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## Γενετικές Βελτιώσεις και Διανεμητική Δικαιοσύνη

### **Επιβλέποντες:**

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Οι απόψεις και θέσεις που περιέχονται σε αυτήν την εργασία εκφράζουν τον συγγραφέα και δεν πρέπει να ερμηνευθεί ότι αντιπροσωπεύουν τις επίσημες θέσεις του Εθνικού και Καποδιστριακού Πανεπιστημίου Αθηνών.

## Introduction

Recent innovations in the field of biotechnology have raised, once more, issues concerning the ethics of applying it to humans. After the successful decoding of the human DNA, many have talked about a potential intervention to it or even copying it. During a long period of time the dominant scientific approach claimed that the genes are fully responsible for both “external” and “internal” characteristics. It has been thought that genetic intervention would completely transform humanity. This genetic determinism and the scenario of “humanity’s breakthrough”, through genetic intervention faced two difficulties: firstly, despite the successful and progressively less costly process of gene sequencing, scientists have been unable to identify specific genes – linked to specific character traits – as multiple genes are responsible for the appearance of most genetic characteristics. Secondly there existed no sufficient method for altering the human DNA. After the invention of certain biotechnological tools such as TALEN and Zync-finger nucleases, some genetic modifications became possible and genetic therapies were applied.<sup>1</sup>

The altering of human genome has been regulated for most European countries by the Oviedo Convention in 1997<sup>2</sup>. According to the convention any genetic modification would apply only to somatic cells (thus changes would be non-heritable) and only for therapeutic reasons. The Oviedo Convention despite the fact that it has not been widely approved (not signed by neither UK nor Germany for example) has set the rules for gene editing over the past years.

The big ethical question concerning the modification of human genome emerged again when a new biotechnological tool, called CRISPR Cas-9 was invented.<sup>3</sup> CRISPR, the acronym of Clustered Regularly Interspaced Short Palindromic Repeats and Cas (CRISPR-associated) proteins, are indispensable components of a defense mechanism which certain bacteria use against viruses. In modern biotechnological applications the CRISPR Cas-9 system allows intentional and directed cutting of a DNA segment and potential replacement with another. In other words it can be used to substitute an “unwanted” part of the gene and replace it with one, which has the desired sequence of bases. CRISPR has brought a revolution in the field of biotechnology as it has rendered gene editing cheaper and more accurate. It has already been applied successfully to animals and also humans for therapeutic reasons.<sup>4</sup> It can help cure diseases like Sickle Cell Anemia or Cystic Fibrosis but, as with every technology, it can also, depending on its use, be ethically problematic or even disastrous. So was the case when in 2018 a Chinese scientist edited the genome of a fertilized egg which resulted to the birth twin babies, trying to make them immune to HIV.<sup>5</sup>

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<sup>1</sup> Among others: Christian M, Cermak T, Doyle EL, Schmidt C, Zhang F, Hummel A, Bogdanove AJ, Voytas DF. Targeting DNA double-strand breaks with TAL effector nucleases. *Genetics*. 2010 Oct;186(2):757-61. or

Carroll D. Progress and prospects: zinc-finger nucleases as gene therapy agents. *Gene Ther*. 2008 Nov;15(22):1463-8.

<sup>2</sup> Convention on Human Rights and Biomedicine (ETS No 164), Council of Europe, 1997

<sup>3</sup> Jinek M, Jiang F, Taylor DW, Sternberg SH, Kaya E, Ma E, Anders C, Hauer M, Zhou K, Lin S, Kaplan M, Iavarone AT, Charpentier E, Nogales E, Doudna JA. Structures of Cas9 endonucleases reveal RNA-mediated conformational activation. *Science*. 2014 Mar 14;343(6176):1247997.

<sup>4</sup> Indicatively: You L, Tong R, Li M, Xue J, Lu Y. Advancements and obstacles of CRISPR-Cas9 technology in translational research. *Mol Ther Methods Clin Dev*. 2019;13:359-370

<sup>5</sup> Nie JB, Cheung A. He Jiankui's Genetic Misadventure, Part 3: What Are The Major Ethical Issues? The Hastings Center Forum. 2019

After considering the serious bioethical implications of this new tool, scientists from all over the world asked for a moratorium against its use on humans.<sup>6</sup> Two influential bioethics commissions: the American National Academy of Sciences<sup>7</sup> and the British Nuffield council<sup>8</sup> propose a prohibition of the use of CRISPR in human germline cells.

Furthermore, the special bioethical value that human DNA carries for the majority of humanity and the potential dangers which may occur during the application of this kind of technology, prompted the members of the committees to condemn the editing of germline modification arguing on the need not to make interventions which are not safe and may affect the future generations. The arguments for and against gene editing develop along two separate axis. The first concerns the kind of cells being edited, whether they can only be somatic or should germline modification be allowed too. The difference being that germline modification will be carried on to the edited persons' posterity. The second axis concerns whether gene editing can only be permitted for therapeutic reasons or whether it can be used for "enhancement" of the species.

The issues raised by this kind of terminology caused the emergence of different interpretations over what may be permissible or not, a discussion already existing from the time of the Oviedo Convention. More specifically, a large part of the scientific community, as well as a great part of society in many countries<sup>9</sup> demands gene editing to be applied only under strict control and by rules set and enforced by an International Institution. Others, embrace this kind of international regulation only for germline cell editing concerning either enhancement or therapy. Others request permission for any kind of gene editing but only for therapeutic purpose, while some talk about a duty to enhance humanity and criticize the prohibition over enhancing or germline operation. They call for a way of use which could bring benefits to the largest number of people.<sup>10</sup>

In the following sections of this essay we will try first, to examine the "grey zone" in cases of germline and somatic operations as well as the problems which occur when either type of operation is prohibited or allowed. Secondly, we will attempt to present the different interpretations of the terms "therapeutic" and "enhancing" as well as issues raised by the various ways of defining them. Subsequently, we will endeavor to analyze the arguments for and against gene editing applications. We will examine the reasoning/ of experts who are : *pro-germline and somatic for therapeutic uses only, pro somatic for any purpose, and pro germline and somatic for any purpose* either therapeutic or enhancing. We will argue that although a prohibition on somatic gene editing cannot be plausible for reasons of self-determination and

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<sup>6</sup> Guttinger S. Trust in Science: CRISPR-Cas9 and the Ban on Human Germline Editing. *Sci Eng Ethics*. 2018;24:1077–1096. doi: 10.1007/s11948-017-9931-1

<sup>7</sup> National Academies of Sciences, Engineering, and Medicine. Enhancement. In: *Human Genome Editing: Science, Ethics, and Governance*. Washington, DC: National Academies Press; 2017:137-162

<sup>8</sup> The Nuffield Council on Bioethics. *Genome editing and human reproduction: social and ethical issues*. 2018

<sup>9</sup> Critchley C, Nicol D, Bruce G, Walshe J, Treleaven T and Tuch B Predicting Public Attitudes Toward Gene Editing of Germlines: The Impact of Moral and Hereditary Concern in Human and Animal Applications. *Front. Genet*. 2019,704,

Müller M, Schneider M, Salathé M, Vayena E. Assessing Public Opinion on CRISPR-Cas9: Combining Crowdsourcing and Deep Learning *J Med Internet Res* 2020;22(8):e17830

<sup>10</sup> Savulescu J, Pugh J, Douglas T, Gyngell C. The moral imperative to continue gene editing research on human embryos. *Protein Cell*. 2015;6(7):476-479, for a less welfarist view see: Doxzen K, Halpern J. Focusing on Human Rights: a framework for CRISPR germline genome editing ethics and regulation. *Perspect Biol Med*. 2020;63(1):44-53.

free will, the ethical implications concerning germline gene editing, especially issues occurring when examining the well-known “ non-identity problem “ and the autonomy or objectification of the embryo, justify a global scale prohibition of it. Finally, after examining some of the potential benefits of somatic gene editing and considering the danger of the new technology turning into another advantage only for those who have the money to purchase/afford such services, we propose a model through which these services may be provided (and controlled by) a public institution. We conclude stating that, although the proposed system may sound utopic, its main principles, namely equal concern and respect for all citizens as well as a shared view of the common good, may be followed by any type of system, especially of a kind of social democracy.

## Part 1

### Arguments for and against gene editing

CRISPR has been characterized as 21<sup>st</sup> century’s greatest scientific discovery. Since 2012, when it was first described, scientists have continuously explored new applications of it. As it can modify potentially any type of DNA ,CRISPR can be used for altering the DNA of any organism, plant or animal. As a result it can be applied to manipulate the genome of vegetables in order to make them, for example, less water demanding or pest resistant. It can also modify the genome of animals, rendering their organs more suitable for transplants, or “bring back to life” lost species like mammoths. Finally, it can be used for altering the human DNA. Scientists had successfully applied this technology in research for the cure of genetic diseases like sickle cell anemia, Huntington’s disease and specific types of cancer. Therapeutic purposes are not the only way it can be used though. It has been claimed that through genetic modifications one can enhance human capacities such as strength, endurance, intelligence and memory.<sup>11</sup>Genetic modification can take place both in somatic as well as in germline cells. If done in a reproductive cell, a gamete, or an embryo, the modification will be conserved to the modified person’s posterity. For both of these reasons : the difference between therapeutic uses and “enhancement” and the somatic-germline dipole, scientists and philosophers have been proposing different, often opposing<sup>12</sup> views of the future uses of CRISPR as well as any other gene editing technology which may be invented.<sup>13</sup>

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<sup>12</sup> We have deliberately avoided to use the terms “bioliberal” and “bioconservatives”. As far as the term “bioliberal” is concerned we believe that it links pro-editing opinions and arguments with a tradition carried on from the French revolution and the Enlightenment but in our view gene editing by itself promotes neither freedom (two generations of edited babies are enough so as to have a population of genetically predetermined individuals) nor equality or fraternity (for the reasons presented). “Bioconservative” on the other hand is a term used to characterize a vast spectrum of theorists with very different approaches on bioethical issues (from Habermas to Fukuyama) solely on the basis of their opposition to a debatable aspect of the procreative right, namely the right to decide your offspring’s genome.

<sup>13</sup> Indicatively:Gyngell C, Douglas T, Savulescu J. The Ethics of Germline Gene Editing. *J Appl Philos*. 2017;34:498–513.

Or Habermas J. *The Future of Human Nature* (trans. William Rehg, Max Pensky, Hella Beister) 2003 Cambridge: Polity Press

Or Baylis F., *Altered inheritance. CRISPR and the ethics of human genome editing* , Harvard University Press , 2019

Initially, as also depicted for example in Nuffield Council's publications, the main considerations concerning the use of CRISPR for editing human DNA has been the significantly high risk of such an operation for humans. An unsuccessful genetic modification, for example, a mistake which could produce off target effects (alteration of other parts of DNA- where the sequence of the bases is quite identical to the targeted one) may cause a painful death.<sup>14</sup> In other words, the potential danger of side-effects has been the main reason for skepticism towards CRISPR's wider use. As one can imagine this argument against gene editing cannot stand for long. When it becomes safe, cheaper and more efficient, humanity must decide the frame within which it will be widely used. As technology is innovating and getting better, these questions become even more urgent.

In what follows, we will try to examine some of the representative contradicting views concerning the application of gene editing in general and gene editing to humans in particular. As far as any editing, other than therapeutic, is concerned (in other words, editing concerning "enhancement" purposes, or editing in germline cells), scientists and philosophers have expressed different views. Some, find the prohibition of germline editing, even for therapeutic reasons, false and claim that giving an embryo the chance to live a healthy life while at the same time gradually eliminating the existence of genetic diseases is a benefit for both the individual and for humanity as a whole. According to some, one is obliged to proceed to such an operation<sup>15</sup>. As the argument for "the best possible offspring" goes, it is for the best of humanity and for the parents to choose the "best" embryo among the fertilized eggs of an IVF. Furthermore, it would be even better if one could design and give the "best" characteristics to one's child. The scientists and philosophers who oppose such a practice are mainly concerned by the "slippery slope", which could lead to germline editing for enhancement purposes and a gradual stigmatization of more and more genetic characteristics as "unhealthy" or "abnormal".<sup>16</sup> These terms carry great ethical weight and should be used with caution. The term "healthy" can be very broadly interpreted so as to mean different things. It is a big question which diseases or genetic characteristics would be permitted to be edited. The slippery slope argument supports that, the more the list of genetic characteristics "to be fixed" develops, the greater the number of individuals will find themselves considered "faulty", excluded or even inferior becomes. Members of the deaf community, for example, find their condition to be a type of human genetic variation with a special kind of culture. Some may believe that the "best possible embryo" for a family with deaf parents may be a deaf one. Progressive exclusion of members of society may lead to alienation and sociopolitical instability.<sup>17</sup> At the same time "promoting" certain characteristics as "better" or more "useful" can also be dangerous for the emergence of a type of eugenics. For supporters of the so called "liberal eugenics" the argument goes as follows: people have the right to the "enhancement" or selection of their offspring

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<sup>14</sup> Hendel A, Fine EJ, Bao G, Porteus MH. Quantifying on- and off-target genome editing. *Trends Biotechnol*, 2015 Feb;33(2):132-40. 54.

Fu Y, Foden JA, Khayter C, Maeder ML, Reyon D, Joung JK, Sander JD. High frequency off-target mutagenesis induced by CRISPR-Cas nucleases in human cells. *Nat Biotechnol*. 2013 Sep;31(9):822-6.

<sup>15</sup> If a genetic disease is cured in the germline, the therapeutic modification is carried on by posterity so it may disappear in the future.

<sup>16</sup> Roberts D. Whose Conception of Human Flourishing? In Parens, Erik, and Josephine Johnston. Human flourishing in an age of gene editing, 2019, Oxford, Oxford University Press.

Harris, J. Is There a Coherent Social Conception of Disability, *Journal of Medical Ethics*, , 2000,26: 95–100

<sup>17</sup> Sparrow, R., Defending Deaf Culture, *Journal of Political Philosophy*, , 2005, 13(2): 135–152.

And Sparrow R. A Not-So-New Eugenics: Harris and Savulescu on Human Enhancement, *Hastings Center Report*, , 2005, 41(1): 32–42.

through in vitro fertilization and can already proceed to practicing a type of eugenics. Why would it be considered unethical if they chose the entirety of their future baby's characteristics? They will not be forced to do it, so why denying this choice to them? Isn't it against their procreative rights? Application of germline gene editing will also enable the "use" of only one fertilized egg cell, avoiding thus the destruction of the others (as it currently often happens in IVF...list of abbreviations procedures). Considering this, people valuing human life and dignity should not be opposed to such a procedure.<sup>18</sup>

The counter arguments to this position in sum go as follows: firstly, either oppose completely the idea of "enhancement", as they remain skeptical about the term's definition or because they consider that "liberty" in "liberal eugenics" is non-existent in reality. Secondly, they either promote a different kind of "slow science"<sup>19</sup> and believe that genetic enhancements should not be a priority for humanity.

More specifically, one may find both empirical and ethical arguments against genetic germline modifications. Ethical arguments include: respect for human dignity, the principle of autonomy, and the liberty of the individual to self-determine.<sup>20</sup> Some also speak of the human DNA as legacy of all humanity. Empirical arguments include the fear of potential danger (as these operations are of high risk), the emergence of another type of inequality – namely unequal access to enhancing technology – due to scarcity of resources, and fear of market or state paternalistic policies which could lead to the disappearance of certain genetic variations – something that is dangerous for the survival of the species.<sup>21</sup>

As far as enhancement arguments are concerned, first of all we should examine both empirical and ethical issues. In the case of IVF and the possibility to select some genetic characteristics of the future child, especially those involved to genetic diseases, through pre implantation testing; one can say that this type of action cannot be considered the same type of enhancement procedure. While IVF pre implantation testing results to the implantation (or not) of an already existing and genetically (not epigenetically) shaped embryo, enhancement gene editing procedure would involve a group of scientists who would actively alter the embryo's genome. Germline gene modification inspires the fear for the emergence of "designer babies" and parents who visit a "genetic supermarket"<sup>22</sup>-clinic choosing the "best" – in their opinion – characteristics in order to help their embryo have the "best possible life".<sup>23</sup> For some experts this might be ethically controversial and socially dangerous. Some ethics experts condemn such a practice as objectifying the embryo reducing human life to a selection process. They consider it a breach with the way humanity distinguished between man and man-made.<sup>24</sup> Although it is true that it is a parent's duty to do the best to secure a happy childhood and good life perspectives, one must admit that choosing the child's eye color cannot be considered the same type of choice as selecting a school.

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<sup>18</sup> Bourne H, Douglas T, Savulescu J Procreative beneficence and in vitro gametogenesis. *Monash Bioeth Rev* 2012;30:29–48

<sup>19</sup> Baylis, 2019 pp 123-147

<sup>20</sup> Kass, Leon, Beyond Therapy: Biotechnology and the Pursuit of Happiness, Report from the President's Council on Bioethics, 2003  
Habermas, 2003

<sup>21</sup> Baylis, 2019 pp 169-213

<sup>22</sup> Gyngell C, Douglas T Stocking the genetic supermarket: reproductive genetic technologies and collective action problems. *Bioethics* 2015;29:241–50

<sup>23</sup> Gyngell C, Douglas T, Savulescu J, The ethics of germline gene editing. *J Appl Philos* 2017;34

<sup>24</sup> Sandel, Michael, *The Case Against Perfection*, 2007, Cambridge: Harvard University Press, p.27

Some may claim that it constitutes also a breach of the way parenting is interpreted. According to one view, a parent's love cannot be related to designing the child so as to fit their own impression of a desirable genetic identity.<sup>25</sup> A parent should accept the child's genetic endowment and do his best to help it flourish. An intuition might be useful. Consider that one poses to a parent the following question: how would you want your child to be if it was not as it is? In our opinion, few would respond as "I wish it was blond", or had blue eyes and a musical talent. In addition, if a parent responded in such a way it would be difficult to think of him as a good parent. By intervening to human germline one violates the principle that every human being must be an end in itself.<sup>26</sup> It rather becomes an instrument, a medium to satisfy the parent's ambition and when that happens (without germline modification), in real life, it is certainly not considered as good parenting.

As far as empirical arguments are concerned, it is true that the current technology can be dangerous. Some interventions may have off target effects by cutting the patient's DNA to undesirable parts and therefore leading to implications such as mosaicism, which can be deadly.<sup>27</sup> Furthermore, the cost of such an intervention can be really high, creating a fear that financial inequality would be "scripted" in the DNA. Therapies and enhancements may become another benefit for the few. Like the existent health inequalities, germline gene editing services may deepen the gap between rich and poor, as the few able to afford enhancements for themselves and their children will gain a serious advantage in a competitive society with the current labor market policies. Such a case would undermine social mobility and would cancel the whole moral justification of the free-market capitalist system. A born rich will not only have access to the best education, health services, cultural and social capital, he will be able right from birth to have increased capacity to develop rare and market-demanded talents, securing thus his position at the top of the social scale.<sup>28</sup>

The fear of leaving the genetic inheritance of posterity, the genetic legacy of the whole of humanity in the hands of market- or culturally and politically-driven forces is common among some experts, as such a case would be dangerous for the species itself.<sup>29</sup> Although a full homogenization of the future generations is not possible, a gradual disappearance of "unwanted" genetic traits may lead to the impoverishment of humanity's genetic variations.<sup>30</sup> In such a case the danger of affecting natural evolution will be high. It will no longer be random natural procedures which, through a large period of time, determine genetic mutations. It will rather be in the hands of humanity to choose the way our species will alter genetically. One cannot just claim that the "natural way" is better, but history has shown that whenever humanity has been in position to decide whether or not to use a new potentially dangerous invention things did not go as expected neither for humans nor for nature.

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<sup>25</sup> Sandel, 2007, p. 29 and Kass, 2003

<sup>26</sup> According to Immanuel Kant and the categorical imperative, in order to act morally, one needs to treat other humans solely as an end and never as means to one's own end. Kant, Immanuel Groundwork of the Metaphysics of Morals. Translated by Ellington, James W. 1993, Hackett Publishing Company (3rd ed.) p. 36. 4:429

<sup>27</sup> Drabiak K. Untangling the Promises of Human Genome Editing. *The Journal of Law, Medicine & Ethics*. 2018;46(4):991-1009 for other views see: Cwik B. Moving Beyond 'Therapy' and 'Enhancement' in the Ethics of Gene Editing. *Camb Healthc Ethics Q*. 2019, Oct;28

<sup>28</sup> Baylis 198-213

<sup>29</sup> Baylis, 188-213

<sup>30</sup> Kamm, F. Is There a Problem with Enhancement?, *American Journal of Bioethics*, 2005, 5(3): 5-14



In addition, other than the serious biological and environmental issues which may occur, germline gene editing will affect society and the social system too. The example of India and the decline of female population after the widespread use of IVF pre implantation sex selection, should warn the optimist supporters of gene editing for the results of a complete control on human reproduction. Some experts argue that the existence of complete control or more potential choices in reproduction does not necessarily lead to more happiness or satisfaction. According to them, interpreting freedom as the ability to choose does not capture the essence of human flourishing. Happiness does not depend only on the amount of alternatives presented for the life of an individual.<sup>31</sup>

Finally, for some who oppose gene editing, the amount of money and brainpower invested on the development of gene editing technologies is vitally needed for other, more urgent, problems such as the reduction of carbon emissions, the protection of the environment (instead of evolving in order to be able to survive in a destroyed planet, it would be better if we tried to fix it), the reduction of wealth inequalities or the improvement of the accessibility of people in need to health services.<sup>32</sup> The examples mentioned above could help eliminate diseases and save millions of lives. Advocates of “slow science”<sup>33</sup> propose to take a step back and reflect on the potential risks, which include not only not having the promised benefits but also may lead to a potential violation of scientific and moral principles. They fear for a new “atomic bomb” project and call for action against action in global scale.

Some people, although not supporters of germline gene editing are skeptical of the establishment of a Moratorium against its application. They find that such a document would be difficult to write, difficult to enforce and are afraid that countries with lenient or even encouraging policies will – if not already done so – proceed independently to such uses of CRISPR. According to them, the fact that a Chinese scientist – not very well known in the scientific community – had the means to proceed to germline gene editing proved that there can be no control over who and where one will be able to repeat such an experiment. Contrary to other dangerous scientific inventions, CRISPR can be easy to use and access. “CRISPR-Toolkits” can be bought and “biohackers” have tried, so far unsuccessfully, to edit their genome. This situation can be interpreted in two ways, either” as state of emergency “urging for instant strict regulation of CRISPR applications – as legislated by many countries through the Oviedo convention, or, secondly, as a proof that this technology is the unavoidable future of humanity for better or worse.<sup>34</sup>

Somatic gene editing pro- and counter- arguments

Somatic gene editing for non-medical reasons has more supporters than germline genetic modification. This maybe explains why self enhancement criticism is not that frequent. The main arguments against somatic gene editing are more or less based on the view which finds that there exists a special moral significance in the human DNA, the importance of natural (over technical) way of evolution, the fear of inequalities and instability, or consider it being a potential mid stop towards germline editing. According to those who oppose somatic gene editing for enhancement purposes, there exist some “grey areas” between the legally

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<sup>31</sup>Sheena Iyengar Tucker Kuman Do More Choices Lead to More Flourishing? in Parens E. Josephine Johnston, 2019

<sup>32</sup> Baylis pp 147-168

<sup>33</sup> Baylis p123-146

<sup>34</sup> Rodolphe Barrangou. *The CRISPR Journal*. Apr 2019.67-67 and Rodolphe Barrangou. *The CRISPR Journal* .Oct 2019.247-248

employed terms “somatic” and “germline” and “enhancement and treatment”<sup>35</sup>. Even the last Nuffield Council’s report leans toward a “therapy- enhancement”<sup>36</sup> distinction of the permissible and impermissible applications of gene editing, while some experts call for a step beyond the somatic- germline modification dipole<sup>37</sup>. It is true that the Oviedo Convention too, is not clear whether the editing of an embryo or a zygote for therapeutic purposes is considered illegal, as such an operation does not aim directly for the modification of the future child’s posterity but at the cure of the fetus itself.<sup>38</sup> It is also true that there exist some interventions which cannot be applied in somatic cells and are purely therapeutic. What are scientists then legally required to do?

Somatic enhancement sceptics draw also attention to the plasticity of the term “therapeutic”. Preventive interventions are always a kind of “enhancement” as they render the individual immune from a disease which was previously threatening its health. The answer to this problem could be a strict rule forbidding any application which could make one’s biological capacities better than that of a “regular human”. As one can easily point out though, terms such as “regular”, “median” or “normal” carry heavy moral weight. A healthy state cannot be easily defined and the WHO has changed its definitions multiple times, the same happens with the list of diseases. A man’s “normal” state can be another man’s post-enhancement state. A crucial point must be the definition of what constitutes an enhancement. The term may mean different things to different people – so do the terms “disease” or “illness”. The “constructivist approach” considers enhancement whatever makes an individual “better off” from an initial stage, which is thought of as an “illness” or even “normality”. Another approach defines as enhancement, whatever makes one’s capacities or characteristics go beyond the typical (for the species) levels. Other experts may find enhancing, only alterations which make an individual surpass the “best version” of humanity (world record athletes for example). All definitions have advantages and disadvantages, taking one as determinant must also be explained by reasonable argumentation. We suggest that if we approach human dignity as a status we find that the definition of “enhancement” must be determinant and not a matter of degree (more enhanced less enhanced individual), as this approach may lead some certain genetic characteristics to be valued more than others. Therefore, we believe that as an enhancement we must consider anything that surpasses each individual subject’s natural capabilities. Then we must consider which of these enhancements may be ethical or not.<sup>39</sup> An Organization with the power to define its meaning and authorities with the power to enforce it is required. But, should it be at a national or a supranational level? How should the scientific community act? According to the

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<sup>35</sup> Johnston, Josephine. "Shaping the CRISPR Gene-Editing Debate: Questions About Enhancement and Germline Modification." *Perspectives in Biology and Medicine*, vol. 63 no. 1, 2020, p. 141-154.

<sup>36</sup> Gyngell C, Bowman-Smart H, Savulescu J Moral reasons to edit the human genome: picking up from the Nuffield report *Journal of Medical Ethics* 2019;45:514-523

<sup>37</sup> Sykora P, Caplan A. The Council of Europe should not reaffirm the ban on germline genome editing in humans. *EMBO Rep.* 2017;18(11):1871-1872. And Savulescu J, Pugh J, Douglas T, Gyngell C. The moral imperative to continue gene editing research on human embryos. *Protein Cell.* 2015;6(7):476-479

<sup>38</sup> Oviedo Convention Article 13

<sup>39</sup> Chris Gyngell and Michael J. Selgelid Human Enhancement: Conceptual Clarity and Moral Significance in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016). *The Ethics of Human Enhancement: Understanding the Debate*. Oxford University Press

global standard or the national? Different cultures value different principles. For this reason we find important to propose a plan in a way that it will be accepted by the greatest part of people<sup>40</sup>.

Another emerging issue concerns the values according to which enhancements will be made, as a world in which some traits gradually become undesirable or what was previously considered an enhancement now becomes the norm may happen in the future. We should think of a future world where our current values may be altered and consider whether this is desirable. One should imagine both the best and the worst scenarios. There might be a world with “better-enhanced” humans with a higher life expectancy than we have, able to decide the genome of their children and being immune to certain types of illnesses. We may then ask, how would they view their world and how would they try to solve its problems: poverty, inequality or climate change? Is any of the “best scenario” changes (moral progress, equitable conscience, environmental sensitivity) possible now? If yes then why don’t we proceed applying them without gene editing? If more talent or IQ is the solution to humanity’s problems as some enhancement supporters claim, doesn’t a huge pool of human genes already exist? Huge part of global population has no access to proper education, nutrition and chances to develop its talents. Talent remains hidden under the blanket of social inequality. People remain trapped in poverty, due to lack of opportunities, in an unjust economic and political system, which does not let them explore and develop their true capabilities, something which costs both to them and to humanity as a whole. Shouldn’t the solution of this problem be a priority? History has shown that huge steps in humanity’s progress were made when greater numbers of the population got included in the social system. The examples of woman emancipation or the abolition of slavery prove it.

Let us imagine three different societies. One in which the rich have the opportunity to become smarter, a society where people already smart get rich or a society which helps individuals to flourish by giving them a chance to develop their talents. Is gene editing a solution to humanity’s problems or merely another alibi for the developed countries to invest funds in other plans and not face the real global issues? The pro-enhancement experts will need to explain how a service of this kind will not only be addressed to a small minority of rich, in a globalized world and economies of scale. Such a development will aggravate the existing inequalities and in particular the lack of prospects for the least advantaged

If one considers the “bad scenario”, according to which human-caused biological inequalities diminish – if not extinguish – any chance of social mobility, a procedure almost already happening without the use of genetic modifications, then one needs to question what the new values will be. There may be a reevaluation of concepts like beauty, desert merit or talent. Such a society would not be able to legitimize any type of economic inequalities on the basis of merit. If, as claimed by the current economic system, unequal income reflects the payment deserved because of one’s talent and contribution to the public product and if we interpret desert as a mix of choices and natural endowments then, in such a society any evaluation will be made in terms on the basis of one’s choices and effort. But what happens to those not given the opportunity to choose or even try, those who cannot afford an enhancement and at the same time have less chance to develop their talents because of the “enhanced” minority<sup>41</sup>? Would

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<sup>40</sup> For an overview of the public’s general opinion on the issue in some countries see: Center for Genetics and Society . CGS summary of public opinion polls [Internet]. [cited 2020 Mar 23]. Available at: <https://www.geneticsandsociety.org/internal-content/cgs-summary-public-opinion-polls?id=401>

<sup>41</sup> See also: Michael Hauskeller Levelling the Playing Field On the Alleged Unfairness of the Genetic Lottery, in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016)

they be considered unworthy? This sentiment of social neglect is a direct insult to one's dignity. In such a society a feeling of biological (not only social economic or political) marginalization will threaten the core of the sentiment of self-respect. It will be once again a concept of biological superiority which will justify the social inequality. In a society of transhumans, humans will be considered a subspecies. Especially germline enhancement interventions may divide the whole species<sup>42</sup>.

To sum up, somatic enhancement may already be happening in other ways, not requiring the use of CRISPR, and financial inequalities existing presently may also result to unequal state of health and capabilities. The question is do we want to make it worse? Editing the germline and enhancing a small part of people who can afford it may instantly change the values and ways of thinking of oneself and society.<sup>43</sup> Editing the germline and excluding some due to scarcity of resources may be like making money the core basis of self-respect. In the transhumanist era being able to afford enhancement will be the measure of transhumanist value. Maybe, being a part of the "new species" becomes a hunt for buying the next genetic innovation and determines whether respectful existence demands just another upgrade.<sup>44</sup>

Another argument concerning the prohibition of germline editing concerns the essence of parenthood. According to supporters of procreative autonomy, parents must be free to use the technology that enables them to control the genome of their offspring. A zygote may after parents' consent, be destroyed and parents may choose to do so for any reason they see fit regardless of whether the zygote is problematic or not. So, wouldn't it show greater respect for human life if it was transplanted after the desired modification? Yet for some thinkers, the idea that parents will really design their child according to taste creates a relationship of maker and creation. Some fear that modification as well as the concept of a designed being may threaten the way parents see their children. Objectification of human life begins from the moment a parent decides the nature of his child. The creation of life, the moment another human being comes to life may be not specifically determined but must be respected. We argue that, although life may not begin in the zygote phase (though for some it does), from the moment one wants to edit the genome of a zygote one has already made the choice to treat it as one's future offspring, therefore one must show the respect one would show for a child and thus not intervene to its genetic identity.<sup>45</sup>

Some experts, but also common people, believe that parenting is more about acceptance of the child's genetic characteristics and trying to help it flourish with respect to its own special nature. Some consider it a gift, and a gift must be accepted as it is.<sup>46</sup> For others, it is crucial to point out that this – previously inexistent – power, forces on parents heavy responsibilities, far more serious than deciding the child's education or nurture. It is also important to underline the

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<sup>42</sup> Giesen, Klaus-Gerd. Transhumanisme et génétique humaine, *L'Observatoire de la génétique*, 2004 16, and Giesen Klaus-Gerd, Le transhumanisme comme idéologie dominante de la quatrième révolution industrielle, *Journal international de bioéthique et d'éthique des sciences*, 2018/3 (Vol. 29), p. 189-203. For discussion over the issue see: Steve Clarke, Buchanan and the Conservative Argument against Human Enhancement from Biological and Social Harmony in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016).

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<sup>44</sup>Michael Hauskeller, Editing the Best of All Possible Worlds? In Parens, Erik, and Josephine Johnston. (2019)

<sup>45</sup> Sandel 2007,p 29

<sup>46</sup>Jackie Leach Scully, Choice, Chance, and Acceptance In Parens, Erik, and Josephine Johnston. (2019)

heavy burden that will fall on the child's shoulders.<sup>47</sup> Admittedly, it is very difficult to overcome the consequences of bad parenting, imagine how much more difficult it would be for a child not to feel trapped in natural endowments chosen by its parents, a duty to live up to their expectations (and investments). Isn't it a threat to its autonomy if it is grown up with the impression that it has been "designed" for a purpose. A zygote, may not be considered a fully grown human, but the human it will become has his autonomy "retrospectively" reduced.<sup>48</sup> Of course one can resist developing a potential talent, but how possible is that? How possible is it that a parent who decided to pay in order for his child to acquire a musical talent e.g to let it decide whether or not it will become a musician? By making "a designer babies" possible, society encourages an interventionist parenting, it grants parents full control over their children. A parent may have the right-duty to send his child to school in order to help it flourish, but editing its genome for the same purpose cannot be considered the same type of choice. Humans make mistakes and the more irreversible they are the more harmful they are considered. Many parents admit having committed mistakes while raising their child, so why make it even harder for a child to overcome these mistakes?

#### Defending gene editing

In the following section we will try to present and briefly analyze some of the arguments proposed by defenders of human genome editing in general and germline editing in particular. These thinkers find skepticism towards genome editing to be an overreaction due to partial understanding of biology. According to them, anti-gene editing argumentation is influenced by a – dominant in previous years – idea that genes determine all physical and mental characteristics of a human. This view has been rejected by scientists in the last years who, stress the importance of epigenetics – the role of environmental factors in the development of special natural traits<sup>49</sup>. As we mentioned, one of the most common arguments against germline gene editing is the idea that a potential genetic modification changes one's nature and threatens one's autonomy. Pro – germline editing thinkers claim that, the view which supports that by altering the DNA one shapes one's characteristics is a deterministic opinion. They say that the conversation is about gene editing not "people editing"<sup>50</sup>. For them it is important to understand that our DNA has gained an aura of being the essence of our humanity without that actually being true. For some pro-editing thinkers, altering the DNA is nothing more than taking a drug which affects our hormones.<sup>51</sup> They consider genetic enhancement just another step of science on the way to improve human capabilities along with smart drugs or gene therapies and transplantations. They find a positive stance towards a liver transplantation and a rejection of gene editing (because it alters one's identity) as contradictory. After all, our DNA is on the most part common with primary apes and almost identical to other humans', it is not DNA that makes us unique. Our DNA may change naturally during our life time.

Furthermore, they argue, not only don't we know how many genes are responsible for traits like intelligence and how they interact with each other and their environment, but even if we did know, we wouldn't be able to create all the necessary circumstances in order for these genes to

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<sup>47</sup>Nicole A. Vincent and Emma A. Jane Parental Responsibility and Gene Editing In Parens, Erik, and Josephine Johnston. (2019)

<sup>48</sup> See also : Sourlas, Paul. Human Dignity and the Constitution. *Jurisprudence* , 2016,7 (1):30-46

<sup>49</sup> *Henri Atlan*, La fin du 'tout génétique'? - Vers de nouveaux paradigmes en. Paris: I.N.R.A

<sup>50</sup> Yet even they cannot deny that genes play a vital role in one's life. We wouldn't be able without genetic predisposition to make great achievements. One cannot just simply become a world-class professional footballer no matter how hard one trains.

<sup>51</sup>Savulescu, Julian Genetic interventions and the ethics of enhancement of human being, In: Steinbock, Bonnie, ed. *The Oxford Handbook of Bioethics*. 2007, Oxford; New York: Oxford University Press,: 516-535

function the way we want. For them, it is important to promote the things that we can do and not prohibit every possible use out of fear of what we cannot.<sup>52</sup> On the other hand, some other pro-editing experts are optimistic about the potential of scientific discoveries and believe that, after abandoning the special value we apply to the DNA we should proceed to altering the genome – it is for them our moral responsibility to enhance.<sup>53</sup> For them, gene editing symbolizes a breakthrough for our species, it gives us the capacity to control evolution and become “transhuman”<sup>54</sup>. As they claim, in the past we were altering our environment in order to ameliorate our lives, now we can alter ourselves and take humanity one step forward. They imagine a world without the current serious genetic diseases with healthy and smart people who will contribute individually to the progress of humanity. According to them enhancement may bring the solution to problems we face today.<sup>55</sup> Their view is that there exist several factors which constitute one problem (natural, social, psychological etc) one of them is human biology. They find that maybe by altering human biology we can influence the way we affect the world, live in it and interact with each other. Such a rather optimistic approach claims that transhumanist values will emerge as well as a new kind of morality, while the global intellectual capital will increase and bring many technological and social innovations.<sup>56</sup>

Supporters of the germline gene editing find that the fear of reducing the autonomy of the child when altering its genome as an embryo has a false philosophical basis. An embryo, they claim,<sup>57</sup> does not carry the same moral weight as a fully grown human being. In addition, each genome can be altered by many different factors. A mother who smokes for example, can have major influence on a child’s health while, on the other side, many parents do their best in order to give birth to healthy children. Germline gene editing is just another step in the effort to promote a child’s life.

The supporters of DNA modification raise the so called non-identity problem<sup>58</sup>. According to them, gene editing in germline cells even if it changes the identity of the embryo in question, it does not harm (nor benefit it) as, after the procedure it constitutes a different embryo (which wouldn’t exist otherwise). In other words, for example, if there exists an embryo A which, after being born is going to become person A, in case it has its genome modified it will become person A’, carrying all the characteristics of its modification. A genetic change which would make A’ a talented artist (if there exists such a possibility) may have reduced the autonomy of A if he was born but not of A’ for he could not exist in any other way but only after the genetic modification. The basis of this argument resembles the one concerning “wrongful life”. According to which, one cannot sue one’s parents for giving one birth. In other words A’ would not exist had the modification not taken place, so A’ has no reason to claim that by intervening to his genome, his parents violated his autonomy. Only A could do so (if we consider that embryos in the womb possess such a right).

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<sup>52</sup> Barrangou, 2019

<sup>53</sup> Savulescu J., New breeds of humans: the moral obligation to enhance (Small parts of this article appeared in Savulescu J Why I believe parents are morally obliged to genetically modify their children. Times Higher Education Supplement (London), 5 November 2004, p. 16., Reproductive BioMedicine Online, Volume 10, Supplement 1, 2005, Pages 36-39

<sup>54</sup> Agar, Nicholas, *Liberal Eugenics: In Defence of Human Enhancement*, 2004, Oxford UK: Blackwell

<sup>55</sup> Savulescu In Defence of Procreative Beneficence, *Journal of Medical Ethics*, 2007 33(5): 284–88

<sup>56</sup> Bostrom, N. In defense of posthuman dignity. *Bioethics*, 2005, 19: 202-214

<sup>57</sup> Buchanan, A., D. Brock, N. Daniels and D. Wikler, *From Chance to Choice: Genetics and Justice*, 2000, Cambridge: Cambridge University Press

<sup>58</sup> For a relevant issue see: Scott R, Wilkinson S. Germline Genetic Modification and Identity: the Mitochondrial and Nuclear Genomes. *Oxf J Leg Stud*. 2017 Dec;37(4):886-915

According to supporters of germline gene editing, even the potential genetic predisposition granted to him by his parents does not necessarily mean that it reduces his choices of becoming something other than a musician. After all, if the parents have the authority to decide whether A will be born at all why can't they have the right to decide whether a modification will take place and A' will be born. These supporters of the parents right to procreation right claim that parental autonomy and self-determination must not be limited by a, yet unformed, person. They believe that giving a child higher IQ is a similar kind of enhancement as sending it to school, at the end of the day, the result is the increase of the child's mental capacities. Why does an "internal" increase of IQ be an unwanted – immoral enhancement and the existing inequalities due to lack of proper education are acceptable? For them the problem is inequality in access not the process itself. Is it immoral for a parent to want the best for his child? What one should consider, according to them is not how to ban such a procedure but how to make it wider available<sup>59</sup>.

As a response to the argument against germline gene editing which considers it a threat to the variation of human genetic legacy – a fact which could lead to serious problems like pandemics due to lack of a specific gene – supporters of gene editing claim that a species genetic variation must be examined through a large period of time. They believe that except from some traits like higher IQ, all other "fashions" concerning genes will come and go. They trust that parents will be conservative in their choices, having in mind that what is considered a gift in their time, may not be seen in the same way in a few years. Therefore there will be no huge difference in the genetic variation of humanity.

As far as the argument claiming a threat to the child's future autonomy (as it will be pressured by its parents to exercise and develop a specific trait) - is concerned, supporters of gene editing find it not different than a problem created by a demanding and strict parent. Again, it is a matter of "the use" not of the procedure, both actions constitute bad parenting. To them, the fact alone of editing an embryo to develop a musical talent e.g. is not immoral. What's threatening for the autonomy of the child is its parent's behavior.<sup>60</sup>

The basis of the fear for an impoverishment of humanity's genetic variation is the image of a world where everyone looks more or less the same and has the same special capabilities. For supporters of gene editing, this view underestimates human originality, the idea that people have different conceptions of a good life<sup>61</sup>. After all, uniqueness is also threatened in our times by the homogenizing power of the globalized capitalist system.<sup>62</sup> Such a problem is not new, maybe by enhancing ourselves we realize the importance of originality and be able to conceive a better view on what is require for as in order to flourish. For them, a threat for an individual's originality does not come from a technology which can grant the means to better reflect, judge and maybe reject different conceptions of a "good life" before finally choosing one. After all, genes are not the only factor determining one's life choices. It is definitely not the case that smart people lead better lives but if science manages to make people smarter there is a case

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<sup>60</sup> Though, as we stressed, it is rather unlikely that a parent who believes that by having a musical talent (in a world where that can be bought, and therefore is not so special) a child has better chances to live a good life, won't pressure it.

<sup>61</sup> According to us this argument is based on a "circular" thought. If we have different opinions for what is good for us it is because in a percentage we have different genetic predispositions. Maybe if this changes we will not be as likely to differentiate ourselves from a "successful" norm.

<sup>62</sup> Moreover, it is important to stress that a certain kind of homogeneity can boost a feeling of equality.

that they will create the conditions of better life for all.<sup>63</sup> Secondly, if we fear that gene editing will enforce the stereotypes, making it even more difficult for the “different” to exist, then we must fight against stereotypes and not gene editing.

We have reached the crucial point where we must decide the values and the rules under which this technology is going to be used, otherwise we are likely to face maleficent unregulated uses such as the editing of the twins in 2018<sup>64</sup>. A good point to start would be by examining whether gene editing violates any of the five principles of bioethics, namely autonomy, beneficence, non-maleficence and justice.<sup>65</sup> Then we can proceed by proposing certain prohibitions according to a principle-based ethical system rather than a consequentialist, cost-benefit, approach. Initially we will analyze whether gene editing in general and germline gene editing in particular may threaten the autonomy of an individual. According to the anti-editing argumentation, it is germline gene editing that is dangerous as it will make the parents and not nature responsible for the genetic predispositions of their offspring. The deeper philosophical problem in these cases is how shall we think about human genetic characteristics which are no longer morally arbitrary, as it happens with natural. We must reflect on the limits humanity needs to set itself when interfering to nature. We must ask whether a child’s autonomy is violated by the genetic intervention of its parents and think if parental autonomy can be restricted even though, as the non-identity problem supports, their choices neither harm nor benefit their future child.<sup>66</sup>

We must then examine if germline gene editing is actually beneficial for the embryo, if the parents by choosing certain characteristics over others actually do the child any good. After all, humans are always going to be partially natural. Is the problem a matter of degree? How many artificial interventions are needed in order for an embryo to be considered as fully designed by humans? Should we draw the line on fertilization (which is already happening technically) or must we proceed our technical intervention on human reproduction even further? Those questions cannot be easily answered but we find that because these problems touch the very essence of being human and the relation with one’s predecessors, one should apply the precautionary principle and abstain from irreversible decisions such as germline gene editing.

## Part 2

A review of the arguments and a personal view

We shall now examine some of the core arguments for and against gene editing and attempt to propose our own view opinion on the matter. As we’ve seen, as far as germline gene editing is concerned, a pro-editing thinker would state that after all, the nature-nurture dipole remains intact, that gene editing only gives more choices to humans for their procreation and that the child born will always be free to lead its life according to its preferences and “enhanced” capabilities. According to pro-editing argumentation gene editing will provide more means for the progress of humanity, individually and collectively. The problem is that throughout all these years of human history we have been unable to determine what it takes for a human to achieve

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<sup>63</sup> For arguments for and against the idea that mental capacities lead to more moral action see Tanner, C. & Christen, M. Moral Intelligence – A Framework for Understanding Moral Competences. In M. Christen et al. (eds.), *Empirically Informed Ethics: Morality between Facts and Norms* (119-136). 2014, Zurich, Switzerland: Springer International Publishing

<sup>64</sup> Nie JB, Cheung A. He Jiankui's Genetic Misadventure, Part 3: What Are The Major Ethical Issues? The Hastings Center Forum. 2019

<sup>65</sup> Beauchamp TL, Methods and principles in biomedical ethics *Journal of Medical Ethics* 2003;29:269-274

<sup>66</sup> For discussion over the issue see: Omerbasic A Genome Editing, Non-Identity and the Notion of Harm. In: Braun M., Schickl H., Dabrock P. (eds) *Between Moral Hazard and Legal Uncertainty. Technikzukünfte, Wissenschaft und Gesellschaft / Futures of Technology, Science and Society*. . 2018, Springer VS, Wiesbaden



“flourishing”<sup>67</sup>. In our opinion germline gene editing must be prohibited on the basis that such a “leap of faith “ towards irreversible genetic interventions must not be made by one generation over the other.

We live in a time in which the heavy price we have to pay for intervening in nature becomes apparent. We believe that we will never have enough knowledge so as to really understand what it takes for a human to flourish and, in our opinion, we must leave all choices open and not limit them according to the needs and preferences of a particular generation.<sup>68</sup> Blue eyes and high stature may mean nothing in the future, not even for fashion (from the moment they can be bought). We are undermining their value (if there is really any value on these random characteristics) the moment we create the possibility of them being purchased upon request. A “designer baby” would benefit if it had these characteristics in a society which values an appearance according to certain standards, but that cannot happen in a society in which “designer babies” are common and almost anyone could possess them. We believe that social prejudices will more or less influence the parental choices. We are also afraid that new kinds of inequality will emerge and may lead to new kinds of discrimination (enhanced-not enhanced humans). Ethics theorists must warn and protect the society from such a case.

We can understand the argument that germline gene editing by itself is not responsible for the existing inequalities or prejudices which may make its uses maleficent but we are of the opinion that our priority should be to resolve some of the current political and social issues before we attempt to bring this technology to wider use.

To sum up, we remain skeptical towards germline gene editing, because of issues concerning the collective inability of humanity to use this type of technology , influencing in potentially harmful ways the existence of future generations. We believe that germline gene editing alters in a crucial way the human-human relation of the parents towards the child as they will no longer be giving life to their infant, but determining a crucial part of its form. In our opinion, this will encourage an interventionist and authoritarian type of parenting. We also find it socially problematic because it creates new types of inequalities and aggravates others. It is also politically controversial because of the different opinions concerning it , as DNA is viewed by a large part of the population as carrying a special weight and many religions will reject its use, because they believe that certain genital characteristics are given by a divine Creator. We find that enhancement-oriented germline edits, particularly, should be prohibited both for the ethical and for the empirical arguments presented above , we are of the opinion(although we hesitate to take part in this discussion, that it must not be a matter of cost-benefit analysis, but of principles) that the benefits that will bring to humanity will be fewer than the harm which may be done.

#### Views on Therapeutic germline editing

As far as therapeutic germline gene editing is concerned, it is our view that it would be preferable if one therapy could be completed in an alternative way. For us, somatic and less controversial therapies should be encouraged. Many scientists claim that germline gene editing

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<sup>67</sup> For the use of the term flourishing see: Evans J.H ,The Dismal Fate of Flourishing in Public Policy Bioethics: A Sociological Explanation in Parens E. Josephine Johnston ,2019

<sup>68</sup> An interesting approach of intergenerational relations and enhancement has been made by Alasdair McIntyre, known as McIntyre’s paradox. See: Tobin B, MacIntyre’s Paradox ,Harmony in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016).

can be substituted by other types of therapy. AIDS for example can be treated by medicaments and turn into a chronic disease. Of course that is not the same as a “once and for all” editing of the CCR5 gene (which is related to the probability to be vulnerable to HIV)<sup>69</sup> but science has made good progress in other ways of treating this disease. As far as genetic diseases are concerned, almost all types of CRISPR operations can be done to somatic rather than germline cells. Although we believe that progress in gene editing may make some of the current genetic diseases inexistent for future generations, we believe that our knowledge of the genes’ function does not allow humanity in 2020 to mess with the genome of humanity in 2030 or even later. At least until we fully comprehend our organism we should be cautious and prudent in the way we influence our future. It is up to us to avoid a new type of environmental disaster.

#### Views on somatic gene editing

After examining arguments for and against germline gene editing and giving our opinion on whether it should be allowed or not we now turn to somatic gene editing, its uses and potential abuses. Somatic gene editing involves editing the DNA of non-gamete or plastic cell. This means that any change to the DNA of the patient will not be carried on by his posterity. Any alteration of the genes concerns only him. Somatic gene editing can be done to a) embryos developed enough so that their cells will not differentiate and become, gametes as well as to b) fully grown humans. Somatic gene editing does not carry the special moral weight of altering future generations so, for some, the precautionary principle should apply only if it is dangerous for the patient. Research in somatic gene editing has achieved serious successful operations and its therapeutic potential is great. Despite not affecting future generations, though, it can also be considered as morally controversial especially when done to embryos (for some of the same reasons concerning its autonomy as we mentioned above). Critics remain skeptical towards somatic gene editing also because of the difficulty to determine the character (whether enhancing or therapeutic) of the operation.

As far as embryo somatic gene editing is concerned one may argue about the potential threat an intervention would be for the future person’s autonomy especially when it does not concern therapeutic purposes. There exists a (well founded) fear of the creation of “designer babies”. What is again at stake is whether parents have the authority to alter their baby’s genetic characteristics. Although our parents are indeed partially shapers of our characteristics and also, they, by using some substances may cause genetic mutations, but we believe that there must be a point up to which their control over the embryo must stop. It is indeed very difficult to answer the “status of the embryo” question at this point, yet we are of the opinion that when gene editing concerns random characteristics and not therapeutic or preventive purposes (if and when this becomes possible) the genome of the embryo, must not be altered.

We believe that an embryo’s natural genome must be thought as carrying a special weight which cannot be undervalued, especially when opposed to cultural and social trends and fashions which demand a certain kind of appearance. After all “the freedom to procreate” of the parents is already limited by certain laws and directives. Laws against sex selection already exist in certain countries (and those that have not yet imposed such laws already face problems with unbalanced sex populations)<sup>70</sup> and must be extended to apply in potential alterations of skin

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<sup>69</sup> Zhepeng Liu, Jin Liang, Shuliang Chen, Kewu Wang, Xianhao Liu, Beibei Liu, Yang Xia, Mingxiong Guo, Xiaoshi Zhang, Guihong Sun, Geng Tian. Genome editing of CCR5 by AsCpf1 renders CD4+T cells resistance to HIV-1 infection. *Cell & Bioscience*, 2020, **10**:1

<sup>70</sup> For an opposite view see: Sterri, AB. Sex selection in India: Why a ban is not justified. *Developing World Bioeth.* 2020; 20: 150– 156

color or other genetic characteristics. Certain human traits must remain indeterminate in order to preserve the status of an individual being physically – as well as psychologically unique<sup>71</sup>. It is our view that an autonomous being must not be shaped by other people's choices concerning its natural capabilities, however small or great the influence of those decisions is.

After mentioning some of the ethical issues concerning somatic gene editing we need to consider the great social impact a possibility of such a genetic manipulation may have. Beyond the inequalities it will deepen and ,perhaps, eternalize and the new kind of burden it may be for the parents, consisting of a new responsibility, it will also alter the way humans perceive the world and ourselves. For some thinkers, humans must accept that part of being human is that feeling of being “thrown into the world” and appreciating what constitutes our natural self, doing what we can to flourish with what is given to us naturally.<sup>72</sup> Although we don't share the view which prioritizes the natural over the artificial, we certainly believe that everyone , including embryos – future persons, must be granted the right to decide whether he or she believes that his natural characteristics need to be altered or not. After all appearance will change more effectively in adult life and technology is continuously developing to that direction. Dignity and procreative liberty

We would now like to explain our conception of dignity and procreative liberty and the reasons why we find that any kind of embryonic gene editing objectifies the embryo. As far as parental liberty is concerned, we argue that society's interest towards its new members has been the reason for the establishment of institutions and legal frameworks guaranteeing a minimum standard of education, financial support and insurance. We find therefore that there exists a relation between the baby and society and this relation sets limits to the parents as members of the same society. There is for this reason a socially established conception of dignity, so that it is respected by all individuals and the state. A parent must take into account the effect that the choices she makes influence the collective. Thus, although the state should not interfere, using paternalistic policies or eugenics programs, the individual should consider her responsibility towards society. Furthermore, from the moment that society also shapes one's conception of the “best” life, or the “best possible embryo”<sup>73</sup> etc one may assume that parents will choose those traits that are socially acceptable and “preferred” in order for their child to become a prominent member of the society. If parental liberty is conceived as letting parents do as they please ,then through social nudging, we will tend to homogenization of the future generations because the characteristics selected will be those considered “the best”, at that moment. By allowing embryo gene editing one is undermining instead of promoting innovation. It is our belief that when we talk about “parental freedom to procreate” we have in mind a right to give birth to an individual, a person, a human being with equal moral worth to whom they bear the responsibility to nurture and treat with respect. Even if parents view their children as ends in themselves, when deciding to proceed to genetic manipulation , we believe that such a procedure violates an abstract conception of autonomy. The desire to control even the slightest natural characteristic of their child is not an act of love but the ultimate effort to control its future. The desire to give the child the best possible future leads them to impose beforehand a conception of the good. Granting the genetic endowments to their child to fulfill their own approach of a good life takes interventionist parenting to the extreme. They seem to violate a right which they claim for themselves: the right to have more options.

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<sup>71</sup> We therefore require some physical continuity “on what matters” to our identity.

<sup>72</sup> Sandel 2007 p.80

<sup>73</sup> Parker, M. “The Best Possible Child.” , *J Med Ethics* ,2007,33: 279-283

We must point out though that it is our view that somatic gene therapies must take priority over germline as they are less controversial and can also successfully cure some impairments, as has been proven. In addition we believe that the argument which compares the, already happening, embryo selection in IVF clinics to germline gene editing and a type of “eugenics” is not sound. Firstly, we must stress the difference between actively altering the embryo and allowing a pregnancy to continue. In the first case one is “acting”, in the second one is “letting happen” those two types of decisions are not of the same kind.<sup>74</sup> Secondly, if we consider gene editing to be the next step in a scale of progress towards even more control upon the future child as part of the parents procreative liberty, we reach again the non-identity problem, as we need to consider: first if there exists a right of the parent to choose the genetic identity of the future child or not, and, secondly, we need to examine whether there is a (retrospectively active) right of self-determination – from the moment the embryo is chosen to be implanted. Initially, we must see if more control over the embryo constitutes an extension of the procreative right of the parents. It is our opinion that a procreative right is none other than the right to give birth to a healthy (according to the universal conception) individual and that justifiable therapies must only be made to somatic cells. We find that the desire for even more control leads to a dead end. We will never be able to control the environment we are going to live in or the exact circumstances which will occur from other people’s choices. We can never be sure of what traits will be considered beneficial in the future or whether they can even guarantee survival. It would be dangerous for humanity if control over genetic identity was based on human decision; dangerous for the species survival: if genetic variations become fewer then it would be more possible for a potential genetic pandemic to kill huge parts of the population.<sup>75</sup> Despite this argument, -even if we’re sure that the genetic modifications are safe and that there will be no danger for the species in the future, in our opinion, there exists no right for humans to manipulate the genes of a fertilized egg. The new DNA created by fertilization is not just a mixture of chemical substances, or the sum of two different monoclonal DNAs of the parents, it is a genetic combination which allows the development of life. For this reason it must be treated with respect and not reduced to a chemical one can experiment with. After all, although the embryonic DNA alters in some parts over the course of one’s life, in principle, it doesn’t change so drastically as it happens with genetic engineering.<sup>76</sup> Concerning the argument of abortion, the view that a mother can decide the life or death of an embryo - therefore genetic alterations can be included in the mother’s right to procreative liberty, given the priority of the woman’s life over the embryo, we believe that this doesn’t mean that the embryo does not possess any special moral worth – so that it can be treated in whatever way possible. Abortion is not just a means for contraception, it takes place when a fully grown human’s life prospects are seriously affected if the pregnancy continues. We don’t see how this happens in the case of parents choosing different genetic characteristics for their embryo.

Another important argument opposing genetic intervention supports that equality between humans is violated through gene editing. For some theorists a crucial characteristic of equality is

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<sup>74</sup> Hammerstein, A.L., Eggel, M. & Biller-Andorno, N. Is selecting better than modifying? An investigation of arguments against germline gene editing as compared to preimplantation genetic diagnosis., *BMC Med Ethics* 2019,**20**, 83

<sup>75</sup> Lander ES, Baylis F, Zhang F, Charpentier E, Berg P, Bourgain C, Friedrich B, Joung JK, Li J, Liu D, Naldini L, Nie JB, Qiu R, Schoene-Seifert B, Shao F, Terry S, Wei W, Winnacker EL. Adopt a moratorium on heritable genome editing., *Nature*. 2019 Mar;567

<sup>76</sup> See also: Millum J. The foundation of the child's right to an open future. *J Soc Philos*. 2014;45

the ability to interact with other humans – to have an expression of your will externalized.<sup>77</sup> Children may accept in the end their parents' choices, but they do so though with their own free will – however that is shaped by their parental environment. An embryo has no will, therefore, a future-genetically-modified person will have another type of relation with its parents, who will not be pro-creators but “creators”. Some theorists respond to this argument by proposing a “binocular view”.<sup>78</sup> More specifically, they suggest to think of humans both as created and creators, both as subjects and objects . But this approach cannot justify a genetic manipulation of an embryo. Intervening directly to the DNA leaves no space for “interaction” between embryo and parent, as for example happens in the case of an embryo and a mother who adopts a healthy lifestyle in order to increase the probabilities of her baby being born healthy or smarter (a behavior which for some is considered a type of effort to achieve enhancement). Gene editing is giving direct control over a future person's genetic identity, meaning that at least some aspects of its identity will be predetermined. We believe that nobody – even parents – possess the right to choose what kind of embryo they will bring to life, only the right to give birth to a healthy individual. Right to procreate is not about the right to choose the traits of the future child but about *having* a child. Another reason we disagree with the genetic manipulation of an embryo is the irreversibility of the decision. A genetic alteration will be carried on to the embryo's life and –if done in the germline – to its posterity, we must not allow future generations to be genetically shaped by our decisions. The autonomy and the existence of future generations matter in various ways.<sup>79</sup>

Furthermore, the issue of germline editing for enhancing purposes must also be examined by balancing liberty (the capacity to procreate without external interventions) and autonomy (the capacity to decide whether or not to have a child) with the desire for even more control and the effort to achieve an approach of perfection. We need to judge whether the liberty and autonomy of the parents outweighs our conception of human dignity, a conception which involves equality between humans, equality based on the randomness of their existence, a conception of life as a unique and unrepeatable experience which one has, being a unique and irreplaceable person not a result of chemical reactions. Some believe that the counter-editing argument is based on an obscure and romanticized view of human nature and falls in the trap of the naturalistic fallacy. But the counter-editing theorists don't believe that what is natural is better, they believe that the way we interpret humanity's uniqueness is, as being part of nature. Blurring the lines between man and man-made , between human- designed and nature is problematic.<sup>80</sup>

From the other side of the question, what happens when the so-called freedom to procreate becomes a duty. What happens when we develop the technology to edit the germline and after some political decision all parents must edit their embryos in a certain way which is judged “better”?

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<sup>77</sup> Habermas 2003 p 52-55

<sup>78</sup> Parens E. Choosing Flourishing: Toward a More "Binocular" Way of Thinking about Disability , *Kennedy Institute of Ethics Journal* June 201727(2):135-150

<sup>79</sup> Koukouzélis (Kostas N. Koukouzelis), Humanity, Future Generations and Bioethics. .2016. *Bioethica*, 2(1), 5-15

<sup>80</sup> For a view on humanity's relation with nature see: Pugh J, Kahane G, Savulescu J, Partiality for Humanity and Enhancement Harmony in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016). and Weckert J. Playing God: What is the Problem? *ibid*

After all we mentioned that the “slippery slope” of liberal eugenics may lead to a future where certain genes will not exist due to the collective parental will, which can be wrong, as the examples of sex selection have shown. Some rules must be set in order for society to avoid extinction. We cannot make choices with so long-term results, as the case of the destruction of the environment proves. Therefore, we believe that a spontaneous procedure such as gene editing cannot be allowed to determine an unknown yet human.<sup>81</sup>

#### Somatic gene editing and enhancements

Let us now turn to somatic gene editing for enhancement purposes. One cannot deny that the right of self-determination is fundamental for one’s flourishing. Whatever one’s conception of the good is, one must be free to develop one’s personality so far as it is not a threat to the others’ self-determining goals. We see no conflict between one trying to alter one’s natural characteristics and the liberty of others. After all, our DNA may change naturally throughout our life time and one is not biologically the same for all one’s life. In our opinion identity is not fully determined by the physical continuity of existence, it is also linked to a person’s chain of decisions relations and social ties with others.<sup>82</sup> It is not necessary that by changing one’s DNA one becomes another person. Especially given that only certain parts of the genome will be altered. Although we believe that natural mutations are of key importance for human evolution we are not sure how one can prohibit a somatic DNA alteration from the moment it affects only the individual in question. Ethically it is not contradictory and perhaps it would be paternalistic to state that one’s dignity is threatened by one’s conception of the good life and one’s opinion that one needs an enhancement to achieve it. Insofar as one does not threaten others one must be allowed to edit one’s genes. As we see it, drawing from the disagreement over suicide, adult somatic gene editing can be accepted by both those for and those against a right to suicide. In our opinion, those who believe that life’s value is of such great importance so that its unnatural termination (suicide) must be prohibited cannot be against one’s effort to live better (through enhancements). On the other hand one cannot value one’s autonomy to the point of accepting a right to commit suicide and not find that a prohibition on somatic gene editing is restricting one’s right to self-determine and have control over one’s body.

A point though we would like to make, which concerns embryo and adult gene editing is that we have reached the crucial point of decision making. Decisions which concern whether to promote a person’s autonomy and liberty and/or care for the evolution of the species cannot be easily justified without some contradiction. From the one hand, one can be pro-editing for the sake of individual liberty, welfare and autonomy, (despite the fact that it may be, on the long, run dangerous for the species) and also deny that embryos have a right to an open future<sup>83</sup>, (a right to develop a free from pre-made decisions concerning their natural traits conception of the good life). On the other hand one can be pro-editing because one values the social and individual benefit of enhancement and therefore encourage nudging or paternalistic policies which in the long term undermine both individual and social good. The same happens on the other side of the question too. One can oppose gene editing because one finds it violates

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<sup>81</sup> For an opposing view : Koplin, JJ, Gyngell, C, Savulescu, J. Germline gene editing and the precautionary principle. *Bioethics*. 2020; 34: 49– 59.

<sup>82</sup> Personal Identity, Parfit D, *The Philosophical Review*, Vol. 80, No. 1. Jan., 1971, pp. 3-27

<sup>83</sup> Bredenoord A. Genetic Dilemmas and the Right to an Open Future. *Am J Hum Genet*. 2010;86(2):108. for another view see: Savulescu J. Justice, fairness, and enhancement. *Ann N Y Acad Sci*. 2006 Dec;1093:321-38 and Emmerich N. and Godjich B, Commentary: From Liberal Eugenics to Political Biology. *Cambridge Quarterly of Healthcare Ethics*, 2019, 28(1), 20-25

aspects of human dignity , denying that it should be included in the rights of autonomy and self-determination , or one can be anti-gene editing because one believes that individual choices *may* threaten the entire species and deny the potential benefits it may bring to the individual.

### Part 3

#### CRISPR and distributive justice

As we tried to present , gene editing is a very controversial subject and , in our opinion both arguments for and against have significant flaws. So for us , taking “a leap of faith” towards a technology which may bring serious damage and have unknown consequences to the future of humanity based on controversial concepts such as “welfare”, “flourishing” and “progress ”is rather impulsive.<sup>84</sup> We believe that the precautionary principle must be globally applied and be very specific on the kinds of cures in which gene editing may be involved, while at the same time encouraging alternative types of medicine as well as inclusionary policies, in order to benefit the most from the existing human capital – rather than creating an enhanced minority . It is not the first time humanity has managed to stay away from scientific “slippery slopes” : it has been achieved in the past with issues concerning cloning. We propose a strict international control of the gene editing technology in order to avoid a new type of “arms race” and “editing heavens” between the states and the possibility of a reappearance of maleficent uses. As we mentioned, this technology can be used equally for the benefit or harm of humanity. Many pro-editing thinkers talk about the progress which will be accomplished by super smart thinkers, yet few consider the damage a supersmart terrorist could make.<sup>85</sup> In this part we will propose a way of organizing the gene editing system, a way which - we believe- respects both equity and justice as well as individual autonomy.

After the development of this cheaper and more accurate method of gene editing , we have entered a new era which, for some, may be proved disastrous . We believe that the scientific community must decide globally proceed only to research on therapeutic and not enhancing applications of CRISPR and only when alternative methods of cure are either impossible, less effective or very expensive, as the greatest part of asked societies seem to want.

#### Approaches of fairness in distribution

After the completion of the clinical phase of CRISPR therapies for preventive (possibly even enhancing) uses , gene editing will become another “good” for distribution, we must therefore find an equitable way of rendering it publically accessible. In the scholarly debate there have been many different approaches concerning the way of managing a good or a service. John Rawls had re-opened the philosophical discussion concerning what is just and proposed three principles of justice<sup>86</sup>. Other thinkers , influenced by Rawls express views which either prioritize liberty instead of equality or the contrary, proposing either egalitarian<sup>87</sup>, liberal<sup>88</sup> or sufficientarian approaches . Some have stressed the importance of “correcting” a situation caused by brute luck or, in other words, helping anyone who is worst off by no fault of one’s

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<sup>84</sup> Cavaliere G, Devolder K, Giubilini A. Regulating Genome Editing: For an Enlightened Democratic Governance. *Camb Q Healthc Ethics*. 2019 Jan;28(1):76-88

<sup>85</sup> The Genetic Engineering Genie Is Out of the Bottle. The next pandemic could be bioengineered in someone’s garage using cheap and widely available technology.  
Accessible at: <https://foreignpolicy.com/2020/09/11/crispr-pandemic-gene-editing-virus/>

<sup>86</sup> Rawls, John, *A Theory of Justice*, 1971, Harvard, MA: Harvard University Press

<sup>87</sup> Indicatively: Carens, J. *Equality, Moral Incentives and the Market*, 1981, Chicago: Chicago University Press.

<sup>88</sup> Nozick, R. *Anarchy, State and Utopia*, 1974, New York: Basic Books

own<sup>89</sup>, while others believe that the most important way to achieve justice is to treat others with equal respect instead of trying to compensate them for a “deficit”, by organizing a material distribution<sup>90</sup>. After a brief examination of the approaches mentioned above we will propose a way of making gene editing technologies accessible to the wider public.

We will first consider a Rawlsian method of gene editing’s wider distribution. It is crucial for us that the liberty principle - guaranteeing that everyone must be provided with rights and be protected from any violation of one’s liberty- is satisfied. But can we speak of a right to genetic enhancement? In our opinion that is possible and in fact enjoined by the equality principle. We argue that, from the point that almost the totality of one’s DNA is identical to every other human’s, one must not treat DNA as being exclusively a part of one’s own and consider it as a common legacy of humanity. Therefore, we believe, as it happens with efforts of patenting nature, that no one has exclusive private rights over DNA. One must not alter but only what makes one special as an individual; not what connects one with the rest of the species. As everyone is member of the human race everyone has the right to genetic enhancements which will transform, and perhaps accelerate evolution. In our opinion, our answer to those who characterize CRISPR as a way of taking evolution to our hands must be: “in such a case, let moral enhancement be humanity’s next evolutionary step” in order to substitute the random and morally arbitrary “survival of the fittest” of Darwinian natural selection, with an “evolution for all”.

Bringing this new era of evolution does not necessarily mean that everyone should “enhance” but that the criterion for applying gene editing cannot be determined by one’s economic capabilities and that the technology which permits such operations must be under public control – as a public commodity. We believe Rawls would find public control and wealth independence essential for a just distribution. Especially if we consider that an essential point for self-respect is to be considered an equal and not belonging to a “subspecies”. We believe that these two characteristics –independence in economic resources and public control – would satisfy the Rawlsian principles of liberty and equality .

If we take a more realistic approach though, one which involves scarcity of resources, it will not be possible for these services to be equally provided to all citizens, thus, the Rawlsian approach requires a way of distribution in order for them to benefit the least well-off<sup>91</sup>. At this point the Rawlsian scheme starts to face several difficulties. How can we judge, for example who will be stronger or smarter and in which way can we define the worst or the better off? How shall we answer to the “genetic counter- levelling down argument”, which claims that by benefiting the least advantaged physically we bring no special progress? According to some, “records” are achieved only by the enhanced who already possess talent and physical predispositions. In our

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<sup>89</sup> Dworkin, R. What is Equality? Part 1: Equality of Resources, *Philosophy and Public Affairs*, 1981,10: 185–246.

And Dworkin R. What is Equality? Part 2: Equality of Welfare, *Philosophy and Public Affairs*, 1981, 10: 283–345.

<sup>90</sup> Anderson, E. What is the Point of Equality?, *Ethics*,1999, 109: 287–337.

And Anderson,E. The Fundamental Disagreement between Luck Egalitarians and Relational Egalitarians, *Canadian Journal of Philosophy* (Supplementary Volume), 2010, 36: 1–23

<sup>91</sup> Inequalities are acceptable if they benefit the least well off according to the rawlsian difference principle:

Rawls J ,Justice as Fairness: A Restatement , E. Kelly (ed.), ,2001, Cambridge, MA: Harvard University Press pp 42-43



opinion the key problem of distributing enhancement therapies is the exact definition of “the well” and “the worse off”. As we mentioned, minority groups like the deaf community express skepticism towards these kinds of characterizations, while even in these communities there does not exist only one view on the subject: others find their deafness or blindness as a constitutive part of their identity and don’t want to be discriminated because of it while others would like to be “cured”. Characterizing some as humans “to be fixed” or “less well off” is insulting.

As we’ve seen it is also difficult to define “normality” or “health”. One can speak of an “average IQ” but it has been stated that IQ tests tend to be socially and culturally biased and can be improved by education. As far as intelligence is concerned one could state that, as we already know what improves the population’s health and intelligence levels, namely: public health systems and better education, maybe this whole effort to promote gene editing ends up being an effort to solve social and cultural problems by biological ways<sup>92</sup>. After all, how can we determine who is in need of an IQ enhancement – will IQ tests become obligatory for the whole population, or shall we take restricting measures towards those who deny to take the test or the potential enhancement? As some theorists argue, society is more benefited by policies that promote acceptance, sense of community and tolerance, these are characteristics which help society progress morally not physically.<sup>93</sup> For some, being considerate of those who differ would help us fight better climate change or poverty than “supersmart” individuals acting on their own.

As mentioned above, there are critics who demand the materialization of the difference principle in economic policies first, instead of biotechnological interventions. In any case we find the difference principle too vague to be applied to biological characteristics and serve as a criterion of distribution. The egalitarian approach on the other hand, faces the same problem as the Rawlsian equality principle: due to scarcity of resources one cannot have access to all enhancements. At the same time it is very difficult to establish a “basic services pack” given to all citizens as everyone has different needs. For the same reason we believe that a sufficientarian approach would fail too, because it cannot be easily defined up to which level of “enhanced capabilities” one is a “normal” citizen of an enhanced society. There exists also the question of inequalities occurring after the distribution and above the “sufficient” enhancement. There might be social unrest as some “enhanced” citizens will still be receiving a smaller part of the total social product. In order for egalitarian or sufficientarian approaches to function there needs to be a socioeconomic paradigm shift as the talent-merit based philosophy of the capitalistic system will no longer justify inequalities in the citizen’s unequal social and economic status. In a society of “enhancements” the most common inequality will be that of inherited income, as the capabilities will be leveled up to more or less the same point. In our view a sufficientarian approach secures a minimum level of “enhanced capabilities” without the economic and social environment for them to be developed and exercised. It would be of little use for one to be mentally enhanced if one cannot develop his capabilities through work for example. Another point of critique could be the possibility of such a policy to tend to

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<sup>92</sup> Stern, AM. *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America*. 1st ed., 2005, University of California Press,

. Kaplan, J.M. Race, IQ, and the search for statistical signals associated with so-called “X”-factors: environments, racism, and the “hereditarian hypothesis”. *Biol Philos*, 2015, **30**, 1–17

<sup>93</sup> Garland-Thomson, R. How We Got to CRISPR: The Dilemma of Being Human. *Perspectives in Biology and Medicine*. 2020, 63. 28-43.

paternalism, as this “basic kit of enhancements” will be predetermined and perhaps mandatory for the population and may even lead to stigmatization of the ones denying it.

A more liberal plan would face difficulties in legitimizing the inequalities in enhancement capabilities caused by economic inequality. When those who can afford obtain access to better services, social inequalities would be eternalized because the already rich would be paying for even better enhancements - making therefore social mobility almost impossible. This would bring social unrest and is also ethically unacceptable. Wealth must not determine the biological characteristics and capabilities of humans.<sup>94</sup> A liberal system of distribution would answer to problems occurring in the egalitarian or sufficientarian system, namely that of obtaining consent (as the enhanced would be those willing and affording to pay for it) and of selecting the type of services which will be offered (as everyone will be free to choose, among the given technological innovations, the preferred one), but it would replicate the current inequalities. The rich will be enhanced and the poor not. Some scholars propose a moral and mental enhancement of individuals which would render them more tolerant and keen to empathize others but we don't share their optimism for the results of such a procedure. We believe that even a morally enhanced society will not be able to answer to the social and financial problems of the rising inequality. After all, a system which will discriminate over more and less enhanced humans insults the core of human dignity : people cannot be characterized as “better or worse versions” of enhancement. Or viewed as models for update like cellphones.

Some liberal eugenics supporters claim, this kind of critique is based on the assumption that there will be a new type of stigmatization. The argument goes as follows, unequal treatment of the unenhanced does not necessarily follow from the possibility of liberal enhancement. They believe that the market will soon balance the costs by offering cheaper and more expensive types of enhancements so that , gradually, everyone will have access to it. In our opinion the existing income inequalities will – in this way – lead to a “multilevel” humanity – a biological depiction of the income inequalities. Given also the fact that the rich will have access to better services it may also lead to a type of caste-system where the “higher classes” will be judged as superior. This type of caste system will be incompatible with current democratic societies. Maybe the enhanced start demanding more access to political power (as mentally superior), they may even dig out the old argument for unequal vote.

As we have stated, though, the feeling of inferiority and the fear of discrimination will not be the only problem the unenhanced would face. They will soon be condemned to work for less demanding and paying jobs and will be trapped in poverty.

We have pointed out that the enhancement effort supporters claim it seeks “the good of humanity”, through the amelioration of human capabilities. If that is the case, then why don't transhumanists aim for more education or global health rather than hoping for the good will of the rich and enhanced to benefit society? We believe that the supporters of liberal enhancement are trying to convince people who are skeptical towards this technology that the problem is that it may create another type of inequality. Though liberal enhancement is not unethical by itself, economic inequality and the current market system are responsible for its unfairness.

A proposed system of distribution

Although, as we stated, we believe that the core of the argument for “enhancement”, “enhanced” and “non-enhanced” individuals is very controversial, we find that the human right

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<sup>94</sup> It is already happening and is already a point of criticism for the inequalities globally. We understand that there exist several types of inequality, here we refer to inequality of resources which may lead to social, political and status inequalities.

of self-development and habeas corpus cannot allow a prohibition of somatic gene editing for enhancement purposes. For this reason we have proceeded to a tough experiment, presenting a social and economic system which would distribute fairly these services.

Our system is founded on two principles: firstly, the universality of enhancement. We believe that as everyone partakes in the human race and is a member of the same society one has equal right as every other member of the society to be enhanced and must not be excluded for financial reasons. Without this right, money and the market will determine the evolutionary process and the randomness of the Darwinian “natural selection” will be substituted by a “biological stock market”. As human nature is the common thread that links all the species, so must “enhanced” nature be accessible to all. We believe therefore that there must be public control of the distribution of enhancement services, as the private sector may answer only to market-money based rules. Enhancement is for us a public commodity: if it is to be done for the good of society then every one of its members must have a saying on what kind of technology will be developed for enhancement purposes and according to which criteria – and the genetic minorities must play a determinant role on that. For these reasons the institution proposed will be under democratic control<sup>95</sup> working under a universally acceptable protocol which will be written by a group of experts and representatives of the citizens, with special care taken for the representation of genetic minorities and approved by a referendum. For the reasons explained previously concerning germline gene editing, we believe that all other kinds of enhancements must be prohibited and allowed only for somatic cells of adults. If technological innovations continue to develop in the future then each generation will have access to better services – in this way there will be no problem of “designer babies”, the babies themselves, when they reach adulthood will have access to a far more progressed technology than the one their parents would use in order to edit their germline.

As we mentioned, we will organize these institutions in such a way so that the distribution of enhancements will not be on market-based principles. We do so because, in our opinion, genetic enhancement and human evolution must be based on procedures not driven by profit. We fear that the consumerist logic will lead to disrespect for the human genome, rendering thus human evolution to be thought of as a product, a type of service like many other biotechnological inventions. As we tried to argue though, the complexity of the issue requires genetic modifications to be free from potential technological abuse. We believe that the viability and stability of the mechanism can be guaranteed by a kind of special taxation among the citizens. We can allow non-profit organizations to develop their own technologies with respect to the values and practices written in the protocol we mentioned but we remain skeptical towards their aims. For this reason the whole procedure must be unrelated to the common currency – we find that human evolution is characterized by a special value, this value must render it independent from other kinds of distribution policies and state or private sector-offered services, such as education.

In our system there will exist a parallel currency, controlled by a public institution which will determine the exact amount of “credit units” each individual will receive. This amount will be calculated by evaluating the potential services which can be offered to the whole of the adult population. Each member of the society, only by becoming a fully grown and active citizen – considered legally as able to decide and be held accountable for his choices – will be granted a certain amount of credit units. This amount will be given equally to all citizens on the principle

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<sup>95</sup> By “democratic control” we mean that the legislative body will control and choose the policies and the directing members of the institution. At the same time the institution proposed will be the only one that can evaluate the services and control the stability of the currency system we propose.

that everyone is equally human, therefore everyone must be equally able to be enhanced. These credit units will not be treated as money. They will not value for any other transaction except for the procedure concerning the purchase of enhancements and will be stable (no speculation on their value will be possible) as they will be under strict control from the public institution. This institution will take all scientific advancements under consideration and will proceed to rendering more units accessible to each citizen when this is economically possible. These credit units will represent the total capacity of a society to enhance its citizens, for this reason the sum will be finite : there can exist no “helicopter units”.

As no one is “more human” than others no one can have more potential to be enhanced and therefore the total amount of credit units per person will change only when the amount of offered services is growing or when new types of services – enhancements are created. The credit unit system and the enhancement “market” will function according to the global standards agreed internationally.

As one can possess only a finite number of credit units one will not be able to enhance oneself in every way possible. Due to scarcity of resources society must provide equally the *opportunity* for enhancement and not a basic “kit” of enhancement services. It cannot offer everything to everyone. Therefore, each citizen shall choose the kind of enhancement he prefers and will “pay” the amount of credit units the controlling institution has determined as a “cost”. As some enhancements will be more costly or more popular than others their price will rise according to the law of supply and demand. We believe that this system is serving in a better way the principles of equal concern and respect<sup>96</sup>.

According to these principles, a just state must be equally considerate of the welfare of each of its citizens while at the same time respecting the citizens’ life plans and treating them as mature humans, fully responsible to make life plans and accept the cost of their choices. A just society must be concerned for the needs of each individual until it reaches the point of being a contributing and functional member. No one is excluded in principle from the system we propose, as everyone carries equal worth. Our system only concerns enhancements and not other types of public services<sup>97</sup>. It only functions for genetic manipulations which “take humanity the extra step”, namely mental and physical enhancements. We think of as enhancing any procedure which renders an individual’s capabilities above a spectrum of what is considered both scientifically but also publically (with great respect to the opinion of genetic minorities) “natural”. We avoid stigmatization and marginalization of the ones denying any need for enhancement by giving them the right to access the services, showing equal concern for everyone. Everyone has different needs ,so, for us it is important that one considers one’s needs without external influence. Equality in this system rests on the shared accessibility of the services. No one shall be excluded from the possibility of being enhanced and for this reason shall stand as equal among others either one chooses or not to benefit from the services. The system grants equal right to enhancement and not equal enhancement.

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<sup>96</sup> Dworkin, R. Liberalism. In Liberalism and its critics, ed. Michael J. Sandel,1984. New York: New York University Press,p64-70

<sup>97</sup> Gene editing concerning health services is a complex subject especially given the vagueness of the terms “treatment”, “prevention”, or “enhancement”. For a way in which genetic therapies can be equitably provided and included in a public health system we have spoken elsewhere: Kolisis (Νικόλαος Κολίσης), N. CRISPR, an innovation in the field of gene editing. Proposing a way to include it in a public health system. *Bioethica*, 2020,6(2), 30-40.

We approach the principle of equal respect as follows. In order to treat every citizen with equal respect, a state must allow enough liberty – as well as the capacity for one to achieve one’s ends so far as one does not violate the liberty of the other members. More specifically, we mean that, after rendering each individual capable of making life plans, one is free to exercise one’s capabilities in order to materialize them. One must be free to decide the way one wants to lead one’s life but also be ready to bear the consequences of the choices made. In order to respect its citizens, a state must abstain from interfering with each citizen’s life plans and not proceed to taking measures of straight interference (paternalistic policies) or nudging, in subjects like procreation, profession selection, sex selection etc. The citizen must, on his part, after having his basic needs covered by a functioning health care and educational system, bear the burden of his own liberty. According to R. Dworkin: one must take one’s life seriously and understand that one’s life has a meaning.<sup>98</sup> Everyone must be free to choose his own approach of what is a good life and try to achieve living it, it is a duty of self-respect. One must reflect seriously on what one finds a good life to be and make serious effort in order to achieve what it requires. If one needs to risk or make difficult decisions, one must be ready to be held accountable for them. In order to treat people as mature humans, the state must guarantee their liberty. So, legislation must protect each individual’s liberty from the actions which may violate it.

Based on these principles of equal concern and respect, our system guarantees that every citizen will be able to choose among the existing enhancements the ones that help him in his life plans. By the choices one makes, one determines the way one – personally and autonomously – wants to lead one’s life. As the total sum of credit units is finite, one must judge carefully which enhancements will be the best for one’s purposes and shall bear the cost of choosing to purchase them. If one considers for example, that an expensive enhancement is going to promote one’s well-being then one must accept that by making this choice one is excluding oneself from the capacity to purchase other, alternative, expensive enhancements.

We believe that the right age for people to be allowed to enhance themselves must be identical to that required for voting. As by voting, one is responsible for the decision one makes for oneself but for the others too, the same happens with this public system of credit units. Each decision is measured in this supply-demand system, altering the prices and the services available. For this reason each choice must be made carefully, treating the genetic identity with respect but also taking under consideration the effects that this choice will have in the whole society.

By this system we believe that equality is secured through equal access to enhancement services. In this way it answers to the arguments underlying the potential social inequality and instability this kind of technology may bring. At the same time it serves the purpose of respecting and promoting the liberty of the individual as well as that of the collective. It balances between the freedom of one to choose and the equal freedom of everyone’s right to choose too. It benefits the individual both by enhancing one’s capabilities but also by encouraging one to consider seriously one’s life plans and reflect on the importance of genetic identity, by not making enhancement services just another product for consumption. Serious reflection by each individual will also help avoid any type of genetic homogenization, because each individual is required to make a serious, life changing decision unaffected by temporary fashions and trends. It also avoids genetic determinism, as enhancements will only help people

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<sup>98</sup> For an alternative view on the relation of equal worth and equal autonomy and its implications see: Finegan T., Dworkin on Equality, Autonomy and Authenticity, *The American Journal of Jurisprudence*, 2015, 60: 2,143–180

to achieve their goals and develop their new capabilities, it is not creating new humans. For this reason a right to enhancement is supplementary to the basic rights and social goods: genes are only one part of the equation for one's flourishing. Furthermore, as enhancement is a valuable investment, it provides extra motivation for achieving one's life plans, it can help exercise one's free will free from genetic-natural obstacles. One will no longer blame one's parents for the way one is. Finally, as we mentioned, it makes people more respectful of nature and their genetic identity, as genetic alterations will not be a matter of money.

As far as society is concerned, first of all, it will reap the benefits of an enhanced population. This system maximizes social benefit by making enhancements accessible to parts of the population which would previously be excluded. By respecting the individual and making access equally possible, society is rendered therefore more stable and equitable. It becomes also a society based on personal effort and merit. After restoring the genetic inequalities and – if the proper social opportunities allow – each individual will have the chance to flourish. It is important to note that this equality and the benefits of enhancements are achieved without paternalistic policies or eugenics projects. Science will be encouraged and helped to provide advancements for all, and the voices and preferences of the least well off – as they are a majority – will be heard. Science will make new findings benefitting the ones who are most in need rather than for those ready to pay. Science therefore will not be linked to the money, market-based system and scientific evolution on these fields will be made according to the real social needs. By this system we let people themselves decide whether they need any genetic alteration and we don't give state or market definitions of "normal" or "healthy".

We would also like to point out that the system we propose would be more or less unsuccessful if not developed at the same time with policies aiming to the reduction of social inequality and the provision of basic means for each individual (proper education and healthcare), therefore it must be a part of a wider distributive policy. An enhanced humanity must be organized in a less competitive society. Such a society can be achieved by encouraging a cooperative rather than a competitive view of democratic societies. An enhancement system must lead us to reconsider our values – our opinions on success, merit etc and promote "what really matters" for one's identity. Maybe the fact that enhanced humans will owe much of their genetic and social means to achieve flourishing to their community will help the development of feelings of solidarity and empathy. People will now be linked by a common bond – that of mutually enhanced humans. By avoiding paternalistic policies and propaganda we believe that this system will help the development of a society constituted by citizens equally respectful of liberty and fairness. Natural evolution was based on the randomness of the Darwinian "natural selection", let the human driven evolution be based on social cooperation and humanist values.

#### Conclusion

Scientific research has reached a point where technology can be used to edit a gene and create a desired DNA sequence in a much cheaper and precise way than in the past. This type of gene editing has been the subject of controversy among scientists, philosophers and the general public especially because it concerns the DNA – which carries a special moral value for some – and may lead to human genetic manipulation. Some states have regulated the uses of this new tool, CRISPR, allowing only somatic (non- heritable) and therapeutic (not enhancing) applications. Some of the first uses of CRISPR show mixed results of success. Some operations managed to cure or are encouraging for the development of a cure for genetic diseases. Others though, have been unsuccessful, causing serious problems or even death. A great part of the scientific community finds that applications to humans are still dangerous.

Discussions concerning the permissibility of its use and the orientation of future research have mainly as subject the question of what can be considered as a disease or disability and what

constitutes an operation therapeutic or enhancing. These subjects demand a definition for “normality” or “healthy conditions” which are controversial terms for many activists. Other issues concern whether even if safe, CRISPR’s use can be allowed at all, and if so, on what kind of cells. Whether it will edit a somatic or a germline cell has been an issue. If used to edit germline cells the modifications will be carried on by the patient’s posterity creating issues concerning a threat to the autonomy of future generations and bring up the non-identity problem. There is also debate for the interpretation of human dignity and liberty, touching issues concerning the essence of humanity or the priority of the natural over the artificial. Some experts have agreed to some uses of this technology while disagreeing on others based on their conceptions of dignity, equity and science, while others seem to encourage gene editing’s advancement in order to enable humans to enhance themselves.

In this essay we tried to present and analyze the arguments for and against genetic modification both in general (whether it must be done at all) and in particular (whether it shall be applied on somatic or germline cells and for what purposes) and treated the subject of enhancements’ desirability. Finally we have presented a system of organizing and distributing the benefits of this technology. We argued that if there must be an enhanced humanity, this can only be achieved in an equitable, dignity- and liberty- respecting way.

Inspired by the arguments of Ronald Dworkin, after examining other philosophical approaches of equality, fairness and justice, we founded our system on an interpretation of “equal concern and respect”. We argued that, in order for these two principles to be applied, a system of distribution of the goods this new technology has to offer (in that case somatic cell enhancement services) must be public and money independent. The proposed system would function with the use of unique credit units which would be neither exchangeable nor valued in money, as we find that the enhancement procedure due to the very special value it carries – linked to the core of human nature, in our opinion, must be independent of any other type of good distribution. We approach enhancement as the next step to human evolution. These units should be of equal sum for all citizens (equal concern) and would grant them the liberty to decide for themselves which – if any – of their traits they want to enhance (equal respect). Despite this proposal, we believe that a real “enhancement” must be social and not individual. We believe that a really enhanced society is the society where every member has the capacity to form an opinion of what constitutes a good life for him and the basic means to achieve it. For this reason we feel the need to stress the point that enhancements and their equitable distribution are not enough. In order to achieve real enhancement one must enjoy a hospitable environment, having enough means so as to live with decency. We find therefore that enhancement distribution must be inseparable from wealth redistribution and strengthening of social ties. Before we try biological enhancements let us try social reform.

## Bibliography

### Books

- Agar, N. *Liberal Eugenics: In Defence of Human Enhancement*, 2004, Oxford UK: Blackwell
- Atlan, H. *La fin du tout génétique ? Vers de nouveaux paradigmes en biologie*. 1999, Éditions Quæ, 1999
- Baylis F. *Altered inheritance. CRISPR and the ethics of human genome editing*, 2019, Harvard University Press
- Buchanan, A. Brock D. Daniels N. and Wikler D. *From Chance to Choice: Genetics and Justice*, 2000, Cambridge: Cambridge University Press
- Carens, J. *Equality, Moral Incentives and the Market*, 1981, Chicago: Chicago University Press.
- Dworkin, R. *Liberalism*. In *Liberalism and its critics*, ed. Michael J. Sandel, 1984. New York: New York University Press
- Habermas J. *The Future of Human Nature* (trans. William Rehg, Max Pensky, Hella Beister) 2003 Cambridge: Polity Press
- Kant, I. [Groundwork of the Metaphysic of Morals](#). Translated by Ellington, James W. 1993, Hackett Publishing Company (3rd ed.)
- Kass, L. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, Report from the President's Council on Bioethics, 2003, Washington, D.C
- Nozick, R. *Anarchy, State and Utopia*, 1974, New York: Basic Books
- Rawls, J. *A Theory of Justice*, 1971, Harvard, MA: Harvard University Press
- Rawls, J. *Justice as Fairness: A Restatement*, E. Kelly (ed.) 2001, Cambridge, MA: Harvard University Press
- Sandel, M. *The Case Against Perfection*, 2007, Cambridge: Harvard University Press
- Stern, Alexandra Minna. *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America*. 1st ed., 2005, University of California Press

### Articles-Book chapters

- Anderson E., "What is the Point of Equality?", *Ethics*, 1999 109: 287–337.
- Anderson, E., The Fundamental Disagreement between Luck Egalitarians and Relational Egalitarians, *Canadian Journal of Philosophy* (Supplementary Volume), 2010, 36: 1–23
- Barrangou R. *The CRISPR Journal*. Oct 2019. 247-248
- Barrangou R. *The CRISPR Journal*. Apr 2019. 67-67
- Beauchamp TL, Methods and principles in biomedical ethics *Journal of Medical Ethics* 2003;29:269-274
- Bostrom, N. In defense of posthuman dignity. *Bioethics*, 2005, 19: 202-214
- Bourne H, Douglas T, Savulescu J Procreative beneficence and in vitro gametogenesis. *Monash Bioeth Rev* 2012;30:29–48
- Carroll D. Progress and prospects: zinc-finger nucleases as gene therapy agents. *Gene Ther.* 2008 Nov;15(22):1463-8.
- Cavaliere G, Devolder K, Giubilini A. Regulating Genome Editing: For an Enlightened Democratic Governance. *Camb Q Healthc Ethics*. 2019 Jan;28(1):76-88
- Christian M, Cermak T, Doyle EL, Schmidt C, Zhang F, Hummel A, Bogdanove AJ, Voytas DF. Targeting DNA double-strand breaks with TAL effector nucleases. *Genetics*. 2010 Oct;186(2):757-61. or



Clarke S. Buchanan and the Conservative Argument against Human Enhancement from Biological and Social Harmony in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016).

Convention on Human Rights and Biomedicine (ETS No 164), Council of Europe, 1997

Critchley C, Nicol D, Bruce G, Walshe J, Treleaven T and Tuch B Predicting Public Attitudes Toward Gene Editing of Germlines: The Impact of Moral and Hereditary Concern in Human and Animal Applications. *Front. Genet.* 2019,704,

Cwik B. Moving Beyond 'Therapy' and 'Enhancement' in the Ethics of Gene Editing. *Camb Health Ethics Q.* 2019,Oct;28

Doxzen K, Halpern J. Focusing on Human Rights: a framework for CRISPR germline genome editing ethics and regulation. *Perspect Biol Med.* 2020;63(1):44-53.

Drabiak K. Untangling the Promises of Human Genome Editing. *The Journal of Law, Medicine & Ethics.* 2018;46(4):991-1009

Dworkin R. What is Equality? Part 2: Equality of Welfare, *Philosophy and Public Affairs*, 1981, 10: 283–345.

Dworkin, R. What is Equality? Part 1: Equality of Resources, *Philosophy and Public Affairs*, 1981, 10: 185–246.

Evans J.H. The Dismal Fate of Flourishing in Public Policy Bioethics: A Sociological Explanation in Parens E. Josephine Johnston, 2019

Finegan T, Dworkin on Equality, Autonomy and Authenticity, *The American Journal of Jurisprudence*, 2015, 60: 2, 143–180

Fu Y, Foden JA, Khayter C, Maeder ML, Reyon D, Joung JK, Sander JD. High frequency off-target mutagenesis induced by CRISPR-Cas nucleases in human cells. *Nat Biotechnol.* 2013 Sep;31(9):822-6.

Garland-Thomson, R. How We Got to CRISPR: The Dilemma of Being Human. *Perspectives in Biology and Medicine.* 2020, 63. 28-43

Giesen Klaus-Gerd, Le transhumanisme comme idéologie dominante de la quatrième révolution industrielle, *Journal international de bioéthique et d'éthique des sciences*, 2018, 29, 189-203.

Giesen, Klaus-Gerd. Transhumanisme et génétique humaine, *L'Observatoire de la génétique*, 2004 no16

Guttinger S. Trust in Science: CRISPR-Cas9 and the Ban on Human Germline Editing. *Sci Eng Ethics.* 2018;24:1077–1096. doi: 10.1007/s11948-017-9931-1

Gyngell C, Douglas T Stocking the genetic supermarket: reproductive genetic technologies and collective action problems. *Bioethics* 2015;29:241–507

Gyngell C, Douglas T, Savulescu J, The ethics of germline gene editing. *J Appl Philos* 2017;34

Gyngell C, Bowman-Smart H, Savulescu J Moral reasons to edit the human genome: picking up from the Nuffield report *Journal of Medical Ethics* 2019;45:514-523

Gyngell C, Douglas T, Savulescu J. The Ethics of Germline Gene Editing. *J Appl Philos.* 2017;34:498–513.

Gyngell C. and Selgelid M. [Human Enhancement: Conceptual Clarity and Moral Significance](#) in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016). *The Ethics of Human Enhancement: Understanding the Debate*. Oxford University Press

Hammerstein, A.L., Eggel, M. & Biller-Andorno, N. Is selecting better than modifying? An investigation of arguments against germline gene editing as compared to preimplantation genetic diagnosis., *BMC Med Ethics* 2019, 20, 83

Harris, J. Is There a Coherent Social Conception of Disability, *Journal of Medical Ethics*, , 2000, 26: 95–100

Hauskeller M. Levelling the Playing Field: On the Alleged Unfairness of the Genetic Lottery, in Clarke, Steve; Savulescu, Julian; Coady, C.A.J.; Giubilini, Alberto; Sanyal, Sagar, eds. (2016) Hauskeller M., Editing the Best of All Possible Worlds? In Parens, Erik, and Josephine Johnston. (2019)

Hendel A, Fine EJ, Bao G, Porteus MH. Quantifying on- and off-target genome editing. *Trends Biotechnol*, 2015 Feb;33(2):132-40. 54.

Iyengar S. Kuman T. Do More Choices Lead to More Flourishing? in Parens E. Josephine Johnston, 2019

Jinek M, Jiang F, Taylor DW, Sternberg SH, Kaya E, Ma E, Anders C, Hauer M, Zhou K, Lin S, Kaplan M, Iavarone AT, Charpentier E, Nogales E, Doudna JA. Structures of Cas9 endonucleases reveal RNA-mediated conformational activation. *Science*. 2014 Mar 14;343(6176):1247997

Johnston J. "Shaping the CRISPR Gene-Editing Debate: Questions About Enhancement and Germline Modification." *Perspectives in Biology and Medicine*, 2020 vol. 63:1,141-154.

Kamm, F. Is There a Problem with Enhancement?, *American Journal of Bioethics*, , 2005, 5(3): 5–14

Kaplan, J.M. Race, IQ, and the search for statistical signals associated with so-called “X”-factors: environments, racism, and the “hereditarian hypothesis”. *Biol Philos*, 2015,30, 1–17

.

Kolisis, N. CRISPR, an innovation in the field of gene editing. Proposing a way to include it in a public health system. *Bioethica*, 2020,6(2), 30-40

Koplin, JJ, Gyngell, C, Savulescu, J. Germline gene editing and the precautionary principle. *Bioethics*. 2020; 34: 49– 59.

Leach Scully J, Choice, Chance, and Acceptance In Parens, Erik, and Josephine Johnston. (2019)

Millum J. The foundation of the child's right to an open future. *J Soc Philos*. 2014;45

Müller M, Schneider M, Salathé M, Vayena E. Assessing Public Opinion on CRISPR-Cas9: Combining Crowdsourcing and Deep Learning *J Med Internet Res* 2020;22(8):e17830

National Academies of Sciences, Engineering, and Medicine. Enhancement. In: *Human Genome Editing: Science, Ethics, and Governance*. Washington, DC: National Academies Press; 2017:137-162

Nie JB, Cheung A. He Jiankui's Genetic Misadventure, Part 3: What Are The Major Ethical Issues? The Hastings Center Forum. 2019

Omerbasic A Genome Editing, Non-Identity and the Notion of Harm. In: Braun M., Schickl H., Dabrock P. (eds) *Between Moral Hazard and Legal Uncertainty. Technikzukünfte, Wissenschaft und Gesellschaft / Futures of Technology, Science and Society*. 2018, Springer VS, Wiesbaden

Parens E. Choosing Flourishing: Toward a More "Binocular" Way of Thinking about Disability , *Kennedy Institute of Ethics Journal* June 201727(2):135-150

Parker, M. "The Best Possible Child." , *J Med Ethics* ,2007,33: 279-283

Pugh J. Kahane G. Savulescu J, Partiality for Humanity and Enhancement in in Steve Clarke, Julian Savulescu, Tony Coady, Alberto Giubilini, and Sagar Sanyal, 2016

Roberts D. Whose Conception of Human Flourishing? In Parens, Erik, and Josephine Johnston. *Human flourishing in an age of gene editing*, 2019

Lander ES, Baylis F, Zhang F, Charpentier E, Berg P, Bourgain C, Friedrich B, Joung JK, Li J, Liu D, Naldini L, Nie JB, Qiu R, Schoene-Seifert B, Shao F, Terry S, Wei W, Winnacker EL. Adopt a moratorium on heritable genome editing., *Nature*. 2019 Mar;567

Savulescu J, Pugh J, Douglas T, Gyngell C. The moral imperative to continue gene editing research on human embryos. *Protein Cell*. 2015;6(7):476-479,

Savulescu J. In Defence of Procreative Beneficence, *Journal of Medical Ethics*, 2007 33(5): 284–88

Savulescu J., New breeds of humans: the moral obligation to enhance, *Reproductive BioMedicine Online*, 2005; vol 10: pp 36-39

Savulescu, J. Genetic interventions and the ethics of enhancement of human being, In: Steinbock, Bonnie, ed. *The Oxford Handbook of Bioethics*. 2007, Oxford; New York: Oxford University Press, : 516-535

Scott R, Wilkinson S. Germline Genetic Modification and Identity: the Mitochondrial and Nuclear Genomes. *Oxf J Leg Stud*. 2017 Dec;37(4):886-915

Sourlas, P. Human Dignity and the Constitution *Jurisprudence* , 2016,7 (1):30-46

Sparrow R, A Not-So-New Eugenics: Harris and Savulescu on Human Enhancement, *Hastings Center Report*, 2005, 41(1): 32–42.

Sparrow, R. Defending Deaf Culture, *Journal of Political Philosophy*, , 2005, 13(2): 135–152.

Sterri, AB. Sex selection in India: Why a ban is not justified. *Developing World Bioeth*. 2020; 20: 150– 156

Sykora P, Caplan A. The Council of Europe should not reaffirm the ban on germline genome editing in humans. *EMBO Rep*. 2017;18(11):1871-1872.

Tanner, C. & Christen, M. Moral Intelligence – A Framework for Understanding Moral Competences In M. Christen et al. (eds.), *Empirically Informed Ethics: Morality between Facts and Norms* (119-136). 2014, Zurich, Switzerland: Springer International Publishing

The Nuffield Council on Bioethics. Genome editing and human reproduction: social and ethical issues. 2018

Tobin B. MacIntyre’s Paradox , in Steve Clarke, Julian Savulescu, Tony Coady, Alberto Giubilini, and Sagar Sanyal, 2016

Vincent N. A and Jane E. Parental Responsibility and Gene Editing In Parens, Erik, and Josephine Johnston. (2019)

Weckert J. Playing God: What is the Problem? in Steve Clarke, Julian Savulescu, Tony Coady, Alberto Giubilini, and Sagar Sanyal, 2016

You L, Tong R, Li M, Xue J, Lu Y. Advancements and obstacles of CRISPR-Cas9 technology in translational research. *Mol Ther Methods Clin Dev*. 2019;13:359-370

Zhepeng Liu, Jin Liang, Shuliang Chen, Kewu Wang, Xianhao Liu, Beibei Liu, Yang Xia, Mingxiong Guo, Xiaoshi Zhang, Guihong Sun, Geng Tian. Genome editing of CCR5 by AsCpf1 renders CD4+T cells resistance to HIV-1 infection. *Cell & Bioscience* , 2020, 10:1

Κουκουζέλης (Kostas N. Koukouzelis), Humanity, Future Generations and Bioethics. .2016. *Bioethica*, 2(1), 5-15

#### Webpages

Center for Genetics and Society . CGS summary of public opinion polls [Internet]. [cited 2020 Mar 23]. Available at: <https://www.geneticsandsociety.org/internal-content/cgs-summary-public-opinion-polls?id=401>

The Genetic Engineering Genie Is Out of the Bottle. The next pandemic could be bioengineered in someone’s garage using cheap and widely available technology  
 Accessible at: <https://foreignpolicy.com/2020/09/11/crispr-pandemic-gene-editing-virus/>