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BIOPOLITICAL VIEWS & NEWS

December 15, 2016

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► Help Build a New Biopolitics

Many thanks for being a reader of *Biopolitical Views & News*. We deeply value your interest in a social justice and public interest perspective on human biotechnologies. As we approach the holiday season, we ask that you consider a year-end <u>contribution</u> to help ensure that these powerful tools are used to support a just and peaceful future.

CENTER FOR GENETICS AND SOCIETY

Warm Welcome and Fond Farewell

We sadly note the departure of Senior Program Associate Elliot Hosman, whom we thank for their invaluable contributions to our work. And we are delighted to announce that Victoria Massie has joined the Center for Genetics and Society as our Communications Coordinator. Learn more about Victoria – and about other CGS staff, fellows, advisors, and consultants – here.



Congratulations

CGS Senior Fellow Osagie K. Obasogie is now a faculty member at UC Berkeley. He is the new chair of the <u>Haas Institute for a Fair and Inclusive</u>

<u>Society's</u> Diversity and Health Disparities research cluster, and <u>Professor of Bioethics</u> in the Joint Medical Program and School of Public Health. Read an interview with Osagie about his new position here.



Work with CGS as a Summer Intern

The Center for Genetics and Society is pleased to announce that it has been selected as a host organization for the Civil Liberties and Public Policy summer internship program. Learn more about the <u>position</u> and the CLPP <u>program</u>. All applications must go through <u>CLPP</u>.



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CGS COMMENTARY

Biopolitical News of 2016

by Pete Shanks, Leah Lowthorp, and Marcy Darnovsky We highlight 2016's trends in and top news stories about human biotech developments.



Trump, Science and Social Justice

by Pete Shanks

President-elect Trump's appointments, so far, are frightening to anyone who cares about science, or social, economic and environmental justice.



Slippery Slopes and Biological Curve Balls: Updates on 3-person IVF

by Leah Lowthorp

There have been several recent setbacks and troubling developments in 3-person IVF technology and applications.



We Comment on UK Decision to Move Ahead with "3-Person IVF"

[Press statement]

The decision is part of a disturbing trend toward the normalization of an experimental technology that is still widely considered unsafe, and whose implications for future generations are unknown.



We Launched a New Website! Surrogacy360

by Kiki Zeldes, Biopolitical Times guest contributor

Surrogacy360 provides accurate information and resources, free of commercial interest, for people considering surrogacy outside the United States.



Review of Blame: A Novel

by Abby Lippman, Biopolitical Times guest contributor Blame is especially important for those unfamiliar with the range of ethical. social, legal, and political issues raised by applications of what is learned in a lab. While a work of fiction, it is definitely not science-fiction.



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NEWS

3 Person IVF Assisted Reproduction Technology

CRISPR Eugenics Gene Testing

Human Germline Modification

Surrogacy

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Trump

► How Will Trump Use Science to Further His Political Agenda?

by Sarah Zhang, The Atlantic

We have a president-elect who appears to believe in his genetic superiority, with a chief strategist who has been reported to believe the same.

Steve Bannon's disturbing views on 'genetic superiority' are shared **by Trump**

by Laurel Raymond, Think Progress

The former Breitbart head's musings on voting restrictions are a dog-whistle to white nationalists. The same goes for his reference to "genetic superiority."

► Who Will Advise Trump on Science?

by Ed Yong, The Atlantic

For 40 years, the Office of Science & Technology Policy has closely counseled the president, but its role in the new administration is unclear.

▶ Why the Deaf Community Fears President Trump

by Sara Novic, VICE

According to his biographer, Trump subscribes to a racehorse theory of human development and the superiority of certain genes — an echo of eugenics.

I'm a disabled American. Trump's policies will be a disaster for people like me.

by Ari Ne'eman, Vox

The anticipated loss of support infrastructure that is essential to living with a disability may lead to greater solidarity from other progressive groups.

► Stem Cell Researchers Anxious About Trump Presidency

by Gillian Mohney, ABC News

Mike Pence opposes federal funding for embryonic stem cell research. But reintroducing a funding ban "would be like putting a genie back in the bottle."

► The Sudden, Inevitable Rewiring of the American Left

by Andrew Burmon, Inverse

It's not clear which direction the Trump administration will be pushed by conservative evangelicals like Mike Pence and technophile wildcards like Peter Thiel.

Trump is considering a radical to lead FDA. That's dangerous for public health

by Ed Silverman, STAT

Imagine being prescribed a medicine when no one has a clue if it will work — because the government never required it to be tested for effectiveness.

With 21st Century Cures Act, the Future of Regenerative Medicine Is "Inject and See"

by Megan Molten, Wired

Critics say it's deregulation in sheep's clothing — and worry that both science and patients will suffer.

▶ Winners and losers of the 21st Century Cures Act

by Sheila Kaplan, STAT

Despite overwhelming bipartisan support, Elizabeth Warren says the bill was "hijacked" by Big Pharma to water down safety requirements for new drugs and devices.

CRISPR - News TOP -

Obama's Science Advisors Are Worried About Future CRISPR Terrorism

by Daniel Oberhaus, VICE Motherboard

While the form biological threats will take in the future is uncertain, what is certain is that the United States is not at all prepared to deal with them.

► CRISPR gene-editing tested in a person for the first time

by David Cyranoski, Nature News

A clinical trial in China used cells edited with CRISPR-Cas9 to treat a patient with lung cancer. Spectators anticipate a biomedical duel with US.

► CRISPR Heavyweights Battle in U.S. Patent Court

by Sara Reardon, Nature

UC Berkeley and the Broad Institute are vying for lucrative rights to the geneediting system. The December 6 hearing was the first and only time the two sides will speak to the judges before the ruling.

Human Germline Modification

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BREAKING THE WALL BETWEEN GENE SCIENCE AND ETHICS.

► How Philosophy Can Provide Frameworks for a Global Biotech Revolution

by Françoise Baylis, Falling Walls

A talk at the Falling Walls Conference, an annual science event in Berlin, reflects on the immense opportunities and threats posed by next-generation biotechnologies.

► Should We Rewrite the Human Genome?

by Alex Harding, Xconomy

Critics worry that a synthetic human genome could be used in unethical ways. Unlike for clinical trials, there is no regulatory body for basic science research.

DNA-editing breakthrough could fix 'broken genes' in the brain, delay ageing and cure incurable diseases

by Ian Johnston, The Independent [UK]

The technique allows DNA changes that have not previously been possible, modifying the genes of non-dividing cells in a living animal.

3 Person IVF - News TOP -

Exclusive: Mexico clinic plans 20 'three-parent' babies in 2017

by Michael Le Page, New Scientist

Mexico has no specific regulations governing mitochondrial replacement or assisted reproduction.

Setting the record straight

by Martin H. Johnson, Reproductive BioMedicine Online

A senior editor writes about some shoddy scientific journalism on mitochondrial transfer that was published in his own journal.

UK doctors to seek permission to create baby with DNA from three people

by Ian Sample, The Guardian

A scientific review concluded that the procedure should be approved for "cautious clinical use" when children are at risk of inheriting specific genetic diseases.

▶ "3-Parent Baby" Procedure Faces New Hurdle

by Karen Weintraub, Scientific American

Mitochondrial disease can somehow creep back in, even if an affected mother's mitochondria are virtually eliminated.

San Diego Scientists Help Develop New Twist On In Vitro Fertilization

by David Wagner, KPBS

The patent holder for a related "3-person IVF" technique reports new work with "polar body genome transfer." Some experts say none of these approaches have been proven safe.

Eugenics - News TOP -

► Historians seek reparations for Californians forcibly sterilized

by Ronnie Cohen, Reuters Health

Alexandra Stern and colleagues investigated over 20,000 documents from the state's eugenics program. Many victims are alive today; California, like other states, should offer them financial compensation.

Palo Alto committee debates whether Jordan school should keep its eugenicist namesake

by Jacqueline Lee, San Jose Mercury News

David Starr Jordan, Stanford University's first president, believed the human race could be improved through selective reproduction, including forced sterilization.

Gene Testing - News TOP -

Why We Need to Rethink Ethnicity-Based Genetic Testing

by Shivani Nazareth, US News & World Report

The problem with genetic tests that assume people exist in neat race and ethnicity categories is that it simply is not an accurate reflection of their ancestry.

► Sorry, that DNA test doesn't make you indigenous

by The 180 with Jim Brown, CBC Radio

Belonging to a particular community can mean sharing beliefs, cultural practice, even official citizenship. But it's not decided by genetic material.

▶ Do Your Family Members Have a Right to Your Genetic Code?

by Emily Mullin, MIT Technology Review

When a woman gets her genome sequenced, questions about privacy arise for her identical twin sister.

▶ Where Traditional DNA Testing Fails, Algorithms Take Over

by Lauren Kirchner, ProPublica

Various "probabilistic genotyping" programs undermine due process as defense attorneys, judges, and jurors can't access their proprietary inner workings.

Stem Cells - News TOP -

<u>Stem Cell Clinics Promise Miracle Cures, but at What Cost to Patients?</u>

by Philip Perry, Big Think

Taking advantage of a regulatory loophole, hundreds of clinics with virtually no oversight are offering stem cell therapies which are virtually untested, and make unsubstantiated claims about helping patients overcome disease.

▶ Disgraced stem-cell entrepreneur under fresh investigation

by Alison Abbott, Nature News

Davide Vannoni was barred from offering a controversial stem-cell therapy in Italy in 2015, but may be continuing his work abroad.

Amid Lawsuit, San Diego Stem Cell Company Pushes Back On Proposed Regulations

by David Wagner, KPBS

Patients currently suing the company say they paid thousands of dollars for treatments that didn't work.

Assisted Reproduction Technology

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Ovarian hyperstimulation syndrome – it's time to reverse the trend

by Geeta Nargund, BioNews

With a 40% rise in hospital admissions for severe OHSS in UK fertility clinics, regulators should intervene to protect the welfare and safety of women undergoing IVF treatment.

▶ 'No solid evidence' for IVF add-on success

by Deborah Cohen, BBC Panorama

A year-long study finds that nearly all costly add-on treatments offered by UK fertility clinics are unreliable, misleading, and risky.

Increase in IVF complications raises concerns over use of fertility drugs

by Hannah Devlin, The Guardian [US]

Stronger drugs used to harvest more eggs could also be linked to a 40% increase in cases of ovarian hyperstimulation syndrome.

▶ ACCC puts IVF clinics 'on notice' over misleading success rate

claims

by Madeleine Morris, ABC [Australia]

Some major Australian fertility clinics changed confusing marketing messages on their websites after a consumer group's investigation documented their misleading claims.

Australian couples' baby plans in limbo as Cambodia bans commercial surrogacy

by Lindsay Murdoch, The Sydney Morning Herald

After being chased out of Thailand in 2014, many IVF doctors and intermediaries moved to Phnom Penh where they openly advertised low costs, Asian surrogates, and an absence of laws excluding gay couples or single parents.

► Cambodia charges Australian nurse for running surrogacy clinic

by Prak Chan Thul, Reuters

As many South Asian countries take steps to clamp down on commercial surrogacy tourism, stakeholders are confronted with charges.

► Germany's sperm bank plans leaked

by Ben Knight, Deutsche Welle

The German government is making good on its promise to the children of sperm donors by setting up a central database to make it easier for them to find their biological fathers.

Various - News TOP -

Seeding Doubt: How Self-Appointed Guardians of "Sound Science" Tip the Scales Toward Industry

by Liza Gross, The Intercept

Sense About Science has downplayed concerns about industry-funded research and promoted science that favors private interests over public health.

NY senator from LI introduces 'familial DNA' legislation

by Chau Lam. Newsday

Critics of familial DNA searches point to high rates of false positives, invasion of privacy, and racial disparities.

America's ambivalence about race is seeping into science

by Taunya English, The Pulse, Newsworks

"Race has been used to oppress people, ... to kill people. Does science really want to be using a concept that is so historically loaded?"

▶ Blood from human teens rejuvenates body and brains of old mice

by Jessica Hamzelou, New Scientist

A biotech company working with mice is hoping to translate animal research into anti-ageing treatments for humans.

With Fertility Rate in China Low, Some Press to Legalize Births Outside Marriage

by Didi Kirsten Tatlow, The New York Times

Civil society groups are calling for greater reproductive freedom for single women, which would also affect lesbians.

► The Field of Synthetic Biology Runs on Speculative Fiction

by Jason Koebler, VICE Motherboard

As technology advances and draws us closer to unknown dimensions that may parallel sci-fi worlds, conversations must be inclusive of voices beyond science and industry.

What's behind those billion-dollar biotech deals? Often, a whole lot of hype

by Damian Garde, STAT

Huge deals are measured in "biobucks" — akin to lottery tickets that pay out if and when an experimental drug hits various milestones along the path to commercialization.

Deaths in CAR-T Immune-Therapy Trials Haunt Promising New Cancer Treatment

by Emily Mullin, *MIT Technology Review*Companies are racing to develop a new type of cancer therapy, but scientists are still assessing its safety.

► <u>Abortion-By-Mail Study Outrages Opponents</u>

by Phil Galewitz, *KQED California Healthline*A pilot study of telemedicine-based medical abortion demonstrates a welcome new option for women. Opponents of abortion find the concept deeply disturbing.

