ALLIANCE FOR HUMANE BIOTECHNOLOGY

WHITE PAPER:

OPPOSING HUMAN GENETIC ENGINEERING

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International scientific organizations are making significant strides towards approving the creation of genetically modified humans (GM Humans) or "designer babies," i.e., embryos whose genomes are genetically altered in laboratories before being implanted in their birth mothers resulting in a birth, nine months later, to a genetically modified infant.

These are developments about which all sectors of society should be made aware and given the opportunity to challenge.[1] GM children will carry genetically engineered changes permanently and will pass them on to potential descendants: to the children to whom they may give birth, the children who may eventually be born to those children, on and on down the line. This type of genetic engineering is, therefore, referred to as 'germline' engineering or sometimes 'heritable' engineering.[2] Individuals born after editing of these cells would not have consented to being genetically engineered. The push to create germline GM Humans comes without broad public knowledge or societal consensus. This paper explains how this is occurring and why it should be opposed.

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[1] NOTE: This position does not adversely affect a woman's right to terminate a pregnancy and does not preclude bipartisan support for the call for an international ban on germline genetic engineering.

[2] Germ cells are eggs and sperm. Early embryos contain the "germline" cells that give rise to them. Individuals born after editing of these cells would not have consented to being genetically engineered. Another kind of cell, somatic cells, are all the other cells of the body that are not related to reproduction. They are not passed on to descendants. This kind of editing may be done with the consent of living individuals. Editing somatic cells is not controversial, though the technology that will make it possible will also enable producing GM humans.

The world's first GM human, created using "Three-Parent Embryo Technology, was born in April 2016.[3] The world's first genetically engineered children using CRISPR technology, twin girls, were born in October 2018. A third GM child, created using CRISPR technology, was born in 2019.[4] Promoters of these technologies routinely emphasize their potential for avoiding or circumventing diseases. This, however, is not assured since a single genetic modification to an embryo can result in unpredictable, multi-faceted metabolic cellular effects upon the developing embryo, developing child, or adult. Accordingly, the attempt to redesign an embryo's genome in the laboratory and subsequently implant it for birth may result in significant harm to that child that may only become apparent years after they are born. There are effective and less ethically fraught measures for avoiding genetic disease. Germline genetic engineering of prospective people is not medically necessary.

Moreover, genetic technologies that might be capable of avoiding disease in ways advertised, may also be used by genetic engineers in attempts to create what they believe is an improved human with "enhanced" traits. Using genetic engineering methods to "improve" the human species constitutes a new eugenics era. The historical record of the cascade of discriminatory injustices and genocide of 20th century eugenics is well documented. With the creation of the first GM humans, we have fully entered a new era of 21st century "techno-eugenics."[5] The serious bioethical and safety issues of techno-eugenics are no longer theoretical. They are real,

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[3] "Exclusive: World's first baby born with 'three parent technique'", Jessica Hamzelou, *New Scientist* September 27, 2016: https://www.newscientist.com/article/2107219-exclusive-worlds-first-baby-born-with-new-3-parent-technique/

[4] Get source

[5] The term "techno-eugenics" was coined by Richard Hayes, cofounder of Center for Genetics and Society, cf. Tina Stevens and Stuart Newman, *Biotech Juggernaut: Hope, Hype, and Hidden Agendas of Entrepreneurial BioScience,* (Routledge Press, 2019), p. 5.

present, and have direct impact upon reproductive safety, human rights, and the genetic identity of the human species.[6] International scientific communities are normalizing the creation of GM humans. How is this occurring?

THE STRATEGIES, THE SCIENCE

Key strategies used to forward a GM Human agenda with limited public awareness involves misnaming technologies to conceal controversy, re-defining terms that constituted elements of earlier public discussion, and limiting societal input at ongoing international summits designed to consider genetically redesigning the human species/gene pool through the creation of GM children.

Three Parent Embryo technology involves creating an embryo using the DNA of three people. Most of an egg's DNA is contained in its nucleus. However, a different inheritable type of DNA, mitochondrial DNA, is found in the remainder of the egg, its cytoplasm. A woman with defective mitochondrial DNA can have the healthy nucleus of one of her eggs removed and placed into the enucleated egg of another woman with healthy mitochondrial DNA. When sperm is added, the resulting embryo contains the DNA of three people.[7]

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[6] An underrecognized human cost to germline genetic engineering research is the increased demand for women's eggs. See, for example: Tina Stevens and Stuart Newman, "Risking Women's Health While Widening the Door to Techno-Eugenics," *CounterPunch* September 26, 2019: https://www.counterpunch.org/2019/09/26/risking-womens-health-while-widening-the-door-to-techno-eugenics/; Jennifer Schneider, "Fatal colon cancer in a young egg donor: A physician mother's call for follow-up and research on the long-term risks of ovarian stimulation," *Fertility and Sterility* 2008. http://www.jenniferschneider.com/pdf/JS%20FertStert%20Fatal%20Colon%20Cancer.pdf

[7] Stevens and Newman, *Biotech Juggernaut*, pp. 130-133.

This technology has not been approved for clinical use in the US. Three-Parent Embryo technology has been approved in the UK. When the UK granted approval in 2015, however, it approved a technology that promoters misdescribed and misnamed to allay controversy. Instead of naming the technology in a way that aptly indicated its most unique, unprecedented feature, (that is, combining genetic material from three different people to create an embryo,) they termed the technique "mitochondrial transfer." In fact, mitochondria are not transferred. The technique is, instead, a type of nuclear transfer akin to cloning.[8] The US doctor, John Zhang, who in 2016 engineered the embryo that resulted in the first child born using this technique, went to Mexico to complete the implantation to avoid violating US restrictions. The baby was declared to be healthy, although he was not independently examined.

The UK's approval of Three-Parent Embryo Technology demonstrates the deliberate misdirection away from controversy by promoters, and the evasion of US restrictions by the researchers and their engagement in uncontrolled human experimentation without adequate oversight. Additionally, the question remains: will technology advertised only in the context of avoiding disease one day be used to combine traits of three people to secure heritable enhancements?

THE STRATEGIES, THE SCIENCE CONTINUED: NEW TECHNOLOGY AND THE THREAT OF HUMAN GENETIC ENGINEERING

[8]Interview with Stuart A. Newman, "Are We Headed Toward a Techno-Eugenic Future?", by Mohsen Abdelmoumen, *Counterpunch,* September 10, 2019:

https://www.counterpunch.org/2019/09/10/are-we-headed-toward-a-techno-eugenic-future/?fbclid=IwAR10UyuPiaI7IgyucijIHhraKx0tiTikFXMvIjNVHXcO3sDxJDSAdE4lt24

In 2018, Chinese scientist He Jiankui announced a medical event that shocked scientific communities around the globe: a woman gave birth to twin girls that Dr. He had genetically engineered. The technology that He employed, CRISPR/Cas9, came to public attention just three years earlier. In 2015 it captivated scientific imagination by its capability for making cuts and alterations to DNA more precisely than previously possible. Jiankui reported modifying a gene to make the girls, pseudonymously known as Lulu and Nana, less susceptible to infection from HIV.[9] Based on knowledge of the altered gene's effects in animal studies, some scientists suggested that the incautious modification of the gene in question, CCR5, could also have resulted in unintended consequences. The girls' intelligence and memory may have been enhanced, and "off target" changes could eventually cause cancer, other health problems, and shorten their life expectancy.[10] Moreover, the editing may have left the twins vulnerable to HIV, the avoidance of which was the stated rationale for conducting the experiment.[11] In 2021, a University of Wisconsin bioengineer familiar with the twins' case history related that, "We've never seen these CCR5 proteins before and we don't know their function in the context of a human being,…we're basically doing that experiment now."[12]

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[9] Because the embryos were normal and did not, in fact, have HIV the edit was, arguably, an enhancement. Anthony Regalado, "Years before CRISPR babies, this man was the first to edit human embryos," *MIT Review*, December 11, 2019:
https://www.technologyreview.com/2018/12/11/138290/years-before-crispr-babies-this-man-was-the-first-to-edit-human-embryos/

[10] Jon Cohen, Did CRISPR help—or harm—the first-ever gene-edited babies?, *Science* August 1, 2019.
https://www.science.org/content/article/did-crispr-help-or-harm-first-ever-gene-edited-babies

[11] Mia Georgiou, "Meet Lulu and Nana, the world's first CRISPR genome-edited babies…", *Get Animated Medical,* September 30, 2020.
https://getanimated.uk.com/meet-lulu-and-nana-the-worlds-first-crispr-genome-edited-babies/

[12] Zaria Gorvett, "The genetic mistakes that could shape our species," *BBC Future*, April 12, 2021.
https://www.bbc.com/future/article/20210412-the-genetic-mistakes-that-could-shape-our-species

He Jiankui was fined three million yuan and sentenced by the Chinese government to three years imprisonment. While some commentators referred to He Jiankui as a "rogue" scientist, others pointed out that scientists who knew that his experiment was underway did nothing to publicize it. Moreover, He Jiankui asserted that he had felt empowered to undertake his research by prevailing professional norms. He cited a 2017 report by the US National Academy of Sciences which concluded that while it was presently unsafe to create a human with CRISPR altered genes, it might one day be justified for compelling reasons. He Jiankui believed that day had arrived.[13] In March 2019, eighteen scientists and bioethicists called for a limited moratorium on this work. This was not intended as a ban, and only pertained to clinical use of germline alteration to make genetically modified children.[14] Research on germline editing of human embryos would be permitted during such a moratorium, during which discussions were to take place to produce relevant guidelines. At the moratorium's end, "any nation could…choose to allow specific applications of germline editing…." Rather than calling for a prohibition on the creation of designer children on ethical grounds, this proposal looked forward to a "broad societal consensus" that could enable those nations that chose to move ahead with the technology to do so.

SCIENTISTS ARE ALREADY DISCUSSING USES OF HUMAN GENETIC ENGINEERING

In July 2019, eight months after He Jiankui made his announcement, the World Health Organization (WHO) released a statement advising regulatory and ethics authorities to refrain

[13] Regalado, op cit.
[14] Eric Lander et al: "Adopt a moratorium on heritable genome editing," *Nature*, March 13, 2019 https://www.nature.com/articles/d41586-019-00726-5

from approving clinical applications of human germline genome editing. WHO declared: "regulatory authorities in all countries should not allow any further work in this area until its implications have been properly considered."[15] This call, like that of the previous March, was not an enforceable legal prohibition. Jennifer Doudna, the UC Berkeley biochemist who was to win the Nobel prize two years later for co-discovering the CRISPR technology, characterized the proclamation as a call for discussion. "Unlike a moratorium," she said, "it invites conversation, and that's really critical right now because there's no doubt in my mind that the interest in human germline editing is not going away."[16]

By not seeking to curtail the research necessary to make a pregnancy with a gene-modified baby possible, the temporary halts called for by mainstream scientists and bioethicists leave unaddressed the likely next step: it will be deemed important to implant experimental genetically modified embryos. This will happen in order to establish feasibility of clinical use of the technique. Any bright line between human germline research conducted in a laboratory, on the one hand, and the eventual implantation of a GM embryo into a woman, on the other, will fade. The line will succumb to continual technology-driven renegotiation. Despite early and continuing calls for moratoria, no government has yet imposed a moratorium, and no official voluntary moratoria are being observed. Instead, the international conversations, insofar as they have occurred, favor informal and optional self-regulation by scientists and bioentrepreneurs.

[15]Statement on governance and oversight of human genome editing, World Health Organization https://www.who.int/news/item/26-07-2019-statement-on-governance-and-oversight-of-human-genome-editing
[16] Megan Molteni, "The World Health Organization Says No More Gene-Edited Babies," *Wired*, July 30, 2019. https://www.wired.com/story/the-world-health-organization-says-no-more-gene-edited-babies/

Even before He Jiankui's 2018 announcement, scientific organizations had begun formal international conversation about human germline engineering. In December 2015, an International Summit convened in Washington, D.C. The event triggering the assembly was the revelation that, for the first time, a researcher successfully altered the germline of non-viable human embryos.[17] The National Academy of Sciences, National Academy of Medicine, Chinese Academy of Sciences, and the Royal Society of the UK convened the meeting to consider the ramifications of this unprecedented development. [18] Three years later, a second International Summit on Human Genome Editing was held at the University of Hong Kong in November 2018.[19] It was just before this Summit that He Jiankui confirmed that he had altered the DNA of embryos and implanted them into women, one of whom gave birth to Lulu and Nana. He also revealed that another woman, pregnant with a genetically altered embryo, was expected to deliver soon. At present, a Third Summit is scheduled to take place in London in 2023, although related online events are already underway[20]

What is the nature of international conversations on germline engineering and what social function do they serve? Statements, proceedings, and other works produced by the summiteers indicate that research on human germline genetic engineering is increasing significantly. They reveal also that scientific organizations are channeling societal input into preestablished

[17] See, Regalado, op cit.
[18] "International Summit on Human Gene Editing: A Global Discussion," National Academies of Sciences, Engineering, and Medicine 2015, https://www.nap.edu/read/21913/chapter/1
[19] Second International Summit on Human Genome Editing: Continuing the Global Discussion
National Academies of Sciences, Engineering, and Medicine. 2019. Second International Summit on Human Genome Editing: Continuing the Global Discussion: Proceedings of a Workshop–in Brief, Washington, DC: The National Academies Press. https://doi.org/10.17226/25343; https://www.nap.edu/read/25343/chapter/1; https://www.ncbi.nlm.nih.gov/books/NBK535994/#sec0001

[20] https://royalsociety.org/science-events-and-lectures/2022/03/looking-ahead-to-the-third-human-genome-editing-summit/

categories, e.g., 'governance' and 'regulation' that discourage discussion of whether or not to proceed with germline engineering. By default, they assume a future that contains GM humans. The conferences are mainly a means of setting up international administrative structures to assist the gradual approval and eventual acceptance of genetically modified children.

The first international summit, held in 2015, included critics of human germline genetic engineering. But by the summit's end, their positions had been *de facto* overruled, as evidenced by their omission from the conclusion of the published report. The possibility of a moratorium leading to a ban was excluded altogether from the summary conclusion even though such a proposal had been put forward. The summit's report acknowledged that it would be irresponsible, at present, to proceed with clinical use of germline editing; *But*, moving forward it could be approved eventually, if conditions were met: safety and efficacy issues needed to be resolved, as well as the fashioning of a "broad societal consensus about the appropriateness of the proposed application." The authors of the Summit report acknowledged that "many nations have legislative or regulatory bans on germline modification," essentially the consensus that they were calling for, but nonetheless insisted that, "as scientific knowledge advances and societal views evolve, the clinical use of germline editing should be revisited on a regular basis." The implication was, therefore, that any consensus against their position was simply provisional. They concluded by "call[ing] upon the national academies that co-hosted the summit…to take the lead in creating an ongoing international forum to discuss potential clinical uses of gene editing; help inform decisions by national policymakers and others; formulate recommendations

and guidelines; and promote coordination among nations."[21] Clearly, the summiteers were not going to take "no" for an answer.

As might have been predicted from the summiteers lack of commitment to the idea, the final statement of the Second International Summit in 2018 made no mention of the need for the "broad societal consensus" called for three years earlier. Moreover, where the 2015 Summit suggested that moving forward with clinical applications was then irresponsible, the 2018 Summit decided that since germline genome editing "could become acceptable in the future…" it was now, "time to define a rigorous, responsible translational pathway toward such trials." For science writer Anthony Regalado, the 2018 Second Summit, "…ended with the clearest call yet by science leaders to move the technology toward medical use in IVF clinics." He described how, "…the dean of Harvard Medical School…took the stage and, though he called He's work a "misstep," did not condemn it. Instead, (he) spoke in favor of using CRISPR in IVF clinics in the future, saying it was time to move past the question of "ethical permissibility" and on to the question of how to do it correctly."[22]

In 2020, the National Academies of Science, Engineering, and Medicine, published what it termed a "consensus report," *Heritable Human Genome Editing.* "Consensus" in this context, seems to refer to "scientific consensus." The "broad societal consensus" touted by the 2015 Summit was deferred to an unspecified time. Instead, the Commission tasked itself with "…addressing the scientific considerations that would be needed to inform broader societal

[21] National Academies of Sciences, Engineering, and Medicine. 2015. International Summit on Human Gene Editing: A Global Discussion. Washington, DC: The National Academies Press. https://doi.org/10.17226/21913.
[22] Antonio Regalado, "Years before CRISPR babies, this man was the first to edit human embryos," *MIT Technology Review,* December 11, 2018 https://www.technologyreview.com/2018/12/11/138290/years-before-crispr-babies-this-man-was-the-first-to-edit-human-embryos/

decision making."[23] As commissioners seemed to view it, setting up administrative structures for developing pathways for lab to clinical applications – in advance of societal consensus about doing so – was a priority. The Commission mentioned "the importance of…societal consideration" (significantly, not consensus) but stated that "the appropriate mechanisms for addressing them lie beyond its charge."[24]

The charge of the Commission, with input from other global academies, would be to "develop a framework for scientists, clinicians, and regulatory authorities to consider when assessing potential clinical applications of human germline genome editing, should society conclude that heritable human genome editing applications are acceptable."[25]

The Commission did not limit its ambit to monogenic diseases.[26] It explicitly included consideration of genetic enhancements.[27] The ethical leap from a rationale of disease prevention to the implied legitimacy of creating enhanced humans had been brought to the table with no

[23] *Heritable Human Genome Editing*, The Royal Society; National Academy of Sciences; National Academy of Medicine; International Commission on the Clinical Use of Human Germline Genome Editing. Heritable Human Genome Editing. Washington (DC): National Academies Press (US); 2020 Sep 3. Summary. Available from: https://www.ncbi.nlm.nih.gov/books/NBK565918

[24] *Heritable Human Genome Editing*, The Royal Society; National Academy of Sciences; National Academy of Medicine; International Commission on the Clinical Use of Human Germline Genome Editing. Heritable Human Genome Editing. Washington (DC): National Academies Press (US); 2020 Sep 3. Summary. Available from: https://www.ncbi.nlm.nih.gov/books/NBK565918

[25] https://www.nationalacademies.org/our-work/international-commission-on-the-clinical-use-of-human-germline-genome-editing

[26] Monogenic diseases are those brought about by variants in only one gene. In recent years the concept has been challenged, since not everyone with even the most disease-associated variant of the gene has the condition. This suggests that background conditions, including variants in other genes, determine whether an individual with the gene in question will be contract the disease.

[27] "Specifically, the commission will: 1) identify the scientific issues (as well as societal and ethical issues, where inextricably linked to research and clinical practice) that must be evaluated for various classes of possible applications. Potential applications considered should range from genetic correction of severe, highly penetrant monogenic diseases to various forms of genetic enhancement…." https://www.nationalacademies.org/our-work/international-commission-on-the-clinical-use-of-human-germline-genome-editing

prior public consideration or public commentary by the scientific organizations involved with the commission. Creating administrative structures for "governance "of highly controversial genetic technologies was thus advanced despite scant awareness of this move and certainly no broad societal consensus for such activities.

A Third International Summit, planned for March 2022 but postponed until 2023, nevertheless held "preparatory" meetings on the originally scheduled date. Posted videos of these meetings indicate that plans for creating an international administration for eventual "governance" of GM human applications are well underway. In his presentation, Andrew Greenfield, a member of the 2020 Commission, made clear that, "… international dimensions of governance were made by the Committee…primarily because there is a collective and global interest in editing the human genome in a heritable fashion."[28] The creation of "translational pathways" (that is, from research on embryos in the lab to implantation of embryos into women) was to include the establishment of an International Scientific Advisory Panel (ISAP). [29] The charge of the ISAP would be to design clinical pathways and standardize tracking of children who have been genetically modified. The Commission acknowledged a role for societal considerations including bringing diverse groups to the table. Calling for a halt to GM humans may find scant airtime from within governance structures, however. The Commission created a way to legitimize clinical possibilities for human genome editing by channeling discussion into two separate processes, one for societal considerations, one for scientific.[30] Societal input, as folded into the Commission's framework, is structured so that it does not occur in advance of scientific research.

[28] Greenfield presentation, 04:3
[29] Andrew Greenfield presentation: https://2022humangenomeeditingsummit.royalsociety.org/Home/GetSessionPage/3
[30] Figure 1-2, Greenfield presentation.

Societal deliberations on possible ethical and legal use and oversight of human heritable editing will take place while the scientific process moves forward, developing clinical pathways for specific germline editing proposals. Siloed in this way, opportunities for resisting germline research as societally unacceptable are curtailed. This is facilitated by the redefinition of terms in a way that enables moving forward with editing the human germline.

The recasting of terminology to assist GM human research was set into bold relief during a presentation on the World Health Organization Expert Advisory Committee on Human Genome Editing [31] Previously, terms used in discussion of germline editing would correspond to the two types of human cells capable of being genetically edited: somatic and germline. At some point during the interim planning, however, a third category was created to remove some of the stigma of germline modification: heritable. Before this reclassification, germline and heritable could be used interchangeably;[32] But these previously synonymous terms were now bifurcated in a move that was more semantic and political than scientific. The targeted cells are the same: the germline of the embryo destined to produce eggs or sperm. The difference between germline and heritable modification is defined solely by the intent of the researcher. Germline editing now refers to lab experiments, while heritable editing refers to experimentally edited embryos destined for implantation into women to be brought to term. The WHO presentation also clarified different "time horizons" for these research areas. While heritable research is deferred

[31] Elena Buyx, March 9, 2022, presenting on Governance recommendations from the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing report https://2022humangenomeeditingsummit.royalsociety.org/Home/GetSessionPage/3

[32] For example, see Lander et al, op cit. Although the title of this 2019 article is, "Adopt a moratorium on heritable genome editing", the terms "germline editing" or "clinical germline editing" are used throughout. Similarly, see Lanphier et al, "Don't Edit the Human Germline," *Nature*, March 12, 2015: https://www.nature.com/articles/519410a

to the longer term, germline research can be conducted now and is expected to expand in the future.[33]

The bifurcated terminology, along with the establishment of two governance processes, scientific and societal, institutionally cordons off research on germline manipulation from the once touted requirement of broad societal consensus. While societal input is formalized and restricted, efforts to experimentally produce modified human embryos poised to be brought to term is readily brought into the realm of normal science.

JOIN US IN OPPOSING HUMAN GENETIC ENGINEERING

On March 14, 2022, the Whitehead Institute conducted an interview with CRISPR co-discoverer, Jennifer Doudna. When asked about the ethical challenges of germline editing, Doudna expressed her view that there was need for open and transparent conversation that includes not only scientists but all stakeholders and anyone who has an interest. But later, when asked if governments had made "real" decisions or left that to scientists, she replied that thus far it's still in the hands of scientists and scientific societies to put forward guidelines. When pressed on the question of whether the scientific community was "strong enough" to "really put forward restrictions" she replied at length:

> I've talked to a number of our legislators and legislators in other countries and for the most part I think they're really well meaning and they want to do the right thing, it's just that if they're not trained as scientists and most of them are not, they feel they're out of their depth…So having scientists engaged in this and putting out reports…that continue to evaluate the technology ***as it advances***, and the field is moving extraordinarily fast, this is the best we can do…We really just have to keep continually evaluating where the

[33] https://2022humangenomeeditingsummit.royalsociety.org/Home/GetSessionPage/3#32

> technology is, what are the opportunities, what are the risks, and what are the costs and benefits of using it in different ways.[34] (emphasis added)

Doudna's point of view is an accurate reflection of the policy prescriptions of international science organizations: scientists will decide while society catches up. But why should the costs and benefits of something so monumental as altering the human species be left to a cadre of scientists who stand to profit so lavishly (in both fame and fortune) from doing so?

The broad social consensus called for by the first International Summit in 2015 and assumed necessary by early promoters appears to have lost its public relations cachet. This is because while society *does* exhibit a consensus about GM humans, it is not the one that summiteers want. There is an impressive history of national and international accords, declarations, treaties, and other instruments that testify to broad societal commitment to protecting human dignity and human diversity.[35] Of particular relevance is the Oviedo Convention. Article 13 of this international treaty permits modification of the human genome only if it does not "introduce any modification in the genome of any descendants."[36]

Along with the substantial opposition to human germline editing, there is little evidence of demand for it from patients or their advocates. In 2019, the President of the Washington D.C. patient advocacy group, Genetic Alliance, related that demand for germline editing was not high.

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[34] Whitehead Institute. "The Code Breaker: A Conversation with Jennifer Doudna, Nobel Laureate and Professor of Biochemistry and Molecular Biology UC Berkeley", March 14, 2022: https://web.mit.edu/webcast/wi/s22/2/

[35] Consider, for example, the Oviedo Convention, Nuremberg Code, Helsinki Declaration, Belmont Report, Convention on the Rights of the Child, Convention on Action Against Trafficking of Human Beings.

[36] "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine," 1997,
Article 13 – Interventions on the human genome:
"An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants. "
https://rm.coe.int/168007cf98

Many families at risk of having children with genetic diseases just wanted to be able to screen their embryos for potential disease.[37] In light of this, the push to develop this highly controversial change in human reproduction and evolution of the species is especially problematic. It is increasingly apparent that a major source of this demand comes from the professional researchers and bio-entrepreneurs who stand to profit and build careers from the endeavor. There is no broad societal consensus for genetically altering the human species, and certainly not as an aggregate of bio-entrepreneurially induced reproductive supply and demand. A resolution denouncing human germline genetic editing will expand and amplify the public voice in calling for a halt to the Era of GM Humans.

[37] Cited in Heidi Ledford, "CRISPR babies: when will the world be ready?," *Nature* June 19, 2019. https://www.nature.com/articles/d41586-019-01906-z