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HUMAN GENOME EDITING VIS-À-VIS RIGHT TO HEALTH

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I. ABSTRACT

The paper explores the feasibility and ethical considerations of using gene editing to improve health outcomes, emphasizing the broader context of the Right to Health. It delves into the complex dynamics between gene editing technology and this fundamental right, highlighting the impact on future generations' health. The author contends that while gene editing could offer significant health benefits, such as the eradication of genetic diseases, it also poses risks to autonomy, privacy, and data security. These risks are particularly significant when considering the potential violation of personal rights in light of right to health, if the technology is misused. Gene editing holds the potential to revolutionize medicine, but it raises profound moral, legal, and ethical questions that science alone cannot answer. Society bears the responsibility of addressing these issues through robust legal frameworks and comprehensive research to ensure that human rights are not compromised. The paper argues that while the allure of disease-free offspring is compelling, this must be balanced against the need for safeguards to protect health as a fundamental right. In light of these considerations, the author advocates for a careful, regulated approach to gene editing, with laws and ethical guidelines that account for both the benefits and the potential harm.

II. KEYWORDS

Right to Health, Genome Editing, CRISPR/Cas9, Intersection, Impact, World Health Organization.

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III. INTRODUCTION

Genome editing involves the precise alteration of the DNA within a cell or organism. CRISPR, short for "Clustered Regularly Interspaced Short Palindromic Repeats," is a cutting-edge technology used for targeted genome editing, offering exceptional precision, efficiency, and adaptability.[2] The CRISPR technique utilizes three major components. The first is the Cas9 enzyme that cuts DNA, the second is the CRISPR RNA that is bound to Cas9, and the third is a guide RNA that binds the CRISPR RNA and also aligns with the target DNA sequence that will be edited. [3] CRISPR/Cas9 system can thus be employed as molecular scissors to precisely change or edit DNA sequences. One major application of CRISPR/Cas9 is to edit and correct defective genes, which are comprised of DNA sequences, associated with genetic disorders. CRISPR/Cas9 technology can be applied to any kind of cell, e.g., somatic cells, germline cells, and embryos, enabling the addition, removal, or alteration of DNA within a genome. Somatic cells, which are not passed on to offspring, have been successfully targeted in addressing conditions such as HIV, sickle cell disease, and transthyretin amyloidosis.

Moreover, CRISPR holds promise for enhancing treatments for various cancers. Despite the promise of CRISPR/Cas9, heritable human genome editing enabled by CRISPR/Cas9 is the subject of intense debate due to concerns over its potential impacts on future generations and society as a whole. Although the technology offers the possibility of correcting genetic defects in embryos, the ethical implications and uncertainties surrounding its long-term effects on offspring health remain contentious. Beyond medical applications, CRISPR/Cas9 has the potential for broader use in enhancing human characteristics, including appearance and cognitive functions in the form of designer babies. These prospects raise ethical questions regarding the potential for altering fundamental aspects of human biology and the societal implications of such interventions. Although promising, CRISPR/Cas9 system is not

[2] Asmamaw, Misganaw, and Belay Zawdie. "Mechanism and Applications of CRISPR/Cas-9-Mediated Genome Editing." *Biologics: targets & therapy* vol. 15 353-361. 21 Aug. 2021, doi:10.2147/BTT.S326422

[3] ibid

fool proof. For example, CRISPR/Cas9 may non-specifically target sequences in the genome other than the intended target sequence and thus cause harm. Another is that even if the target sequence is correctly edited, one may not know any side effects of that change until much later. For example, changing genes that may underlie appearance of cognitive function may unpredictably impact physiology.

Because using CRISPR/Cas9 system may have unintended effects that are not yet known, using these genetic scissors to ensure disease prevention in future generations may also not be the safest course of action.[4] The road from diagnosis and treatment to prediction and prevention is fraught with many unknowns.[5] The growing body of research on the human genome and its implications for freedom, human rights, and dignity as well as the outlawing of all forms of discrimination based on genetic traits led to the creation of the Universal Declaration on the Human Genome and Human Rights.[6] Genome editing may impact a person's right to life, right to privacy, right to dignity, right to personal autonomy, right to procreate, and other rights. This paper investigates the feasibility and ethical implications of using gene editing techniques to enhance health outcomes, addressing potential challenges and opportunities in safeguarding human health within the framework of the International Right to Health, and exploring the intersection of gene editing technology and the Right to Health.

IV. RIGHT TO HEALTH

Right to health was first recognised by the World Health Organization in 1946.[7] It is described as "the enjoyment of the highest attainable standard of health". Complete physical, mental, and social well-being is stated in the preamble; it goes beyond simply being free from disease or disabilities. The states that signed the agreement also concurred that health protection is worthwhile and crucial for each and every

[4] Albertsdóttir, Ellen. *Gene Therapies Raise Difficult Legal and Ethical Questions*, 22 Dec. 2022, www.lunduniversity.lu.se/article/gene-therapies-raise-difficult-legal-and-ethical-questions.
[5] ibid
[6] United Nations General Assembly. The Universal Declaration of Human Rights (UDHR). New York: United Nations General Assembly, 1948.
[7] "WMA - The World Medical Association-Right to Health." *The World Medical Association*, www.wma.net/what-we-do/human-rights/right-to-health/. Accessed 23 Mar. 2024.

state.[8] Other than the world health organization, Article 25 of Universal Declaration of Human Rights[9] mentions Health as a part of its right to an adequate standard of living, The International Covenant on Civil and Political Rights[10] and also the committee on economic, social and cultural rights[11] which monitors its implementation, mentions right to health as a comprehensive one that covers the underlying factors that influence health as well as prompt and appropriate medical care.

Furthermore, the right to health encompasses a wide range of rights, such as the right to privacy, the right to autonomy, and the right to information within its ambit. A detailed discussion of how these rights overlap with the right to health is done later in the paper. The Indian Constitution does not specifically mention the right to health as a fundamental right under part III of the Indian Constitution, however, over a period of time, judicial interpretations have led to its recognition under Article 21, protection of life and personal liberty. This definition of the right to health centres on its importance as a fundamental right that is essential to the exercise of other Human Rights. In Francis Coralie Mullin vs The Administrator the court observed life under article 21 to be life with dignity and not merely animal existence or survival. [12]

In *Bandhua Mukti Morcha v. Union of India* the court read dignity and health within the ambit of life and liberty under Article 21.[13] Therefore, it is an implicit a fundamental right in India. Once that is concluded, another consideration would be that of future

[8] WHO, Constitution of World Health Organization, 22 July 1946, Article 2. https:// www.who.int/publications/m/item/constitution-of-the-world-healthorganization, 2006 (accessed 16 March 2024).
[9] The UN General Assembly, Universal Declaration of Human Rights, Article 25 (1). https://www.ohchr.org/en/human-rights/universal-declaration/translations/english, 1995 (accessed 16 January 2022)
[10] The UN General Assembly, The International Covenant on Civil and Political Rights (adopted 16 December 1966), Article 12. https://www.ohchr.org/en/ instruments-mechanisms/instruments/international-covenant-civil-and-politicalrights, 1966 (accessed 16 March 2024).
[11] The UN Economic and Social Council, E/C.12/2000/4: General Comment No. 14 on the highest attainable standard of health (2000), The Committee on Economic, Social and Cultural Rights. https://www.ohchr.org/en/documents/generalcomments-and-recommendations/ec1220004-general-comment-no-14-highestattainable, 2000 (accessed 16 March 2024).
[12] Francis Coralie Mullin vs The Administrator, Union Territory of Delhi AIR 1981 746
[13] Bandhua Mukti Morcha v. Union of India AIR 1984 SC 812

generations. Maastricht Principles on The Human Rights of Future Generations[14] as adopted in 2023 accounts for future generations' rights, which is crucial to consider because the decisions taken today may have a substantial influence on their right to health and well-being. Genome editing has the potential to bring profound benefits but also poses significant risks. Decisions about its use could have long-lasting effects, on the future generation. When considering these implications, it's vital to recognize that even though they are not yet born, have an inherent right to health.

This concept aligns with the World Health Organization's definition of health as complete physical, mental, and social well-being, not merely the absence of disease. Any decisions should prioritize not only current benefits but also the potential risks and long-term impacts on those who will inherit the outcomes of choices made in the present. The preamble to various other international documents, such as the Universal Declaration of Human Rights and the Convention on the Rights of the Child, underscores that the rights to health and well-being aren't limited to the current generation but extend to those who will follow. The paper continues by talking about the potential consequences of gene editing, which can be used to stop diseases and guarantee that the right to health of future generations remains unaffected. In addition, the potential negative effects of gene editing have long been considered in regard to the commercialization of the technique and the health rights of future generations.

V. POSITIVE IMPACT OF GENE EDITING ON RIGHT TO HEALTH

Human gene editing will be able to cure monogenic hereditary diseases such as Huntington's disease, muscular dystrophy, and cystic fibrosis.[15] As a result, by editing zygotes to fix genetic errors that are likely to result in health issues down the road,

[14] Liebenberg, Sandy, et al. *Maastricht Principles on The Human Rights of Future Generations*, www.ohchr.org/sites/default/files/documents/new-york/events/hr75-future-generations/Maastricht-Principles-on-The-Human-Rights-of-Future-Generations.pdf. Accessed 23 Mar. 2024.

[15] "Genome Editing Pros and Cons." *Nationale Akademie Der Wissenschaften Leopoldina*, 29 June 2023, www.leopoldina.org/en/topics/genome-editing/genome-editing-pros-and-cons/.

they can help prevent disease. The first therapeutic germline intervention using CRISPR/Cas9 was reported in August 2017, and it was successful in demonstrating that gene editing is a feasible method for correcting a gene mutation in viable human embryos.[16] Similarly, another possible application would be infertility treatment by Oocyte editing and spermatogonial editing.[17] Gene editing may increase resistance to potential threats by selecting more resilient traits and passing them on to the next generation.[18] By lowering their risk of contracting diseases that can be treated through gene editing, this raises their standard of living and lengthens their life expectancy.

Researchers are becoming more aware of the effects of any genetic imbalances that children have on their bodies, which is one of the main benefits of the growing body of knowledge regarding the role that genetics plays in disabilities. With this discovery, doctors will now explore the possibility of genetic problems, something they did not do earlier and took a long time to consider, frequently placing the blame on the patient's behaviour and fault. But having too much knowledge can also be a burden if there is no known treatment or preventive measure for the condition, which could cause a healthy person to manifest illness as well. Without a preventative measure, the information could have a negative effect on every aspect of a person's life.

The first person to genetically alter human embryos to prevent HIV infection was a Chinese scientist. The procedure was successful, and the children now lead happy lives. The issue with the Chinese incident is not so much the application of gene editing as it is its premature application in the absence of scientific proof that

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[16] Ma H, Marti-Gutierrez N, S-W Park JW, Lee Y, Suzuki K, Koski A, Ji D, Hayama T, Ahmed R, Darby H, Van Dyken C, Li Y, Kang E, Park A-R, Kim D, Kim S-T, Gong J, Gu Y, Xu X, Battaglia D, Krieg SA, Lee DM, Wu DH, Wolf DP, Heitner SB, Izpisua Belmonte JC, Amato P, Kim J-S, Kaul S, Mitalipov S. Correction of a pathogenic gene mutation in human embryos. *Nature.* 2017;548:413–419. doi: 10.1038/nature23305.

[17] Rubeis G, Steger F. Risks and benefits of human germline genome editing: An ethical analysis. Asian Bioeth Rev. 2018 Jul 16;10(2):133-141. doi: 10.1007/s41649-018-0056-x. PMID: 33717282; PMCID: PMC7747319.

[18] Withers, Andrew, and Megan E. Jenkins. "Can Gene Editing Increase Ecosystem and Species Resilience?" *The CGO*, 30 Nov. 2023, www.thecgo.org/research/can-gene-editing-increase-ecosystem-and-species-resilience/#:~:text=By%20selecting%20more%20resilient%20traits,well%20as%20its%20genetic%20diversity.

CRISPR/Cas9 is safe.[19] Before coming to a decision, it's crucial that we comprehend the entire ramifications for the right to health, going beyond its potential to shield children from illness and provide them with a better, healthier existence.

VI. NEGATIVE IMPACT OF GENE EDITING ON RIGHT TO HEALTH

The next question is whether, in the event that genome editing does not turn out as intended, the right to health would also take the associated risks into consideration. The consequences of gene editing include the potential for unintended, off-target effects that could change genes in a way that prevents some types of cancer while causing others.[20] The issue with this is that there could be situations where the altered gene affects not just the child but also all the subsequent generations. When it comes to the right to health, the unpredictable ways of nature are not taken into consideration, nor is the effect they will have on all future generations. Patient safety is another concern in all of these therapies. It is the responsibility of genetic engineers in these kinds of cases to weigh the advantages and disadvantages. This means that since these therapies may have an impact on the patients' offspring and how they interact with society, the parties should give their informed consent.[21]

WHO recognizes the right to health to include the right to be informed about any health service or treatment they might undergo.[22] These aids them in coming to a well-informed conclusion. But when the rights of the next generation are established, this becomes an issue. It is impossible to obtain the child's consent to give them genetically modified DNA. In addition to the right to informed consent, patients also have the

[19] Raposo VL. The First Chinese Edited Babies: A Leap of Faith in Science. JBRA Assist Reprod. 2019 Aug 22;23(3):197-199. doi: 10.5935/1518-0557.20190042. PMID: 31436399; PMCID: PMC6724388.
[20] "Genome Editing Pros and Cons." Nationale Akademie Der Wissenschaften Leopoldina, 29 June 2023, www.leopoldina.org/en/topics/genome-editing/genome-editing-pros-and-cons/.
[21] Leifan Wang, Xiaohui Liang, Weiwen Zhang, Genome editing and human rights: Implications of the UNGPs, Biosafety and Health, Volume 4, Issue 6, 2022, Pages 386-391, ISSN 2590-0536, https://doi.org/10.1016/j.bsheal.2022.10.002
[22] "Right to Health." *World Health Organization*, World Health Organization, www.who.int/news-room/facts-in-pictures/detail/right-to-health#:~:text=Individuals%20have%20the%20right%20to,for%20themselves%20on%20their%20health. Accessed 23 Mar. 2024.

right to autonomy, which allows them to make decisions after carefully weighing all available options. This is a common expression that even the Supreme Court has acknowledged that getting the patient's permission is crucial before a doctor does anything. The outcome of gene editing would change the genes of the next generation, who would then technically be the patients; therefore, parental consent should not be the only requirement. But they are not allowed to participate in the same decision-making process in any way.

When a person is terminally ill or incapable of making decisions for themselves, their right to autonomy is suspended. The doctors can depend on the immediate family in these situations. This could serve as a defence against the future generation that their parents' agreement is sufficient because the goal is to give them better, disease-free healthcare. Since the right to health guarantees a person's ability to live in society with dignity, respect, and personal autonomy, it also includes the right to privacy with regard to medical data.[23] Genetic data reveals important details about a single person as well as their entire family tree. Even in the lack of any medical information, this information may be used to forecast the risks that a person and his biological relatives may face in the future.

The International Bioethics Committee states that discovering one's genetic endowment may have an impact on one's emotional well-being in addition to endangering the health of future generations. In situations where the genetic component of phenotype is over-emphasized, certain other behavioural, psychosocial, and environmental factors may be underestimated. This could be a factor in cases where the true cause of the illness is not discovered until much later.[24] The sanctity of the human genome is another major concern with genetic interventions because

[23] Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information: The HIPAA Privacy Rule; Nass SJ, Levit LA, Gostin LO, editors. Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research. Washington (DC): National Academies Press (US); 2009. 2, The Value and Importance of Health Information Privacy. Available from: https://www.ncbi.nlm.nih.gov/books/NBK9579/

[24] "Report of the International Bioethics Committee (IBC) on Updating Its Reflection on the Human Genome and Human Rights. Final Recommendations." *Revista de Derecho y Genoma Humano = Law and the Human Genome Review*, U.S. National Library of Medicine, pubmed.ncbi.nlm.nih.gov/27311162/. Accessed 23 Mar. 2024.

altering it would be tantamount to tampering with God's creation.[25] Another concern is undermining of the entire human genetic pool.[26]

One of the most significant aspects of gene editing is the fact that, once gene editing is completed, the changes made to human DNA are transferable to subsequent generations and cannot be undone. As a result, there's a chance that if gene editing ever has an effect beyond what is necessary, the genes will be permanently altered. We also run the risk of losing the original set of genes we were born with and evolving into a new, defective genetic pool from which there is no way to return. The right to health also includes the States obligation to provide equal access at the same time refrain from marketing of drugs that might be harmful and unsafe for consumption.

This demonstrates that until the effectiveness of genome editing has been established and its right to health is not violated, the states should not support it. The potential of commercialization of the technology to create designer babies should consider how social inequality—which already exists in society—may be made worse in addition to the health of the offspring. Allowing parents to check their children's genetic makeup, which would determine how they look, would exacerbate the prejudice already present in society. People would want kids who are fair, thin, coloured iris and such other specific features. This would lead to further discrimination within the society based on appearances that go beyond the reach for humans, now only accessible to rich people who can afford such technology.

Additionally, this might be abused in a way that results in eugenics, which would introduce genetic discrimination.[27] The world would then be controlled by eugenicists who would determine who deserves to live and who doesn't. However, what is

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[25] Habermas J. *The Future of Human Nature (trans. William Rehg, Max Pensky, Hella Beister)* Cambridge: Polity, Press;
2003. https://monoskop.org/images/3/36/Habermas_Jürgen_The_Future_of_Human_Nature_2003.pdf

[26] Committee on Science, Technology, and Law; Policy and Global Affairs; National Academies of Sciences, Engineering, and MedicineOlson S, editor. International Summit on Human Gene Editing: A Global Discussion. Washington (DC): National Academies Press (US); 2016.
https://www.ncbi.nlm.nih.gov/books/NBK343651/

[27] Walsh, Fergus. "Gene Editing Technique Could Transform Future." *BBC News*, BBC, 5 June 2016, www.bbc.com/news/health-36439260.

considered undesirable today may be beneficial in the future as our environment, disease susceptibilities, and our concepts of beauty and intelligence change. This is the conundrum of making decisions now that will affect future generations. In addition, we ought to take into consideration the loss that would result from not advancing the technology. Determining whether to proceed with the technology or not requires more thought than just adding up the advantages and disadvantages.

VII. CONCLUSION AND SUGGESTION

The boundaries of one person's fundamental rights end where those of another begin. In this instance, too, the rights of present parents end where the fundamental rights of prospective parents begin. Gene editing becomes problematic when it is applied in a way that affects the rights of future generations and cannot be undone in the event that the affected person decides against it due to a heritable trait. Gene editing would primarily affect the future generation's right to health, so even after accounting for all other factors, it is impossible to conclude that it will only have beneficial effects on this right. A disease-free lifestyle is just one aspect of the right to health; other, more limited rights included in right to health, such as autonomy, privacy, and data, are violated if technology is permitted. But the promise of disease-free offspring outweighs any possible negative effects on other rights, making gene editing an irreversible necessity. As a result, society cannot operate without this technology; nevertheless, having right norms and structure in place will make going forward with the technology simpler.

Because we cannot eliminate technology that may have the potential to save the right to health of future generations. The only issue with scientific advancement is that it cannot provide us with guidance on how to live our lives and cannot provide answers to moral, legal, or ethical dilemmas. The onus ultimately rests with society to bring up the appropriate legal concerns and stop human rights violations. In order to prevent violations of other rights, even minor ones, comprehensive research should be done beforehand, and solid laws and regulations should be in place both before and after the technology becomes standardised.

Making certain that technology has no unintended consequences for future generations' rights can only be accomplished when extensive study has been conducted to guarantee that everything is taken into consideration and that no unintended consequences occur. Only once this has been ensured can the device be given a green signal, ensuring that there are no unintended consequences. The right to health of future generations is not the only right available to them; thus, it is critical to guarantee that no other right is infringed when they are granted the right to health. Because who is to say whether one right supersedes another or whether one can be violated in the name of achieving another?