

<http://somatosphere.net/2018/12/web-roundup-crispr-babies-and-bioethics.html>

Web Roundup: CRISPR Babies and Bioethics

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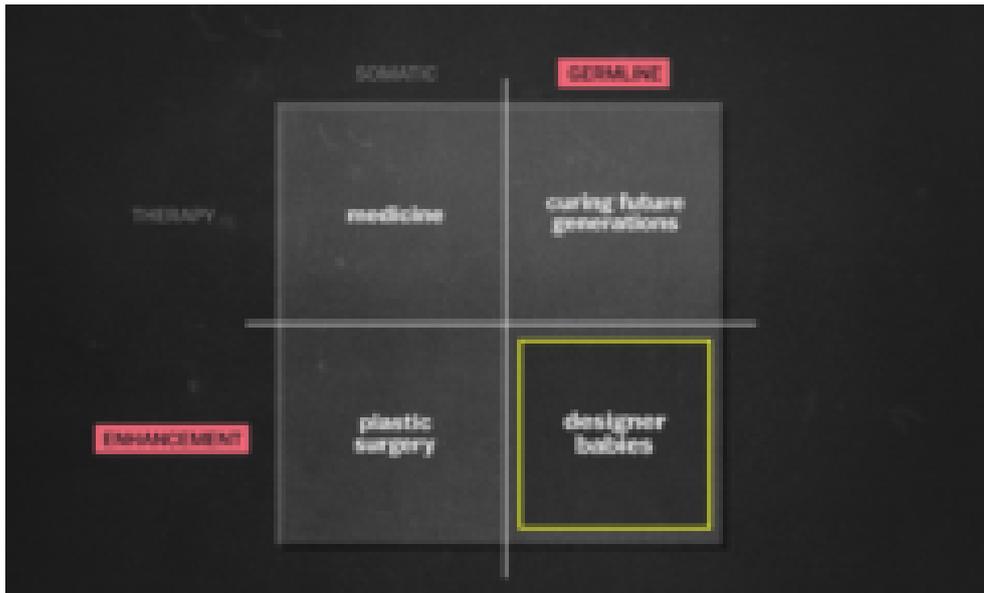
In late November, [He Jiankui, a scientist in China, announced that he had created the first “CRISPR babies,”](#) meaning that he performed germ-line genome edits on human embryos, which were implanted through in vitro fertilization (IVF), and has now resulted the birth of twin girls. He used [CRISPR-Cas9](#), a [genome editing technology](#) that can [target DNA at precise locations to modify specific genes](#), to perform edits on [CCR5](#), a protein that HIV uses to infect cells, in an attempt to [create HIV resistance in future generations](#).

Gene editing itself is not new. The earliest [genetically modified animal](#) was born in 1974 and the first [genetically modified food from a lab](#) went on sale in 1994; the CRISPR-Cas9 technology is currently being used to [make chemicals](#) and in genetic alterations to [plants](#) and [animals](#). [Somatic gene editing](#), meaning the changes in the DNA are limited to the individual that the technology is used on, is also currently being tested in human clinical trials in China and Europe, and in [October the FDA announced the approval of a trial for use of CRISPR-Cas9 technology in human trials in 2019](#). These trials are to test CRISPR-Cas9 for use in medical therapy on diseases such as [cancer](#) and [sickle cell anemia](#).

However, the scientific community was thoroughly unprepared for the announcement of the first germ-line editing in humans. Germ-line gene editing is still fairly controversial, because editing in the germ-line means that genetic changes will be [passed on through sexual reproduction to the not just the babies resulting from edited embryos, but to their future offspring, and to their children](#), and children’s children, and so on. The [ethical concerns](#) and public outcry about this experiment swiftly followed the announcement, and the [Chinese government is currently investigating the experiment](#). The [PR video](#) released by The He Lab about this discovery received wide [criticism](#), first for [not following scientific protocols](#), as it was not published in a scientific journal where it could first be vetted and independently confirmed by other experts; He also [failed to list the study on the registry of clinical trials](#) until long after the research had started. There has also been speculation about the [consent process](#) of the parents participating in this experiment and about understanding the long term implications of this intervention. The parent participants were all

HIV positive men with HIV negative wives, and the CRISPR-edited embryos were not at risk for HIV infection because of the sperm washing process undertaken during IVF; this led many scientists to ask [where the ethical justification for performing these edits was at all](#) as there are easier and cheaper ways to [prevent HIV infection](#) than gene editing. While genome-editing technology has advanced substantially, many scientists also claimed that [He's experiment was premature](#), as other scientists using CRISPR on human DNA have reported [mosaicism](#) and [off-target edits](#) resulting from human embryo edits, meaning that if these have occurred, the twins [could pass on unintended genome edits](#) if they choose to have children in the future.

Additionally, many scientists were shocked by what they perceived as a violation of the the bioethical and moral principles of gene editing; there is currently a [scientific convention against germ-line gene editing](#), although the laws governing gene-editing [vary by country](#) and many places [do not have specific laws in place](#) against gene editing. In the U.S., gene-editing is closely [monitored by the FDA \(Food and Drug Association\)](#), however in China, there is significantly [less oversight on the use of CRISPR technology](#), resulting in [the first human trials several years ago](#). Currently, scientists agree that gene-editing should only be used to fulfill "[unmet medical needs](#)," but what qualifies as a medical need is [not universally agreed upon](#). For example, [He argued that HIV discrimination and stigma in China made it a reasonable target for gene-editing](#), although the embryos were not at immediate risk for HIV infection. Gene-editing for therapeutic purposes, such a medical problem like cancer, is considered ethically permissible, while gene-editing for enhancement, which is gene-editing to enhance physical traits like muscle tone or select certain genetic traits over another, like eye color, is not. However, some diseases blur the lines between therapy and enhancement, such as stopping [age-related diseases](#) or [enhancing metabolisms](#) to deal with high calorie diets. See [this chart](#) for examples of different kinds of gene editing in both the somatic and germ-line, and where the ethical lines between genome editing for therapy versus enhancement, and somatic versus germ-line, might (or might not) be drawn:



The most well-known concern of the future of gene editing is that of “[designer babies](#),” or genetic alterations to select for desirable traits in embryos such as intelligence, eye color, sex/gender, skin tone, etc. This popular concern with designer babies grew after the [first IVF baby was born in 1978](#), and these CRISPR babies could be considered the first step toward designer babies and the new normal in IVF. The [past 40 years of using IVF technology](#) may prove a useful guide to considering the future legal, bioethical, moral, political, and religious debates which may develop about the use of new genetic technologies like CRISPR-Cas9, especially in [conjunction with IVF for editing the DNA of embryos that will be passed on to future generations](#). However, it is also important to note that genetic technologies are already being used to make genetic decisions about future generations; for example, we already use genetic screening such as [amniocentesis](#) to screen for inheritable genetic disorders and make incredibly personal decisions about continuing a pregnancy. Furthermore, the bioethical debates about genome editing in embryos might have particularly relevant implications for the disability rights movements around genetic conditions such as [Down syndrome](#) and [learning disabilities](#) like [autism](#), where gene-editing of embryos could potentially be used to [edit out these genetic conditions from the human genome, which some people have argued is a modern day form of eugenics](#). It is incredibly important to consider the far-reaching societal impacts along with the potential benefits of genome editing technologies, to strive for [equity and justice](#) for historically marginalized communities and to preserve and value human diversity while using genome-editing technologies.

This commercialization of genome-editing technologies is a place where ethics and social justice combine; [issues of equity](#) such as who has access to gene editing technology and what they are able to use it for may increase existing social inequalities. With the birth of the first CRISPR babies, the future depicted in the science fiction film [Gattaca](#) becomes

slightly closer to reality (in the film people who have the resources to take advantage of the potential of gene editing for human enhancement gain social and economic advantages over those who do not edit their future offspring, creating lastly social inequality between the two classes and [limiting the autonomy of future generations](#)). Indeed, CRISPR technology is becoming cheaper all the time, and is now publicly available at a low cost with [DIY gene editing kits](#); for example, the [Odin CRISPR gene-editing kit retails for \\$159](#). While this is not the same level of experimentation as the recent germ-line gene edits on human embryos (and most people cannot perform germ-line gene edits in their garage), the increased access to similar technology by people who are not biologists highlights the need to extend bioethical debates about how to ethically use CRISPR into the public sphere. With the growth of lower cost and unregulated use of gene editing technologies, many experts are concerned about [accidents in experiments on humans or viruses which could have harmful or far-reaching consequences](#), as well as the potential for more nefarious uses like the creation of biological weapons.

Before the Second International Summit on Human Genome Editing, where He's experiment was announced, the chair [David Baltimore noted that this was an opportunity to discuss the future of genetic research with the scientific community and general public](#), as so far no one has performed genetic edits that would impact future generations – now all this has changed. A wide variety of international organizations have put out their [own guidelines on gene-editing](#), and He is also a co-author on [potential ethical principles](#) that should be followed by those using reproductive technologies for germ-line gene-editing. With no universally agreed upon standards of what is an acceptable practice in gene editing, and a [wide variety and disparity of opinions on the subject](#), many have noted that there needs to be a [convention of experts to develop agreed upon, worldwide ethical standards](#). There have been several articles recently dealing with the [need to revise ethical principles in terms of gene-editing](#), as the ways that we currently think about [patient autonomy](#) will be altered by germ-line editing of embryos, as parent autonomy will impact multiple generations as well as entire communities in new ways. This begs the question of how to establish global bioethical principles on gene-editing, where different ethical philosophies and principles may not agree on shared definitions for concepts like autonomy, or differ on [understandings of collective versus individual rights](#); approaches which take the global ethical impacts of biotechnologies into account might be useful in this current and future debate. Regardless, the current controversy on “CRISPR babies” is a bioethical debate we will be having for years to come, especially as [gene editing technology continues to advance](#). and becomes more commonplace.

Additional Resources:

An easy to understand [video of how CRISPR, short for \(Clustered Regularly Interspaced Short Palindromic Repeats\) works](#), and additional links about CRISPR technology.

[Netflix Explained on Designer Babies](#)

[Anthropology Now Article: The CRISPR Hack: Better, Faster, Stronger](#)

David Baltimore, et al., "A prudent path forward for genomic engineering and germline gene modification," *Science* 348 (2015): 36-38.

[Feminist Bioethics](#)

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AMA citation

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Harvard citation

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