

Craig Venter's Latest Production

by Arlene Weintraub, *MIT Technology Review*For now, at least, it's "only the rich who can pay right now for genome sequencing."

THE HACKS WE CAN'T SEE: What Can a Hacker Do with Your Genetic Information?

by Kaleigh Rogers, VICE Motherboard

People might become vulnerable if hackers access genetic information through genetic testing databases.

▶ 23andMe data points to genes affecting depression risk

by Malcolm Ritter, Associated Press

But hundreds of genes may be at play, and environmental risk factors likely overwhelm genetics.

► Genome Tea Leaves

by Sheldon Krimsky, Los Angeles Review of Books

Over-the-counter genetic tests leave some people knowing they may develop a serious illness but unable to do anything about it.

Sweden's national DNA database could be released to private firms

by Tom Mendelsohn, ARS Technica

The country has a closely guarded registry of every citizen under the age of 43.

One Country's Disturbing Project to Build a Complete DNA Databank of Every Citizen and Foreign Visitor Is Already Underway

by Ava Kofman, Iternet

The Gulf nation of Kuwait plans to build the world's largest DNA database this year.

▶ U.N. rights panel urges Kuwait to amend broad DNA testing law

by Stephanie Nebehay, Reuters

The compulsory DNA testing would be a significant violation of people's privacy.

Can genes really predict how well you'll do academically?

by Daphne Martschenko, *The Conversation*Genetic intelligence research has eugenic histories and may minimize the role of social and political environments.

▶ Who should we believe when it comes to fertility?

New Scientist

Difficult choices over when to start a family are not made any easier by conflicting signals from doctors and fertility clinics.

What No One Tells You About Egg Donors

by Leah Campbelln, Mom.me

The profit-driven egg industry does not take the medical needs of egg donors or their right to informed choice seriously.

Fertility doc Antinori indicted

ASNA

The fertility doctor is charged with forcibly removing eggs from a patient, who told police he bound and sedated her. The doctor has accused her of being a member of ISIS.

► Turning back the biological clock comes at a price

by Rhiannon Lucy Cosslet, The Guardian

Egg freezing is marketed as the answer to precarious young lives yet excludes most of those it claims to help.

Sperm Banks Accused of Losing Samples and Lying About Donors

by Tamar Lewin, The New York Times

Sperm banks are not required to verify information provided by sperm donors.

It's time for a conversation on parental surrogacy rules

by Celine Cooper, Montreal Gazette

Is Montreal inching closer to relaxing or even abandoning its entrenched disapproval of procreative surrogacy?

35 couples used surrogates since new law in place

The Nation [Thailand]

Government agencies will track outcomes for women working as surrogates and children born in surrogacy arrangements, and analyse information on ways to improve regulations.

US firm begins to market Cambodia-based surrogacy service

by Will Jackson & Vandy Muong, *he Phnom Penh Post* Surrogacy Cambodia markets cross-border surrogacy despite the Cambodian government's tacit disapproval..

<u>Uncle Sam Wants You — Or at Least Your Genetic and Lifestyle Information</u>

by Robert Pear, The New York Times

The Precision Medicine Initiative will seek participants from various geographies

and socioeconomic statuses across the country.

► Taking Genomic Data Global

by Elizabeth Woyke, *MIT Technology Review*Precision medicine startups are now focusing on Asia.

The White House Is Pushing Precision Medicine, but It Won't Happen for Years

by Mike Orcutt, *MIT Technology Review*Costs are high and the science is not developed enough.

▶ Roma women share stories of forced sterilisation

by Renate van der Zee, *Al Jazeera [Czech Republic]* The systematic sterilisation of Roma women was state policy in the former Czechoslovakia. The Czech government has rejected a compensation law.

► These People Were Likely Victims of a Swedish Eugenics Institution

by Jordan G. Teicher, *Slate* A photographer highlights the photos of eugenics victims whose stories have been ignored over the years.

► State should settle quickly with eugenics victims

The Lincoln Times-News

The General Assembly has allocated \$10 million for 220 victims, but those funds have yet to be distributed.

In clinical trials, for-profit review boards are taking over for hospitals. Should they?

by Sheila Kaplan, STAT

Commercial IRBs often have conflicts of interest.

Nudging patients into clinical trials

by Bradley J. Fikes, *The San Diego Union-Tribune* Incentives include money and rewards such as iPads.

▶ Price Gouging and the Dangerous New Breed of Pharma Companies

by A. Gordon Smith, *Harvard Business Review*Some pharmaceutical companies prioritize profits instead of research.

► Growing Pains for Field of Epigenetics as Some Call for Overhaul

by Carl Zimmer, The New York Times

Epigenetic marks have been thought to cause illness but that causal relationship has been greatly exaggerated.

