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BIOPOLITICAL VIEWS & NEWS

December 14, 2017

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### **ANNOUNCEMENTS**

#### Contribute today to strengthen our work

Supporters like you make possible a just future in the genetic age. Please help ensure that the strides we've made together continue. Your gift will be matched by a small group of generous CGS supporters, up to \$5000. Donate today!



### Work with CGS: Summer 2018 internship applications open until January 16

CGS is a host organization for the Reproductive Rights Activist Service Corps (RRASC), a program through which undergraduate students participate in 10-week paid internships. Learn more and apply <a href="here">here</a>.



#### Farewell and appreciations to Victoria Massie

CGS sends a bittersweet farewell to former Communications Coordinator and veteran intern Victoria Massie MA, ABD, as she transitions into completing her dissertation fieldwork in Cameroon. We are thankful for her invaluable contributions to our work.



## <u>Join us January 23: *Talking Biopolitics* with Alondra Nelson and Jenny</u> Reardon

We're kicking off the new year by bringing together two leading scholars to discuss their work on genomics and social justice as part of our *Talking Biopolitics* live webinar series. Alondra Nelson and Jenny Reardon will explore how institutions are responding to histories of racism in which genetics plays a role; the problems of knowledge that living in a genome-oriented world present; and how we can develop new understandings of racism, morality, and genetic justice. Reserve your spot now, by <u>registering!</u>



JANUARY 23 10 am PT/ 1 pm ET/ 6 pm GMT

## Now Available: Video of "Talking Biopolitics with Shobita Parthasarathy and Tania Simoncelli"

Watch this compelling conversation about why and how the politics of patents matter for those committed to social justice, focused on Parthasarathy's recently released <u>Patent Politics: Life Forms, Markets, and the Public Interest in the United States and Europe</u>. A video recording of the event is now available on YouTube, and a written transcript is forthcoming on our website



## CGS presents at the American Association of Pharmaceutical Scientists annual meeting

Hosted by AAPS, CGS Executive Director Marcy Darnovsky was a panelist for a debate and dialogue on "Gene editing in clinical disease: scientific, ethical and societal questions."



#### **Engaging high school thinkers and leaders**

CGS Program Director Katie Hasson spoke to a Palo Alto high school class on biotech and bioethics. To view more CGS classroom presentations from 2017, click <a href="here">here</a>.



### **CGS COMMENTARY**

#### Senate HELP Committee Holds Hearing on Gene Editing Technology

By Katie Hasson, Biopolitical Times

In one of the first Congressional discussions of gene editing and its potential applications, the Senate Health, Education, Labor, and Pensions Committee held a November 14 hearing titled "Gene Editing: Innovation and Impact."



#### **Biopolitical News Highlights of 2017**

By Pete Shanks, Kayla Tolentino, Leah Lowthorp, and Katie Hasson, *Biopolitical Times* 

Here is a brief overview of some of the most important biopolitical developments from this year.



## Nature, Nurture, and Assisted Reproduction: The Musings of a Comics Fan

By Silvia Yee, Pop A.R.T. Guest Columnist

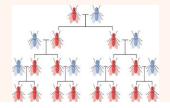
Should we hasten to a future in which our offspring can be the superheroes we dreamed of becoming when we read comics under the blankets with a flashlight? Before we do, let us consider again the notion that superheroes are born that way.



#### **Gene Drive Hits Speed Bump**

By Pete Shanks, Biopolitical Times

The much-touted techno-fix to the problem of invasive species is not ready for use, and not close. But it is still being promoted.



#### Nature Biotechnology Special Focus on "Humans 2.0"

By Katie Hasson, Biopolitical Times

The compilation of these materials by a high-impact journal like *Nature Biotechnology* reflects the importance of the ongoing controversy over modifying the human germline.



#### Ethical principles for the use of human cellular biotechnologies

By Paul Root Wolpe, et al., Nature Biotechnology

This statement, which grew out of the May 2015 conference in Atlanta, Georgia called <u>BEINGS 2015 – Biotech and the Ethical Imagination Summit</u>, was produced over 18 months by some 60 "delegates" (including Marcy Darnovsky) in five topic-specific working groups.



TOP

### CGS in the NEWS

#### **Better Beings?**

[citing CGS' Marcy Darnovsky]

by Amber Dance, Nature Biotechnology

As gene editing technology advances, what questions should we ask before such procedures are contemplated?



#### Parents may one day be morally obligated to edit their baby's genes

[cites CGS' Marcy Darnovsky]

by Tina Hesman Saey, ScienceNews

"We would be inscribing those kinds of social prejudices in biology. We get to very troubled waters very quickly as a society once we start down that road."



### **NEWS**

**Assisted Reproduction** 

**Biohacking** 

**DNA Testing** 

Gene Editing

**Gene Therapy** 

**Various** 

#### **GENE EDITING**

#### Query the merits of embryo editing for reproductive research now

by Insoo Hyun & Catherine Osborn, *Nature Biotechnology*Mitalipov et al.'s study raises many scientific uncertainties and questions. It also brings to light some questionable value assumptions that have largely flown under the radar in the social discourse around embryo editing.

#### ▶ Even if genes affect intelligence, we can't engineer cleverness

by Jim Kozubek, Aeon

In evolution, there are no superior genes, only those that bargain some risk, and a few that are optimal for particular environments and tasks.

#### ► The best and worst analogies for CRISPR, ranked

by Rebecca Robbins, STAT

*STAT* evaluated CRISPR-metaphors based on three questions: Is it creative? Is it clear? And is it accurate?

### Could the Whole CRISPR Patent Kerfuffle Have Been Completely Avoided?

by Kristen V. Brown, Gizmodo

If UC Berkeley and the Broad Institute of Harvard and MIT had adhered to a controversial 1997 US patent rule known as the written description doctrine, the whole mess probably could have been avoided, argue two researchers in *Science*.

#### **GENE THERAPY**

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#### ► Gene Therapy Shows Promise For A Growing List Of Diseases

by Rob Stein, NPR

Many more patients will have to be studied for longer periods before anyone really knows how well the therapies work, how long the benefits last, and whether the therapies are safe.

### Fat stem cells are drugs & more: FDA final guidances point to a new era

by Paul Knoepfler, The Niche

In a major announcement on stem cell policy, the FDA clarified its current thinking on oversight of regenerative medicine and issued four guidance statements, including two each in final and in draft form.

### 9-year-old boy with rare disease now has engineered skin covering 80% of his body

by Melissa Healy, Los Angeles Times

The activity of the corrected cells over the last two years suggests that they will oversee the production of a continuous supply of healthy new cells to heal this young patient's wounds and replace his sloughed-off skin.

#### US scientists try first gene editing in the body

by Marilynn Marchione, Associated Press

In a human trial experiment to treat Hunter syndrome, Sangamo Therapeutics used zinc finger nucleases to edit patients' genes inside their bodies.

#### Scientists use CRISPR to turn genes on without editing their DNA

by Deborah Netburn, Los Angeles Times

For the first time, researchers at the Salk Institute in San Diego were able to use CRISPR to activate beneficial genes in live mice suffering from muscular dystrophy, Type 1 diabetes, and acute kidney injury.

#### Gene therapy shows promise against blood-clotting disease

by Marilynn Marchione, Associated Press

In a recently published study, all 10 men given the therapy now make clotting

factor in the normal range.

#### ► Crispr Therapeutics Plans Its First Clinical Trial for Genetic Disease

by Megan Molteni, Wired

Crispr Therapeutics announced it has asked regulators in Europe for permission to trial a cure for the disease beta thalassemia. The company also plans to file an investigational new drug application with the FDA to treat sickle cell disease in the US in early 2018.

BIOHACKING

## Genetically Engineering Yourself Sounds Like a Horrible Idea—But This Guy Is Doing It Anyway

by Kristen V. Brown, Gizmodo

A few years ago, Josiah Zayner decided to quit the scientific establishment—and a fellowship at NASA—to devote his time to selling inexpensive DIY bio supplies online, seeding the biohacking revolution one made-in-China pipette sale at a time.

# Alarmed by Recent Events, Scientists Speak Out Against DIY Gene Therapy

by Kristen V. Brown, Gizmodo

A recent statement from the American Society of Gene and Cell Therapy expresses concerns that "do it yourself" gene therapies are potentially dangerous and highly unlikely to provide therapeutic benefit.

#### ▶ Why I injected myself with an untested gene therapy

by Jessica Lussenhop, BBC

In hopes of curing HIV, Roberts experimented on himself with hundreds of viewers watching via Facebook Live.

#### **ASSISTED REPRODUCTION**

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### Rep. Trent Franks of Arizona, who asked staffers if they would bear his child as a surrogate, says he will resign

by Mike DeBonis and Michelle Ye Hee Lee, *Washington Post*Franks' announcement came as the House Ethics Committee said it would create a special subcommittee to investigate conduct "that constitutes sexual harassment and/or retaliation for opposing sexual harassment."

### ► Secrets of IVF: high rate of failure and heavy toll on mental health

by Sheila Wayman, Irish Times

"You have a lot of people in the 'hope' business... I just think there could maybe be some more emphasis on acceptance."

#### ► IVF tourism: The Chinese women travelling to Australia for a baby

by Rosemary Bolger, SBS News

Demand for IVF in China has surged since the one-child policy was scrapped, but unmarried women are denied access. This article follows one hopeful mother on her international journey to start a family.

### Investors see big money in infertility. And they're transforming the industry

by Rebecca Robbins, STAT

Sensing a lucrative market, private equity firms are pouring money into building national chains of fertility clinics.

### Fertility treatments are becoming a financial and physical risk for many Americans

by Sophie Bearman, CNBC

As the demand for IVF rises, insurance coverage remains limited.

#### ▶ Veterans with genital injuries aren't getting the care they deserve

by Arthur Caplan, Wendy Dean and Brendan Parent, *Washington Post* Restoring our veterans to lives of hope, dignity, intimacy, individuality and purpose is essential to honoring their service and to our health commitment to those who sacrifice for our country.

#### Russia Considers Ban on 'Immoral' Commercial Surrogacy Industry

by Anastasia Maunilova, News Deeply

Russia's rapidly developing surrogate industry may now grind to a halt, as members of the parliament debate banning the practice.

#### Fertility clinics are fudging IVF stats to look more successful

by Sheila Wayman, Irish Times

Evidence suggests that at least some clinics are finding ways to boost their scores—even if it means "hiding" some IVF cycles, changing the way they treat patients, or turning away people with a low chance of success.

#### **DNA TESTING**

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#### ► Senator calls for more scrutiny of home DNA test industry

by Daniella Silva, NBC News

Senator Chuck Schumer wants the FTC to "take a serious look" at DNA testing companies and their privacy practices.

### Genealogy Companies Say They're Willing to Give Law Enforcement Your DNA

by Angela Helm, The Root

This can't be good for black people—who may over-index on such testing sites because we're so thirsty to find out our ancestry as a result of the trans-Atlantic slave trade.

# I paid \$300 for DNA-based fitness advice and all I got was junk science

by Angela Chen, The Verge

Consumer-genomics company *Helix* promises insights so you can live your best life—but it's little more than genetic astrology.

### More Gut-Wrenching Decisions About Abortion Due to Advanced Prenatal Testing

by Bonnie Rochman, KQED

The ethics of abortion are set to become more complicated as more women have access to powerful genetic tests that identify health risks that are not readily understood.

Argentine woman stolen as a newborn baby 40 years ago by the country's former dictatorship is reunited with her relatives after DNA testing

by Kelly McLaughlin, Daily Mail

Since 1977, the Grandmothers of Plaza de Mayo have fought to recover their stolen grandchildren.

VARIOUS - News TOP -

#### The Dark, Unknown Story of Eugenics in New Zealand

by Tess McClure, Vice

Although the eugenics movement has largely faded from public memory, the ideas were public policy, and at the heart of the developing mental health system for decades.

#### ▶ 'Gene Drives' Are Too Risky for Field Trials, Scientists Say

by Carl Zimmer, New York Times

The principal inventor of gene drives, Kevin Esvelt, created a detailed mathematical model describing what happens after the release of CRISPR-altered organisms. He and his colleagues discovered an unacceptable risk: Altered genes might spread to places where the species isn't invasive at all, but a well-established part of the ecosystem.

## US Military Is Working to Turn Plants Into a Network of Environmental Spies

by David Nield, Science Alert

DARPA launches the Advanced Plant Technologies Program, in hopes of creating a self-sustaining network of plants that can be remotely monitored to detect signs of environmental shifts.

#### ► There's No Such Thing As 'Sound Science'

by Christie Aschwanden, FiveThirtyEight

The sound science tactic exploits a fundamental feature of the scientific process: Science does not produce absolute certainty.

## Choosy Eggs May Pick Sperm for Their Genes, Defying Mendel's Law

by Carrie Arnold, Quanta Magazine

There is a growing realization in biology that the egg is not the submissive, docile cell that scientists long thought it was. Instead, researchers now see the egg as an equal and active player in reproduction, adding layers of evolutionary control and selection to one of the most important processes in life.

