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## **CGS COMMENTARY**

## The Science and Ethics of Genetically Engineered Human DNA

by Pete Shanks

Discussion of germline genetic modification continues, most recently in the House of Representatives Research and Technology Subcommittee, Committee on Science, Space, and Technology.

# UK Seeks Regulatory Advice for "Mitochondrial Replacement," Fails to Mention Cross-Generational Implications

by Jessica Cussins

How does one go about regulating the world's first cross-generational biological experiment in human germline modification? The regulating body in charge isn't exactly sure.



## No Más Bebés: A Documentary on the Sterilizations of Latina Mothers at an LA County Hospital

by Jonathan Chernoguz

During the late 1960s and early 1970s, some women who went to Los Angeles County-USC Medical Center to deliver their babies went home without the ability to have children again.



#### Reframing

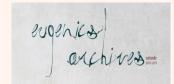
by Pete Shanks

Beth Shapiro is advocating for a new definition of "de-extinction" that stresses the ecological niche over genetic identity. She envisages using novel creatures to change entire ecologies.

#### The Scope

by Jonathan Chernoguz

The four-day workshop, organized by the Edmonton-based Living Archives Project on Eugenics in Western Canada, brought together early-career scholars interested in eugenics to discuss historical models and forms of "Newgenics."



## **NEWS**

## US Science Academies Take on Human-Genome Editing

[Quotes CGS's Marcy Darnovsky]

by Sara Reardon, Nature

The academies will hold an international summit this autumn, and establish a working group to develop a consensus statement.

## Academies Wrestle with Germline Editing

[Quotes CGS's Marcy Darnovsky]

by Alex Philippidis, *Genetic Engineering & Biotechnology News* "We need many Asilomar-type meetings" and participants should include "both scholars and non-scholars — people from public interest organizations of different kinds, labor unions, community groups, and church groups."

#### DNA 'Printing' A Big Boon To Research, But Some Raise

#### Concerns

[With CGS's Marcy Darnovsky]

by Rob Stein, NPR

"Heinz talks openly about everybody being able to create entirely novel creatures... Do we want the teenager next door to be creating Godzilla in the bathtub? I don't want that."

#### A Note on Genome Editing

by John P. Holdren, *Office of Science and Technology Policy*The Administration believes that altering the human germline for clinical purposes is a line that should not be crossed at this time.

#### ► The Lessons of Asilomar for Today's Science

by Alexander Capron, *The New York Times*Four decades ago, concerns about the science of recombinant DNA led to a global moratorium on cutting-edge research.

# National Academies Will Meet to Guide 'Gene Editing' Research

by Lisa M. Krieger, San Jose Mercury News

The landmark conference will gather researchers and other experts. One

observer warns, "This is an ethical, social and human issue, not a technological issue. I don't think the scientists are the right people to be addressing it."

## Why We Need To Talk Now About The Brave New World Of Editing Genes

by Carey Goldberg, WBUR

Suddenly, it's no longer purely science fiction that humankind will have the ability to tinker with its own gene pool. But should it?

#### ▶ Let's Talk About the Ethics of Germline Modification

by Gregor Wolbring, Impact Ethics

We need clarity about where the public discussion should take place, what exactly it should focus on, and who should participate.

#### ► Eugenics Lurk in the Shadow of CRISPR

by Robert Pollack, Science

This opening to germline modification is, simply put, the opening of a return to the agenda of eugenics: the positive selection of "good" versions of the human genome and the weeding out of "bad" versions.

# Francis Collins on CRISPR: "Designer Babies Make Great Hollywood — And Bad Science"

by Julia Belluz, Vox

There's a strong consensus that is a line we should not cross.

# Public Polling on Human Genetic Modification: Mixed, but Favor Moratorium

by Paul Knoepfler, Knoepfler Lab Stem Cell Blog

The results make a case for more inclusion of the public in the dialogue on the use of gene editing in humans.

#### ► The Genome Engineering Revolution

by Ryan Clarke and James Hyun, *Tech Crunch* A brief introduction to the CRISPR-cas9 system.

## Gene Editing of Human Embryos – More Ethical Questions to Answer

by Dr Calum MacKellar, BioNews

It is clear that the safety and efficiency of gene-editing procedures on early embryos give rise to significant biomedical challenges. Ethical questions also need to be addressed.

#### **▶** Does Biotech Need Limits?

by Azeen Ghorayshih, BuzzFeed News

A group of the world's top scientists and bioethicists just got together to hammer out the goals and limits of 21st-century biotechnology. And

some of them really, really don't agree.

#### ► The New Ethical Frontier: DIY Eugenics

by Michael Cook, MercatorNet

A disruptive technology promises both medical advances and moral controversy.

#### ▶ UC, MIT Battle Over Patent to Gene-Editing Tool

by Lisa M. Krieger, San Jose Mercury News

UC Berkeley's Jennifer Doudna filed for a patent first. But in a shocking turn of events, MIT and Zhang won last month, earning the patent that covers use of CRISPR in every species except bacteria.

#### ▶ Regulate Gene Editing in Wild Animals

by Jeantine Lunshof, Nature World View

Unless properly regulated and contained, this research has the potential to rapidly alter ecosystems in irreversible and damaging ways.

# So You're Related to Charlemagne? You and Every Other Living European...

by Adam Rutherford, The Guardian

The advent of cheap genetic sequencing has given birth to a burgeoning ancestry industry. But before you pay to spit in a tube, let me give you a few facts for free.

# Study Reveals Shortcomings in Gene Testing; Results on Estimating Disease Risk Often Conflict

by Marilynn Marchione, Associated Press

The first report from a big public-private project to improve genetic testing reveals it is not as rock solid as many people believe.

#### Weighing The Promises Of Big Genomics

by David Dobbso, BuzzFeed

Your DNA may be up for sale. And the sale depends on an exaggerated picture of genetic power and destiny.

# U.S. Introduces New DNA Standard for Ensuring Accuracy of Genetic Tests

by Robert Pear, The New York Times

The National Institute of Standards and Technology has developed "reference materials" that could be used by laboratories to determine whether their machines and software are properly analyzing a person's genome.

#### ▶ Is DNA the Next Frontier in Privacy?

by Nikhil Swaminathan, Aljazeera America

The president has called for a million people to volunteer their DNA sequences, health records and sensor tracking data, but the government is mum on how it will protect their privacy.

### ► <u>Microbiomes Raise Privacy Concerns</u>

by Ewen Callaway, Nature News

Call it a "gut print." The collective DNA of the microbes that colonize a human body can uniquely identify someone, researchers have found, raising privacy issues.

# The Feminist History of Surrogacy: Should Pregnancy Give a Woman Rights Over a Baby?

by Glosswitch, New Statesman

Our current thinking, with its impulse towards gender neutrality and the insistence that female reproduction isn't inherently different from its male counterpart, is flawed.

## Do Most Women Who Get Fertility Treatments Take on Debt to Do It?

by Neil Shah, Wall Street Journal

Nearly half of women who were going through or had gone through fertility treatments took on over \$10,000 in debt, according to a new survey.

#### ▶ Is it Time to Question the Ethics of Donor Conception?

by Olivia Gordonith, The Telegraph

Donor-conceived children now have the right to identify their genetic parents. But for some, the change came too late, and not knowing can be "excruciatingly painful."

# <u>Unregistered Surrogate-Born Children Creating 'Legal Timebomb', Judge Warns</u>

by Owen Bowcott, The Guardian

Without a court-sanctioned parental order and improved international legal frameworks, children could end up "stateless and parentless."

## ► The Ethics of International Surrogacy

by Anne Schiff, The Jerusalem Post

Sometimes it takes a tragedy to draw public attention to otherwise unconsidered problems. The recent earthquakes in Nepal, and their consequences for Israelis hiring surrogate mothers there, represent such an instance.

#### Fertility Industry in Dire Need of Oversight

by Editorial, The Washington Examiner

Recent clashes highlight the necessity of revisiting the ethical and legal questions at the heart of a business that's based on the creation and

commercialization of human beings.

#### ► U.S. Couple Stuck in Mexico Due to Surrogacy Snafu

by Rafael Romo, CNN

An American couple who say they have been stuck in Mexico for weeks because officials there won't provide a birth certificate for their son believe a resolution could be close.

## Here's a Greek Business That's Booming: Making Test-Tube Babies

by Maria Petrakis, Bloomberg

"There might be a financial crisis, but people will still pay to get a child when they want one."

# <u>Do We Really Need an Even Better Prenatal Test for Down Syndrome?</u>

by Chris Kaposy, Impact Ethics

Because of their ease of use and their non-invasiveness, the new non-invasive prenatal tests for Down syndrome could contribute to increased numbers of selective terminations of pregnancy.

#### ► <u>Stem Cell 'Wild West' Takes Root Amid Lack of US Regulation</u>

by Matthew Perrone, Associated Press

More than 170 US clinics are selling experimental stem cell procedures — a mushrooming industry that has flourished despite little evidence of its safety or effectiveness.

#### ▶ \$15 Million for Calimmune and California Stem Cell HIV Trial

by David Jensen, *California Stem Cell Report*Calimmune, Inc., which has received \$8.3 million from the California stem cell agency, announced it has rustled up another \$15 million to help out with the work that the agency is backing.

## ► The University of Minnesota's Medical Research Mess

by Carl Elliott, The New York Times

Rather than dealing forthrightly with these ethical breaches, university officials have seemed more interested in covering up wrongdoing with a variety of underhanded tactics.

#### Science is Often Flawed. It's Time we Embraced That.

by Julia Belluz and Steven Hoffman, Vox

That science can fail shouldn't come as a surprise to anyone. It's a human construct, after all. And if we simply accepted that science often works imperfectly, we'd be better off.

