

# CGS COMMENTARY

## **CRISPR Research on Human Embryo Development in Context**

#### CGS Press Statement

A paper recently published in Nature describes the use of CRISPR-Cas9 to study the functions of a particular gene involved in very early stages of human embryonic development. Notably, the authors, led by Kathy Niakan of the Francis Crick Institute in London, do not describe their work as seeking to develop gene editing for direct use in human reproduction, in stark contrast to the approach taken in a recent paper by Shoukhrat Mitalipov at the Oregon Health and Science University

## Editing Human Embryos for Research: Do Intentions Matter?

by Katie Hasson, Biopolitical Times

While there are similarities between two recent papers on gene-edited human embryos published in Nature, the differences between them provide a glimpse into different approaches to gene editing research using human embryos, and the repercussions that could follow.

## **Reproductive genome editing and the U.S. National Academies Report:** knocking on a closed door or throwing it wide open?

by Leah Lowthorp and Marcy Darnovsky, Bioethica Forum This commentary outlines some of the main problems with the National Academies' report on human gene editing, and argues that despite presenting its conclusions as cautious, in effect it throws the door open for reproductive human gene editing, with serious implications.

## How Bollywood Stars Are Shaping Assisted Reproduction in India

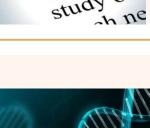
by Ayesha Chatterjee, Biopolitical Times Pop A.R.T. Guest Contributor As more and more Bollywood stars turn to assisted reproductive techniques like surrogacy, popular attitudes in India towards these activities may shift.

#### How Tabloids Use Kim Kardashian Rumors to Misrepresent Surrogacy by Kayla Tolentino, Biopolitical Times

Months after pop-culture superstar Kim Kardashian mentioned her interest in exploring surrogacy during the last season of Keeping Up with the Kardashians,









tabloids are pushing sensationalist stories that misrepresent how surrogacy actually works.

## FDA gives DTC genetic tests a partial restart

by Pete Shanks, Medical Laboratory Observer

Genetic analysis for medical reasons can be critical in some situations, and its utility may grow in the future. But at least for now and probably for the long run, it needs careful regulation. Many believe the recent FDA ruling loosening its restrictions on direct-to-consumer genetic testing goes too far. Surely, the situation bears watchful waiting

# CGS in the NEWS

## Biopower in the Era of Biotech

[citing CGS]

by Jim Kozubek, Los Angeles Review of Books

"The Center for Genetics and Society in Berkeley, California has counted as many as 45 countries that ban germline modification. The United States is not one of them, and instead it handles germline editing in vitro much as it does stem cell research — by prohibiting funding to scientists to do this research and prohibiting funding to the FDA to review applications for clinical trials of CRISPR babies."

## Editing Embryo DNA Yields Clues About Early Human Development

[citing CGS' Marcy Darnovsky] by Rob Stein, *NPR* 

"The concerns are that we would be opening the door to fertility clinics vying to offer gene-editing to make future children taller or stronger or whatever they wanted to market. That could put us into a situation where some children were perceived to be biologically superior to other children."

## Ethical and social implications of gene editing [AUDIO]

[featuring Marcy Darnovsky]

by Malihe Razazan, KALW's Your Call

When should gene editing be used? Who will control it? And how can we make









sure its benefits are available to all? Marcy Darnovsky joins the conversation with UC Berkeley biochemist Samuel Sternberg and KALW host Matt Martin.

## Why Mitalipov's 'magic' room for human embryo CRISPR may give

## us pause

[citing CGS' Marcy Darnovsky] by Paul Knoepfler, The Niche

"There's no way to accurately think through the enormous safety and societal risks of human germline editing without knowing just how weak its medical justification is. You don't need to engineer your future child's genes to avoid passing on serious genetic conditions. The embryo screening technique PGD can accomplish that in pretty close to every situation. Embryo selection itself raises questions about what counts as serious disease and what's just human variation. But the fact is, PGD is safe, effective, and has been available in fertility clinics for decades."

## Who Gets to Be Perfect?

[citing CGS' Marcy Darnovsky]

by Corin Feife, How We Get To Next "Everyone can see that this is a technology that could, literally, reshape human beings, and reshape social relationships," says Darnovsky. "Everyone has a stake in it, so all experts are saying that this is not just a scientific question, it's a political and social question, so we need widespread public participation."

## **CRISPRcon Explores the Future of Gene Editing**

[citing CGS' Marcy Darnovsky]

by Michael Fernandez, George Washington University Food Institute The blurring of lines between disease eradication and genetic enhancement raised the specter of 'designer babies' and significant questions about how we make these decisions. As Marcy Darnovsky, Executive Director of the Center for Genetics and Society pointed out, "This (human genome editing) is a door that is hard to open just a crack - it's not a slippery slope, it's jumping off a cliff."

## NEWS

Human Gene Editing

**DNA Forensics** 

**Assisted Reproduction** 

## **Direct-to-Consumer Genetic Testing**

Various





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## HUMAN GENE EDITING

## Wearing 'Good Genes': Trump & Eugenics

## by Paul Knoepfler, The Niche

Trump hasn't said much of anything about CRISPR 'gene editing' technology that can readily alter the genetic code of cells of nearly any organism, including humans, but Trump has a fascination with the concept of "good genes" that sounds eerily similar to eugenics and could link together CRISPR & eugenics.

## **Genome editing of human embryos broadens ethics discussions**

#### by Françoise Baylis, The Conversation

As genome editing of human embryos becomes more widespread, it is important to understand the differences between one project and the next so that we can meaningfully discuss the range of ethical, social, political and regulatory issues associated with the research.

## Mulling over that Mitalipov human embryo CRISPR pub, still many <u>questions</u>

### by Paul Knoepfler, The Niche

What really happened at the DNA level in the experiments in that high-profile CRISPR of human embryos paper from a team led by Shoukhrat Mitalipov at OHSU? Did the team successfully correct a mutant gene or are their results muddier than they reported, as some scientists have pointed out.

## Canada's Prohibition on Altering the Human Genome

by Françoise Baylis and Alana Cattapan, Impact Ethics

Gene editing developments around CRISPR-Cas9 are leading some in Canada to consider lifting Canada's against human genetic modification as established in the 2004 Assisted Human Reproduction (AHR) Act. But should it be abandoned or strengthened in light of what we know (and don't) with gene editing today?

## New Gene-Therapy Treatments Will Carry Whopping Price Tags

## by Gina Kolata, New York Times

The first gene therapy treatment in the United States was approved recently by the Food and Drug Administration, heralding a new era in medicine that is coming faster than most realize — and that perhaps few can afford.

## Artificial Human Embryos Are Coming, and No One Knows How to Handle Them

by Antonio Regalado, MIT Technology Review

Stem cells can be coaxed to self-assemble into structures resembling human embryos, raising ethics about what, if anything, scientists should to do with these structures that aren't really embryos.

### **DNA FORENSICS**

# Legal Aid Society slams state's familial DNA testing proposal as abuse of power

by Graham Rayman, New York Daily News

#### - News TOP -

The Legal Aid Society is calling out New York State's Commissions on Forensic Science for approving familial DNA searches, calling the move "an abuse of power" that could lead to further over-policing of people of color.

## When Bad DNA Tests Lead to False Convictions

### by Kristen V. Brown, Gizmodo

Most people think of DNA testing as a monolithic, infallible technique. But there are many different kinds of tests—and many different ways of interpreting them. Sometimes, somewhere between the process of collecting evidence at the scene and processing it in the lab, something goes awry.

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by Ann Givens and Robert Lewis, *The Trace* New York City is ramping up its efforts to collect genetic material. But the absence of oversight alarms forensic and legal experts.

## ASSISTED REPRODUCTION

- News TOP -

- News TOP -

Egg donors and surrogates need high-quality care

by Alana Cattapan and Françoise Baylis, *The Conversation* As Health Canada moves forward with the latest regulatory review process for the Assisted Human Reproduction Act, it is critical that all who participate in assisted human reproduction come to be understood as key actors in the use of reproductive technologies.

#### Crackdown on the IVF cowboys after probe reveals financial incentives to entice women into giving away eggs

by Paul Bentley, Sara Smyth, Katherine Faulkner, *Daily Mail* The UK fertility watchdog recently launched a major crackdown on clinics exposed by the *Daily Mail* for exploiting desperate women, censuring doctors after undercover reporters revealed that financial incentives were being used to entice women into giving away their eggs.

# French government pledges to legalise assisted reproduction by 2018

## by Brian Love, Reuters

Lesbian couples and single women rights to have access to assisted reproduction was "a matter of social justice" and will likely be legislated next year, a French government minister has said.

## DIRECT-TO-CONSUMER GENETIC TESTING

## Here's What Happened When A Football Team Decided To Give Out Free DNA Tests

by Stephanie M. Lee, Buzzfeed News

A biotech startup tried to give out free DNA tests at a Ravens game — that is, until the Maryland Health Department stepped in and said no.

## 23andMe's second act sits squarely in drug research and

development

by Sarah Buhr, Tech Crunch

23andMe appeared to double down on its consumer health report effort soon after receiving funding from Seguoia Capital, announcing a new therapeutics division, recruiting Genentech's Richard Scheller to lead the program, and bringing on veteran scientists from the pharmaceuticals industry. 23andMe Is Mining Your DNA For The Next Big Drug. It Just Raised \$250 Million by Stephanie M. Lee, Buzzfeed News After collecting more than 2 million people's DNA and winning hard-fought federal clearances to sell certain health tests, 23andMe has big plans including using its customers' genetic data to develop drugs of its own — thanks to a new round of funding it received from venture capital firm Sequoia Capital. VARIOUS - News TOP -Groundbreaking new California stem cell law gives consumer protections on clinics by Paul Knoepfler, The Niche With more 570 stem cell clinics in the US and more than 100 here in California alone, more efforts like these are needed on the consumer protection and educational outreach front. Four Good Reasons You Should Be Skeptical of the Claim That **Biology Explains Inequality** by Michael White, Pacific Standard Magazine It makes little sense to speculate about innate biological causes of racial and gender inequality, backed by little or no evidence, while downplaying the much more firmly grounded social explanations. Scientists grow bullish on pig-to-human transplants by Kelly Servick, Science Exhilarated by recent results in monkey experiments, some researchers at a meeting of the International Xenotransplantation Association are eyeing human testing. Nobel Prize winners worry about the state of science funding by Deirdre Fernandes, Boston Globe Nobel scientists said the government is tilting toward funding research that targets specific diseases or problems, and is less inclined to finance basic questions, such as how the universe works or what makes the body's clock tick. As Long As It's Healthy by Sarah Michael HollenbecK, Shondaland "What is new about this era is a top-down unkindness. It is the bracing reality that there is no one but us taking care of us. Instead of making a new human, I feel a responsibility to be a better caretaker for the humans who are already here." DONATE NOW BY GROUNDSPRING.org