

Review Paper

Altered Human: A Moratorium on Human Germline Editing as a fundamental violation of the rights of The Unborn, our future generations

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ABSTRACT

With the advent of CRISPR-Cas9, Clustered regularly interspaced short palindromic repeats (Crispr), touted to be the best gene editing tool by the scientific and medical community, it is currently possible to practice human germline editing with efficiency, accuracy, and affordability, to eradicate fatal diseases, and correct faulty gene mutations, for future generations. If human germline editing becomes law, it will have the power to create humans without fatal diseases and faulty gene mutations. However, International organizations such as UNESCO, and The Oviedo Convention have placed a moratorium on human germline editing because of its capability to end the heritage of humanity itself.

This paper will take the position that human germline editing will not end the heritage of humanity. On the contrary, it will bring forth not just the preservation of humanity, but the preservation of better specimens of humanity. As such, a moratorium on human germline editing should be lifted, and in its place, solid legal guidelines put in place to conduct further research in this field. In support of its position, this paper will extend two arguments. The first will be based in Galton's eugenics "better to be good rather than bad specimens of their kind" argument, while the second will be based in a humanistic "for the benefit of future generations" argument, already contained within the premise of the Oviedo Convention itself.

This paper is divided into 5 sections. The first section will explore human germline editing as a scientific innovation that can alter unborn humanity. In section two, a revolutionary gene editing technology, Crispr will be explored. In section three, this paper will explore international organizations, and their laws, that have placed a moratorium on human germline editing as, according to them, it has the capability to end the heritage of humanity. In section four, this paper will extend two arguments, one based in eugenics, and the other based in human rights, in favour of lifting a moratorium on human germline editing. In its fifth section, this paper will take a humanistic stance that while preserving the heritage of humanity is important, such a preservation cannot be maintained at the expense of benefits that can be conferred upon our future generations brought upon by science and technology such as gene editing technologies, and human germline editing. Preventing such benefits to our future generation, is a fundamental human rights violation of the unborn, the voiceless in our society.

Key Words: Human Germline Editing, Crispr Cas-9, Eugenics, Human Rights, Unborn

Human Germline Editing as a scientific innovation that can alter unborn humanity

Genome editing technologies enable changes to be made to the DNA of living organisms such that physical traits, and the risks of fatal diseases, and faulty gene mutations, in these living organisms can be altered [1]. For the purposes of this paper, the focus will be on human genome editing. In human genome editing, it is important to distinguish between somatic and germline editing. Somatic gene editing “affects only the patient being treated (and only some of his or her cells)...[while] germline editing affects all cells in an organism, including eggs and sperm, and so is passed on to future generations.”² In germline editing, the entire genome is altered. As per the National Human Genome Research Institute, somatic editing targets non-reproductive cells [2] and affects the human edited...while germline editing targets reproductive cells (sperm, eggs, embryo) and are passed down from generation to generations [3].

If human germline editing becomes law, it will become possible to not only manipulate the genetic makeup of humanity, with efficiency, accuracy, and affordability, but also to design, produce, and pass on the best heritable human population, with efficiency, accuracy, and affordability. Currently, Crispr is seen as a revolutionary tool that can facilitate human germline editing with efficiency, accuracy, and affordability. More importantly, Crispr, if used to edit germline, is seen as a revolutionary scientific innovation that can alter unborn humanity.

CRISPR, a revolutionary gene editing technology

It is important, therefore, to explore Crispr. Crispr was popularized by Dr. He Jiankui, a scientist from Southern University of Science & Technology. Dr. He was condemned for using Crispr to genetically modify human embryos to make them immune to HIV, and then implanted them into a real live woman, who gave birth to twins. While Dr. He was severely condemned by the Chinese government, and punished with 3 years of imprisonment, and a hefty fine, the world did take notice of the revolutionary capability of Crispr to alter unborn humanity.

Simply put, it is a gene editing tool that works by means of a homing device guiding a molecular scissors (cas9 enzyme) to a target a section of DNA. Together, the device, and the scissors, work to insert, delete, modify, replace disable, repair, or insert something new to the area that was cut. In medical terms, the words often used are “disable.... repair.... insert....” [4].

As noted in section I, Crispr is considered a revolutionary scientific innovation as it trumps older gene editing tools in terms of efficiency, accuracy, and affordability. With its potential to be efficient, accurate, and affordable, if human germline editing using Crispr becomes legal, it will become accessible to all of humanity, to not only eradicate heritable fatal diseases, and correct heritable faulty gene mutations, but to also modify and perfect the genetic makeup of humanity itself. As a result of its capability to alter future unborn humanity, some international organizations, in the name of human rights, have placed a moratorium on human germline editing for fear that it will alter the heritage of humanity itself. For the purpose of this paper, the two organizations’ international laws that will be discussed in this paper are UNESCO, and The Oviedo Convention, respectively.

International laws: Human germline editing as an end to the heritage of humanity, A morphed moratorium

The first act of international law that has placed a moratorium on genetic editing of the human germline was found in UNESCO’s Universal Declaration on the Human Genome and Human Rights. Quoting 29 C/Resolution 17 entitled: “Implementation of the Universal Declaration on the Human Genome and Human Rights,” the organization stated in no unclear terms that if human germline editing is allowed, it will be the end of the “heritage of humanity”.

Through the declaration, they pointed out the need to “protect and pass our heritage to future generations and protect human rights.” Human genome editing should only be allowed for “preventive, diagnostic, or therapeutic reasons and without enacting modifications for descendants” [5-6].

It is crucial to understand that “modifications for descendants” should be interpreted to mean germline modifications, which can only be made to human embryos. As such, the declaration was referring specifically to a moratorium on human germline editing.

Likewise, The Convention on Human Rights and Biomedicine (Oviedo Convention), which is part of the council of Europe (an international organization based in human rights, democracy, and rule of law), the only internationally legally binding instrument on the protection of human rights in the biomedical field, has placed a moratorium on human germline editing, using an almost verbatim ad litteratim phrase:

Under Article 13: “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*”. This is interpreted as judiciously permitting human somatic gene editing, while imposing a “complete ban” on human germline editing.

It is crucial to understand that “any modification in the genome of any descendants” should be interpreted to mean germline modifications, which can only be made to human embryos. As such, Article 13 was referring specifically to a moratorium on human germline editing.

Arguments in favor of lifting a moratorium on human germline editing: Eugenics and Human Rights

While this paper agrees with the two organizations above that preserving the heritage of humanity is to protect fundamental human rights, it questions the failure of these human rights organizations to protect the human rights of humanity not yet born, our future generations. It, therefore, takes the stance that in line with the same reasoning, that is to protect human rights of the unborn, the voiceless in our society, a moratorium on human germline editing, should be lifted.

In support of its stance, this paper will offer two arguments, one based in Galton’s eugenics, and the other in human rights itself.

Argument 1: Galton’s “Better to be good rather than bad specimens of their kind”

Eugenics is a set of beliefs, and practices that focus on producing a human population with the best genetic makeup [7]. In an attempt to define the essentials of eugenics in his 1904 article, Galton referred to a fable in which animals in a zoological garden, agreed that:

“...it was better to be healthy than sick, vigorous than weak, well-fitted than ill-fitted for their part in life; in short, that it was better to be good rather than bad specimens of their kind, whatever that kind might be [8].”

Most of humankind will agree with this definition. In fact, it will be irresponsible to humanity not to agree with the above statement. Most of us aspire to be mentally, and physically fit. Being indisposed mentally, or physically, not only carries with it the burden to oneself, in the form of pain and suffering, but a burden to others, who will have to take care of the indisposed, and witness the pain and suffering. In addition, the cost of medical care, and the financial drain on society at large to take care of the indisposed cannot be ignored. Ultimately, we must suffer the pain of losing loved ones, when death ensues from fatal diseases, or faulty gene mutations.

We cannot possibly aspire to be “bad specimens” of our kind. As such, it can be safely concluded that a human who will be born in the future will most probably not wish to inherit fatal diseases, and faulty gene mutations, even from his or her own loved ones. In conclusion, unborn humanity will most probably be in favor of germline editing, as performed on them.

It is important to note that human germline editing can only be performed on humans not yet born, and as such, it will be futile to discuss informed consent here as it cannot be given.

Argument 2: Human Rights’ “Solely for the benefit of future generations”

This paper could not ignore the fact that while the two international organizations mentioned above have placed a moratorium on human germline editing as a way to preserve the heritage of humanity as a fundamental human rights, they seemed to have failed to adequately defend their decision based in human rights, for future generations. While human genome editing should be allowed for “preventive, diagnostic, or therapeutic reasons...”, the fact that “*any modification in the genome of any descendants*” should be excluded from this equation should be interpreted to mean that there are no protections for our future generations, which is a human rights violation in itself. Hypothetically, if an already born human, wishes to have children, and has a fatal predisposition in his or her genetic makeup, according to these organizations, he or she must simply refrain from

having children. There will be no option, despite scientific innovations, such as Crispr, to be able to correct this predisposition at germline. There are other possibilities of course, such as Preimplantation Genetic Testing (PGT) that can facilitate the selection of good genes to be implanted into the uterus in order to correct the fatal pre-dispositions. However, fertility treatments such as PGT are costly. While the elite will have no issue with expensive medical treatments, the rest of the world will not be able to afford these treatments, opting for no children at all. If we follow the human rights argument, it can be argued that placing a moratorium on germline will have the opposite effect of not preserving the heritage of humanity but contribute towards its extinction.

Interestingly, it is crucial to note that Article 13 is “in contradiction with one of the motivations of the Oviedo Convention, that progress in biomedicine would be used solely for the benefit of future generations” [9].

Conclusion: A voice for the voiceless

This paper is cognizant of the fact that germline editing can open a floodgate of nonmedical, non-essential, and cosmetic enhancements into play. Humanity in its natural form can aspire not only to be healthy, but to be beautiful too. While there is nothing wrong with wanting to be healthy, and be beautiful, it is important to focus human genome editing, and human germline editing especially, in the eradication of fatal diseases, and faulty gene mutations. In protecting human rights, we must at the least, consider the right to be healthy, and placing a moratorium on human germline editing takes away that fundamental right for the unborn, our future generation.

Additionally, when we consider human rights, it is important not only to consider humanity that exists but also humanity that will exist in the future. In particular, it is important when we consider human rights to pay attention to the most vulnerable in our society, the ones without voices, such as the unborn. In placing a moratorium on human germline editing, we have completely ignored our future generations. Any scientific innovation that has the capability to better the genetic makeup of humanity, should not be compromised in the name of protection of human rights, when such a protection has the effect of violating the fundamental human rights of the unborn, the ones without voices. In fact, it is more important to protect the rights of those without a voice, the voiceless, the unborn in our society. This paper rests its case

REFERENCES

1. What is genome editing? (2019, August 15). Retrieved September 25, 2020, from <https://www.genome.gov/about-genomics/policy-issues/what-is-Genome-Editing>
2. Bergman, M. (2019, October 28). Harvard researchers share views on future, ethics of gene editing. Retrieved September 23, 2020, from <https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/>
3. What is genome editing? (2019, August 15). Retrieved September 21, 2020, from <https://www.genome.gov/about-genomics/policy-issues/what-is-Genome-Editing>
4. What are genome editing and CRISPR-Cas9? - Genetics Home Reference - NIH. (2020, August 17). Retrieved September 21, 2020, from <https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting>
5. “Declaration on the Human Genome and Human Rights.” OHCHR, www.ohchr.org/en/professionalinterest/pages/humangenomeandhumanrights.aspx.
6. Implementation of the Universal Declaration on the Human Genome and Human Rights. UNESCO.ORG, www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/SHS/pdf/Guidelines-Genome_EN.pdf.
7. Galton F. Eugenics: Its Definition, Scope, and Aims. *Am J Sociol* 1904;10(1):1-25.
8. Ibid (Galton).
9. Sykora P, Caplan A. Germline gene therapy is compatible with human dignity. *EMBO Reports* 2017;18(12):2086.

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