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Gene-edited Babies and Human Rights

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Gene-edited Babies and Human Rights

Presented by:

Marcy Darnovsky, Center for Genetics and Society

Session: Tech and “Human” Rights

Abstract:

New gene editing technologies, rapidly being adopted in laboratories around the world, could enable researchers and fertility doctors to create genetically altered – even “genetically enhanced” – humans. In fact, an experiment that resulted in the birth of twin gene-edited babies was revealed in late 2018. Though it was widely condemned as reckless and premature, proponents of heritable genome editing doubled down on their efforts to chart a “path forward.” The debate is spilling from scientific and biotech industry circles, themselves divided on the issue, into the policy, public, and civil society mainstreams. It is now an urgent human rights and social justice challenge.

Using human gene editing to treat sick patients is widely supported. Engineering the traits of future children, who would pass their altered genes to subsequent generations, would be an entirely different matter. Heritable genome editing would threaten the health of resulting children without offering any medical advantage to parents at risk of transmitting serious genetic diseases, since safer options are already available. Permitting it for any reason would likely lead to its adoption for purported genetic enhancements, and commercial pressures toward a market-based eugenics that would exacerbate existing discrimination, inequality, and conflict.

For these and related reasons, heritable genome editing is prohibited by law in dozens of countries, and by a binding international treaty whose formal name is the Council of Europe Convention on Human Rights and Biomedicine. UNESCO’s 1997 Universal Declaration on the Human Genome and Human Rights cautions that heritable genome editing could be “contrary to human dignity.”

Human rights advocates can build on these documents to ensure that human biotechnologies are not used to usher in a world of genetic “haves” and “have-nots,” but are reclaimed for the common good.

Presenter information:

Marcy Darnovsky, PhD, is Executive Director at the Center for Genetics and Society, a Berkeley, California-based public interest organization that works to ensure an equitable future in which
human genetic and assisted reproductive technologies benefit the common good. She speaks and writes widely on human biotechnologies, focusing on their social justice, equity, human rights, and public interest implications, and has been interviewed by hundreds of television, radio, and other news outlets.