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# CENTER FOR GENETICS AND SOCIETY

BIOPOLITICAL  
VIEWS & NEWS

February 8, 2019

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## ANNOUNCEMENTS

### [CGS-organized workshop: Engineering Future Generations?](#)

[Engineering Future Generations? The New Debate about Societal Governance, Public Engagement, and Human Gene Editing for Reproduction](#) took place at the Brocher Foundation in Hermance, Switzerland from January 14-16. The meeting, co-organized by the Center for Genetics and Society and Professor Roberto Andorno, University of Zurich, gathered some two dozen scholars and public interest advocates from Europe, North America, and New Zealand. The workshop generated rich discussions about a number of exciting collaborations, including a draft statement laying out minimum guidelines for meaningful public engagement. We will keep you updated on continuing developments.



### [CGS presentation: The Dangers of Bracketing the Social](#)

On February 19, CGS Program Director on Genetic Justice Katie Hasson will give a presentation to the UC San Francisco Bioethics Group titled, "The Dangers of Bracketing the Social in Ethical Consideration of Human Germline Modification." The talk will be held from 3:30 to 5:00pm on the Mission Bay Campus in Room 114 of Genentech Hall (600 16th Street, San Francisco). Those not able to attend in person are welcome to join via Zoom, using [this link](#).



## CGS COMMENTARY

### [Scientists Disagree About the Ethics and Governance of Human Germline Editing](#)

By Françoise Baylis and Marcy Darnovsky, *The Hastings Center* | 01.17.2019  
A narrow group of scientists is claiming the authority to decide whether to proceed with human germline genome editing – no matter that this technology could reshape societies with new divides between genetic haves and have-nots.



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### [The Bitcoin Baby Project](#)

By Pete Shanks, *Biopolitical Times* | 02.08.2019

Old-school transhumanism, biohacking, and modern cryptocurrency have come together with a surprising goal: monetizing the production of designer babies.



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### [Recent Human Germline Editing News](#)

By Pete Shanks, *Biopolitical Times* | 02.07.2019

Last year's heritable human gene editing scandal continues to reverberate.



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### [Direct-to-Consumer and Forensic DNA Tests](#)

By Pete Shanks, *Biopolitical Times* | 02.07.2019

Federal and local law enforcement seem to be ramping up their reliance on DNA matching, even as the accuracy of DNA tests is increasingly being questioned.



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### [Book Review: "Personalised Medicine, Individual Choice and the Common Good"](#)

By Gina Maranto, Guest Contributor, *Biopolitical Times* | 02.06.2019

A new edited volume brings together a group of far-reaching essays on the much ballyhooed trend toward personalized medicine.



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### [Lose Weight with 23andMe and an AI App!](#)

By Pete Shanks, *Biopolitical Times* | 01.23.2019

23andMe has partnered with Lark Health to offer an automated coaching program that uses artificial intelligence to help you make healthy lifestyle choices. Caveat emptor.



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### [A Tip of the Hat to Bill Gates](#)

By Pete Shanks, *Biopolitical Times* | 01.22.2019

Bill Gates is surprised that human germline gene editing hasn't generated more attention from the general public.



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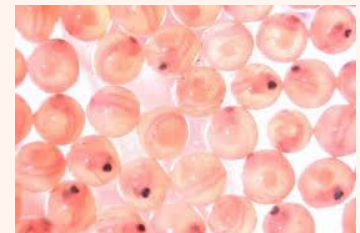
## CGS in the NEWS

### ▶ [New U.S. Experiments Aim To Create Gene-Edited Human Embryos](#)

[cites CGS' Marcy Darnovsky]

by Rob Stein, *NPR* | 02.01.2019

A developmental biologist at Columbia University says, "Right now we are not trying to make babies." The associate director of the Altius Institute for Biomedical Sciences sees these experiments as "really disturbing" and would like to see a hiatus in even basic research.

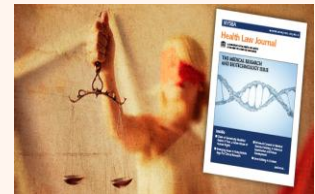


### ▶ [Reprints in Health Law Journal](#)

[cites CGS]

by New York State Bar Association | February 2019

Two pieces by CGS are reprinted in the February 2019 issue of *Health Law Journal*: [Claim of Genetically Modified Babies: If true, a grave abuse of human rights](#), CGS' November 2018 press release about He Jiankui, and [Reproductive Gene Editing Imperils Universal Human Rights](#), the February 2018 article by Marcy Darnovsky, Leah Lowthorp and Katie Hasson on [OpenGlobalRights](#).



## NEWS

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### SCIENTIFIC SELF-REGULATION?

### ▶ [American Nobel Laureate Knew About Chinese Scientist Gene-Editing Babies, But Did Not Report Him, Emails Show](#)

by Candice Choi and Marilyn Marchione, *Time* | 01.28.2019

He Jiankui told Craig Mello about the pregnancy in April. Mello disapproved but kept the news secret and remained a scientific adviser for He's company until December.

### ▶ [Stanford will investigate its role in the Chinese CRISPR baby debacle](#)

by Antonio Regalado, *MIT Technology Review* | 02.07.2019

Three of its faculty—more than at any other institution—were aware of He Jiankui's plans to create the gene-edited children. The university wants to learn what ties its faculty members had to He.

### ▶ [American scientist played more active role in 'CRISPR babies' project than previously known](#)

by Jane Qiu, *STAT News* | 01.31.2019

New information indicates that a scientist at Rice University was far more involved in the widely condemned “CRISPR babies” experiment than has previously been disclosed.

▶ [How to Stop Rogue Gene-Editing of Human Embryos?](#)

by Pam Belluck, *The New York Times* | 01.23.2019

Some U.S. researchers knew of a Chinese scientist’s intentions to implant edited embryos but did nothing to stop him. One, who was also involved with He’s genomics companies, appears to have actively supported him.

▶ [Are scientists’ reactions to ‘CRISPR babies’ about ethics or self-governance?](#)

by Nina Frahm and Tess Doezema, *STAT News* | 01.28.2019

Issues currently treated as matters of research ethics are in fact political and social questions of fundamental human importance.

▶ [Should Scientists Toy With the Secret to Life?](#)

by The Editorial Board, *The New York Times* | 01.28.2019

The gene-editing technology Crispr has the power to remake life as we know it. Questions about how to use it concern everyone.

▶ [The Myth of Genetic Superbabies](#)

by Jim Kozubek, *Scientific American* | 01.21.2019

The greatest ethical test of biotech regulation in our times is not how it will stop the creation of GMO babies, a probable misadventure of ambiguous improvements, but how it relates to the equity and treatment of the living.

## HUMAN GERMLINE EDITING

- News TOP -

▶ [The DIY designer baby project funded with Bitcoin](#)

by Antonio Regalado, *MIT Technology Review* | 02.01.2019

A transhumanist biohacker and Bitcoin investor who has put together a business proposal to make transgenic children says the company is “focused on the production of designer babies” and notes that “we have an initial parent-couple customer.”

▶ [He Jiankui’s Genetic Misadventure, Part 3: What Are the Major Ethical Issues?](#)

by Jing-Bao Nie and Alexander T.M. Cheung, *The Hastings Center* | 01.10.2019

He and his associates have given the world a perfect paradigm case to demonstrate how a scientific project can breach almost every ethical norm of biomedical research.

▶ [Gene-Editing Scientist’s ‘Actions Are A Product Of Modern China’](#)

by Rob Schmitz, *NPR* | 02.05.2019

Scientists and legal experts say China’s economic, social and political environment contributed to He Jiankui’s reckless and unethical pursuit of a scientific “first.”

▶ [Scientist behind CRISPR twins sharply criticized in government probe, loses job](#)

by Dennis Normile, *Science* | 01.21.2019

The Southern University of Science and Technology has rescinded He Jiankui’s

contract and terminated his teaching and research activities, effective immediately.

▶ [Is the world ready for gene-altered babies?](#)

by Mark Kennedy, *Times Free Press* | 12.20.2018

Doesn't a baby have the right to be born imperfect? Might designer babies do damage to the gene pool? Could reproductive technology lead to the end of individualism as we know it?

## DNA FORENSICS

- News TOP -

▶ [One Of The Biggest At-Home DNA Testing Companies Is Working With The FBI](#)

by Salvador Hernandez, *BuzzFeed News* | 01.31.2019

Family Tree DNA is allowing FBI agents to access its million-plus DNA profiles and its testing technology, giving law enforcement the ability to match DNA from crime scenes to a vast library of possible relatives. Some customers and commentators are outraged.

▶ [Coming Soon to a Police Station Near You: The DNA 'Magic Box'](#)

by Heather Murphy, *The New York Times* | 01.21.2019

With Rapid DNA machines, genetic fingerprinting could become as routine as the old-fashioned kind. Many legal experts and scientists see potentials for misuse.

▶ [Should Cops Use Family Tree Forensics? Maryland isn't so Sure](#)

by Megan Molteni, *Wired* | 12.19.2018

State legislators have introduced a bill that would prohibit law enforcement from searching any DNA databases to find people who are genetically related to crime scene DNA. So-called "familial searches" of police DNA databases have been banned in the state since 2008.

## ASSISTED REPRODUCTIVE TECHNOLOGIES

- News TOP -

▶ [IVF linked to slightly higher risk of maternal complications: study](#)

by Sheryl Ubelacker, *The National Post* | 02.04.2019

The complications around the time of delivery include post-partum bleeding that may require a blood transfusion, admission to an intensive care unit, infection of the reproductive system, and — in extremely rare cases — death. But the absolute number of women who develop these remains quite small.

▶ [Another use of an egg-swapping IVF technique has just been reported in Europe](#)

by Antonio Regalado, *MIT Technology Review* | 01.22.2019

Spanish scientists announced that a 32-year-old Greek woman is 27 weeks pregnant after what they claim to be the first successful use of maternal spindle transfer, a form of "3-person IVF." The technique was used not to prevent transmission of mitochondrial disease, but because the woman had undergone four unsuccessful IVF cycles.

▶ [In Spain, international adoptions plunge while surrogacy grows](#)

by Pilar Álvarez, *El País* | 01.30.2019

The number of foreign children adopted by Spanish parents has plunged over the same time period as a rise in couples going abroad to seek surrogacy

services, which are illegal in Spain.

## GENOMICS

- News TOP -

### ▶ [Is Our Future Really Written in Our Genes?](#)

by Kevin Mitchell, *Scientific American* | 01.07.2019

A recent book by Robert Plomin argues that your DNA can predict your future from birth with 100 percent reliability. That assertion is not 100 percent reliable.

### ▶ [It's the End of the Gene As We Know It](#)

by Ken Richardson, *Nautilus* | 01.03.2019

The hype now pouring out of the mass media is popularizing what has been lurking in the science all along: a gene-god as an entity with almost supernatural powers. But at the same time, a counter-narrative is building, not from the media but from inside science itself. We have reached peak gene, and passed it.

## STEM CELLS

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### ▶ [The FDA is going after stem cell clinics that peddle unproven treatments](#)

by Max Levy, *Vox* | 01.13.2019

Fat-derived stem cells “may have a positive effect,” says an expert stem-cell researcher. “[But] the research hasn’t been done.” The FDA insists on clinical trials that clinics don’t want to do.

### ▶ [California has gone crazy for sketchy stem cell treatments](#)

by Usha Lee McFarling, *Los Angeles Times* | 01.23.2019

Scientists should now take every opportunity to explain to the public both the long-term goals of their research and the absurdity of the so-called cures now flooding the market.

## GENETIC TESTING

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### ▶ [Why You Should Be Careful About 23andMe's Health Test](#)

by The Editorial Board, *The New York Times* | 02.01.2019

“F.D.A.-approved” does not necessarily mean “clinically useful.” Doctors and geneticists say that the tests are still more parlor trick than medicine. Here’s how they work — and why you should interpret them with caution.

### ▶ [Baby DNA tests raise as many questions as answers](#)

by Carolyn Y. Johnson, *The Washington Post* | 12.19.2018

Enthusiasts claim DNA sequencing tests for newborns will anticipate problems, while others are less certain and question the possible effects on the child’s autonomy and even on the bond between parent and child.

### ▶ [23andMe Will Add Weight-Loss Advice to Its DNA-Testing Services](#)

by Kristen V. Brown, *Bloomberg* | 01.08.2019

The company has partnered with Lark Health, which sells an artificial-intelligence coaching app, claiming that DNA data can be a motivating force.

### ▶ [Twins get some 'mystifying' results when they put 5 DNA ancestry kits to the test](#)

by Charlise Agro and Luke Denne, *CBC* | 01.18.2019

Five companies all returned different results for the twins' ancestry, and none of them gave the same result for both twins, despite their statistically identical DNA.

## VARIOUS

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### ▶ [It's Time to Rethink Who's Best Suited for Space Travel](#)

by Rose Eveleth, *Wired* | 01.27.2019

Some people with what are considered disabilities, including blindness and deafness, may actually fare better in space and should be encouraged by NASA.

### ▶ [China's Latest Cloned-Monkey Experiment Is an Ethical Mess](#)

by Ryan F. Mandelbaum, *Gizmodo* | 01.23.2019

The team of scientists behind the new announcement tout the monkeys' suffering—*anxiety, depression, and "schizophrenia-like behaviors"*—as a success.

### ▶ [These Patients Had Sickle-Cell Disease. Experimental Therapies Might Have Cured Them.](#)

by Gina Kolata, *The New York Times* | 01.27.2019

In clinical trials already underway, researchers are testing several ways to correct the problem at the genetic level, which would be the first genetic cure of a common genetic disease.

### ▶ [Nobel Scientist James Watson Stripped Of Titles For 'Reprehensible' Race Remarks](#)

by Mary Papenfuss, *Huffington Post* | 01.14.2019

Cold Spring Harbor Laboratory removed Watson from his role as chancellor in 2007 following previous racist remarks, and has now stripped him of his remaining titles, including honorary trustee and chancellor emeritus.

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