

# **Enhancing Mankind**

## **The Role of Bioethics in Genome Editing Technologies**

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Il presente lavoro tratta dei più recenti progressi nel mondo della biologia genetica, in particolare delle tecnologie di modificazione del genoma, e delle sfide etiche che tali progressi suscitano. Ho cominciato il lavoro illustrando la storia della biologia genetica, dalla scoperta del DNA all'ultima innovazione nel campo: la tecnologia CRISPR/Cas9, che permette di modificare il genoma velocemente, efficientemente ed economicamente. Ho parlato della conferenza sul tema tenuta dalla *American Academy of Sciences* per discutere i problemi etici legati a tale ricerca; ho menzionato l'applicazione, la prima nel suo genere, della tecnologia CRISPR su embrioni umani da parte di un gruppo di ricercatori cinesi. Ho infine parlato della notizia, del primo febbraio 2016, di una nuova regolamentazione nel Regno Unito che permette la sperimentazione di CRISPR sugli embrioni umani. Ho discusso poi i problemi etici legati al cosiddetto *enhancement* genetico, cioè la modificazione di tratti non patologici e l'aggiunta di tratti desiderabili nel genoma di una persona. Ho analizzato l'equiparazione all'eugenetica fatta da molti. Ho poi illustrato l'ipotesi di un mondo ideale post-genomico che, adeguandosi al principio di equa eguaglianza delle opportunità di matrice rawlsiana, potrebbe produrre una società ingiusta; ho illustrato una possibile modifica del principio per far fronte a tale possibilità. Infine ho incluso la sintesi di un'intervista al Professor Crescenzi dell'Istituto Superiore di Sanità da me personalmente condotta durante la mia ricerca, su CRISPR, genetica ed etica.

The present work is about the most recent progress in the world of genetic biology, in particular of genome editing technologies, and about the ethical challenges that such progress raises. I started my work by illustrating the history of genetic biology, from the discovery of DNA to the last innovation in the field:

the CRISPR/Cas9 technology, that allows to modify the genome quickly, efficiently and economically. I mentioned the conference on the subject held by the American Academy of Sciences to discuss the ethical problems that go along with it. I mentioned the application, the first of its kind, of CRISPR technology on human embryos by a group of Chinese researchers. I talked about the news, of February 1st, 2016, of a new regulation in the UK which allows CRISPR to be used on human embryos. I discussed the ethics behind genetic enhancement, that is, editing non-pathological traits and adding desirable characteristics to a person's genome. I analyzed the accusation made to genome editing technologies to resurrect eugenics. I then surveyed the hypothesis of a ideal post-genomic world that, although following the Rawlsian principle of fair equality of opportunities (FOE), could produce an unfair society; I illustrated a proposed modification of the Rawlsian principle to face this possibility. Finally, I included the summary of an interview to Professor Marco Crescenzi of the *Istituto Superiore di Sanità* that I personally conducted during my research on CRISPR, genetics and ethics.

## **1. Genetics: an overview**

It was the late 1860s when Friedrich Miescher, a Swiss biologist and physician, first isolated and identified deoxyribonucleic acid (DNA for short), which can be found in the nucleus of every cell of a living body, and raised the idea that nucleic acid could have a central role in heredity. The scientific community did not understand the significance of his discovery at first: however, slowly but surely, new advances were made during the Twentieth century, until in 1953 James Watson and Francis Crick discovered the double-helix structure of DNA. The 1970s saw the birth of the famous genome sequencing technique known as *The Sanger Method*, which quickly became the most widely used method to sequence genome. As progress in the field increased, in 1983 Mullis invented the Polymerase Chain Reaction, which made it possible to identify diseases, viruses and bacteria, and to help law-enforcement authorities to recognize convicts at crime scenes.

Perhaps the greatest endeavor ever undertaken so far in the field of DNA mapping was the well-known Human Genome Project. A genome is the complete set of DNA of an individual, including all its genes. The genome contains the totality of information needed for that particular organism to function. It is found in every cell of the body that has a nucleus and is different for each specimen of a species. The genome of the human species has more than three billion DNA base pairs, which are the building blocks of the double helix of the deoxyribonucleic acid. Men and women have what is known as a diploid genome, that is, a genome which is provided with two copies of chromosomes of the same type. Our species has in most cases forty-six

couples of chromosomes, of which twenty-three are inherited from the father and twenty-three from the mother.

The Human Genome Project was proposed and financed by the government of the United States of America starting in 1984: its objective was to map all the genes of the DNA of *Homo Sapiens* and to understand their function. This mega project represented a revolutionary exploration of our species, in collaboration with researchers from all over the world and from twenty universities, in the United States and other countries. This great bold study took years to reach its goal, and the Human Genome Project was declared complete in 2003<sup>1</sup>.

Mapping the human genome has brought several benefits to science and the way it can help the welfare of humankind: it helped us understand better many diseases, including mutations associated with the development of cancer, human evolution and anthropology. Interesting discoveries of the project were the approximate number of genes in the human body (20,500, similar to the number of genes in mice) and that fewer than seven percent of proteins in our body are specific to vertebrates. Ethical concerns were raised at the onset of the Project, as many feared that being able to map someone's DNA would lead to discrimination based on people's genes and propensity to develop certain diseases. To address these issues, the U.S. government was prompted to direct a part of the budget to the Ethical Legal and Social Implication Program, and to promote the adoption of an Act of Congress which prohibited the non-consensual release of someone's identifiable health information to an entity not directly involved with health care.

The step which followed the mapping of the human genome was to investigate ways to edit it. This began to seem possible in 2012 with the development of epigenetic editing. Epigenetics is the study of the expression of genes, also known as its phenotypic traits. In fact, even though each individual carries the same DNA for all their life, the expression of their DNA changes due to external and environmental pressures which activate certain genes of the genetic makeup while de-activating others.

Genome editing refers to genetic engineering techniques where pieces of DNA are cut, replaced or added artificially to the genetic makeup of a live specimen. Such techniques are quite new to the scientific world, having been developed in the last decades. The capacity to edit an individual's DNA has enormous consequences for scientific progress in medical matters. In fact, one of the practical applications on humans of such techniques would be to remove a person's DNA sections responsible for hereditary diseases and

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<sup>1</sup> <http://genomeediting.weebly.com/history.html>

replace them with healthy ones, or to modify the genetic makeup of an individual in order to correct some undesired traits and characteristics. Although few object to the first aim from an ethical point of view, some concerns have been raised from the world of Bioethics regarding the latter practical application of the method.

Modifying someone's DNA in order to change characteristics that pose no health threat to the individual, or giving them advantage over other humans by conferring them above-average features undoubtedly raises important questions and ethical dilemmas that have just begun to be discussed by bioethicists, as these techniques are rather new and represent a frontier of bio-engineering that has just started to be explored by the scientific community. Editing the genome of people is but a dream right now: a dream which, however, is getting everyday surprisingly closer to reality.

## 2.1 CRISPR/Cas9

The latest introduction in the field of genome editing is called *CRISPR/Cas9*<sup>2</sup> (which stands for *clustered regularly-interspaced short palindromic repeats*), a new and revolutionary method still in its beginnings which is shaking the academic world, raising enthusiastic reactions from researchers the world over. CRISPR/CAS9 was discovered almost randomly, while some biologists were running some standard research on bacterial defense mechanisms. What they found out is that some bacterial life forms have the capacity to alter the RNA of viruses that are trying to invade them by inactivating some of the viruses' genes to render them inoffensive. The tool used by the bacteria to do that is a nuclease that carries the name of Cas9.

The use of Cas9 allows a much easier infiltration into the genome of a cell than previous genome editing techniques used in laboratories, such as TALEN or Zinc Finger. Modifying the genome of a pluripotent cell, such as a stem cell, allows for all of the cells born out of the first one to carry with them the genetic modification and even, if the gametes end up carrying the modified DNA too, transmit it to future generations. CRISPR/CAS9 is still a new technique, but it has already enjoyed a surprising success and several papers have been published during the last few years about it, and numerous laboratories have been applying it already to simple and complex organisms, including animals.

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<sup>2</sup> <http://www.nature.com/news/crispr-1.17547>

The first species which scientists targeted for the first application of CRISPR/CAS9 on an animal specimen was the zebrafish, a tropical freshwater fish native to the Himalayan region, that is now very popular in aquariums. The zebrafish has had a central role in many genetic researches throughout the years, due to its regenerative abilities and, incidentally, was the first vertebrate animal to be cloned<sup>3</sup> (the first mammal to be cloned would be the famous Dolly, a sheep, which was born in 1996 and euthanized in 2003), and amongst the few species of fish to have been sent into space. The scientific community has even created a vast scholarly database about the fish and has fully sequenced all its genome, which is made available to researchers in the *Zebrafish Information Network*. Surprisingly, the zebrafish presents strikingly similar toxicity responses to those of humans and most mammals, and exhibits a diurnal sleep cycle like that of primates, and that is part of the reason why it is so widely used in genetic studies. Using CRISPR/CAS9 successfully on zebrafish demonstrated how efficient the technique was and how useful it could prove in the future. It took just a year before researchers were able to apply the CRISPR/CAS9 method to mice on human-related genes, with the intent to correct a mutation and create a healthy phenotype.

Today, the most common genome editing techniques remain Zinc Finger Nucleases, TALEN and CRISPR/Cas9. Zinc Finger was the first method which relied on proteins to attain gene editing, however it has proved quite unpredictable and can be negatively impacted by normal body functions. Among the advantages that CRISPR/CAS9 has over TALEN is the fact that it is more precise and safe, and that it can target multiple cells at once. It is a very simple and inexpensive process compared to the other, and the guide RNAs can be easily programmed.

CRISPR/CAS9 has been in fact applied by Chinese researchers from the University of Nanjing in 2013 on macaque embryos, that were successfully born in 2014.<sup>4</sup> The mutations were inserted into 83 specimens of embryos, of which 10 were successfully implanted. One of these pregnancies came to full term and resulted in the birth of a pair of twins with genetic mutations. This accomplishment paves the way for numerous others, especially considering how genetically close humans and other primate species are. This and other significant accomplishments make it seem extremely likely that CRISPR/CAS9 may hold the key for future application of such discoveries to human beings.

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<sup>3</sup> [http://www.neuro.uoregon.edu/k12/george\\_streisinger.html](http://www.neuro.uoregon.edu/k12/george_streisinger.html)

<sup>4</sup> <http://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378>

## 2.2 CRISPR/Cas9: the history

CRISPR/CAS9 has been a revolution that has quickly swept the world of biology and genomics. As we now know, CRISPR/CAS9 is an adaptive immune system used by some species of microbes, utilized as a defense mechanism against the attacks of viruses. This mechanism, initially discovered randomly by a researcher in Spain, was soon recognized as a possibly explosive innovation for the future of biology, if only scientists could learn to apply the procedure safely and reliably. Although by now, the year 2016, the popularity of CRISPR/CAS9 has risen enormously, and virtually every scholar of the subject knows about it, few are interested to know exactly how it came to be discovered, as often happens in the scientific world once a fact is firmly established. To explore the origins of CRISPR/CAS9, we must go back 20 years, and look at the work, often independent from each other, of a handful of scientists, whom author Eric Lander calls *The Heroes of CRISPR*. What follows is a brief story of how CRISPR/CAS9 came to be discovered, how the first papers about it were published and how it rose to prominence in the academic world of biology<sup>5</sup>.

Francisco Mojica, a 28-year-old graduate student from the the University of Alicante, joined a study analyzing the characteristics of a microbe, *haloferax mediterranei*, which presented an extreme tolerance to salt. Restriction enzymes seemed capable of cutting the microbe's genome, among which a curious palindromic structure was found. He was fascinated by the anomaly and devoted the following ten years of his career to solving the puzzle. Mojica found the same patterns also in a few other species of microbes, and, after turning to bioinformatics to investigate about the uncommon repeats, he found them in 20 different microbes. The name which was given to them was *clustered regularly interspaced palindromic repeats*, for friends, CRISPR/CAS9.

Still, hypotheses abounded about what it could possibly be the function of the CRISPR/CAS9 system. Some proposals suggested gene replication or DNA repairing to be the function pursued by the system. It was only after later experiments, in particular one involving an *e.coli* strain which carried the CRISPR/CAS9 spacer and was resistant to P1 infection, that Mojica realized that the system was in fact an adaptation to render the microbes immune to specific infections. Mojica wrote a paper to document his discoveries and submitted it to *Nature* and other important scientific

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<sup>5</sup> [http://www.cell.com/cell/pdf/S0092-8674\(15\)01705-5.pdf](http://www.cell.com/cell/pdf/S0092-8674(15)01705-5.pdf)

reviews, but only later was it accepted by the *Journal of Molecular Evolution*, where it appeared in February 2005.

Meanwhile, CRISPR/CAS9 was being independently discovered by two French researchers, Gilles Vergnaud and Christine Pourcel, who were working under the direction of the French Ministry of Defense, after concerns in the late 1990s the the regime of Saddam Hussein in Iraq was developing biological weapons of mass destruction. These two authors reached the same conclusions as Mojica: the CRISPR/CAS9 locus served as a defense mechanism, or in other words, as a memory of past genetic aggressions. Their paper was published in *Microbiology* in 2005. Finally, research on CRISPR/CAS9 was independently being conducted by a third researcher, Alexander Bolotin, a Russian immigrant in France, who submitted his paper one month after Mojica's research had been published. Another great contribution to the progress in the field was given by Luciano Marraffini, an Italian-Argentinian working at the University of Chicago, who successfully demonstrated that the target of CRISPR/CAS9 is DNA and not RNA, as previously thought.

Thanks to the work of Sylvain Moineau the field reached a historic milestone: the three components of the CRISPR/CAS9 system were now known: Cas9 nuclease, *crRNA* and *tracrRNA*. The next great step was demonstrating that it was possible to reprogram Cas9 with custom-designed spacers to cut a chosen target site in vitro. Applying the system in mammalian cells, though, which have very different internal environments compared to microbe cells and have a genome a thousand times larger than theirs which resides in the nucleus, had never been tried yet. Feng Zhang, a Chinese émigré to Iowa and an undergraduate student at Harvard, set out to create a version of *S. thermophilus* Cas9 for use in human cells. He managed to show that it was possible to mutate genes with accuracy and efficiency, by targeting sixteen sites in genomes of humans and mice. His work was published in a paper which appeared in *Science* in January 2013. This and other contemporary researches made CRISPR/CAS9 very popular.

In early 2013 Google searches for CRISPR/CAS9 skyrocketed, and the trend has continued ever since. What had once been an obscure defense mechanism of microbial systems discovered in Spain 20 years before, was now the most popular frontier for biology. And, as history has amply taught, once a new knowledge is available, it is a matter of time before it is used and applied, no matter any ethical objections that can be brought against it.

Thanks to its rising popularity and its feasibility, there has been a surge in the past years of commercial activity and investment on the technique. The roots of the dispute go back to 2012, when after succeeding in

cutting chosen strands of DNA with the method, a group of scientists files for a patent application in 2013. Pharmaceutical companies have been scrambling to invest on the technology and acquire some of the rights needed to operate it. Among these, AstraZeneca, Novartis, CRISPR/Cas9 Therapeutics, Editas Medicine, and a startup named Caribou.

While these applications remain in review, the ones applied for by dr. Feng Zhang have been granted in 2014, and he has since been awarded others. Zhang is involved with Editas, founded by him and a colleague of his, Doudna<sup>6</sup>.

### 2.3 CRISPR/Cas9: issues and concerns

Having the ability to modify a person's genome opens the door to two types of interventions, which carry with them very different connotations and very different challenges for bioethicists<sup>7</sup>.

One is a *corrective* intervention, which seeks to eliminate defects present in someone's genes in order to fight diseases, prevent the likelihood of the insurgence of health problems, or correct the defective expression of some genes. This type of intervention can also have the aim of modifying an individual's characteristics which pose no threat to health but may be sub-standard compared to the population average, for example a height below average or precocious hair whitening.

The other type of intervention, one far more interesting from an ethical point of view, would be an *enhancing* intervention, whose goal is to confer to an individual above average characteristics, such as strength, intelligence, resilience, or whatever feature that can give an advantage to the person. This second application of the recent discoveries is far more problematic for ethics, as it touches very sensitive questions of justice, fairness, equal opportunities, discrimination, etc.

We find ourselves in a stage of progress in genetics today, that gives these questions still a very hypothetical character, as the day where these methods will be able to be applied to humans is still quite ahead of us, but makes them already very impellent and prompts bioethicists to start seeking answers to them, not for a mere exercise of argumentation for the sake of it, but to avoid being caught unprepared when the day will come (and it is

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<sup>6</sup> <http://www.nature.com/news/bitter-fight-over-crispr-patent-heats-up-1.17961>

<sup>7</sup> <http://www.economist.com/news/leaders/21661651-new-technique-manipulating-genes-holds-great-promise-but-rules-are-needed-govern-its>



coming sooner than we think), where genetically enhanced humans will walk this earth. The aim of this part of my work is precisely to address these issues.

After a brief overview of the exact functioning of the CRISPR/CAS9 technique I will explore why this new frontier really represents a revolution for humanity and future societies. I will then analyze objections to enhancement and point how it could lead to an unfair society under principles of Rawlsian justice. As often in ethical debates, there is no right or wrong answer that will meet a unanimous agreement. Ethics does not work like physics, and a few algebraic calculi cannot solve the complex problems that Bioethics faces. These are problems that directly affect the life and happiness of families and individuals, and, by extension, communities. Alas, we are left alone to solve them, and only us, the human inhabitants of this planet, can work together to find together solutions and alleviate the sufferings that many of us face on their brief sojourn in life. As much as we look, there is no help from above, no assistance from the sky. The universe is a strikingly silent and indifferent place, but we do have each other to help, assist, cooperate with, and seek together a fairer future for every man and woman who will be brought to life on here. I think that it is with this spirit that Bioethics may advance, with the gravity that these issues rightly require, but also with the joy of knowing that the opportunity for a juster world is within our reach if we only work for it, together.

CRISPR/CAS9, once thoroughly tested and perfected, will be able to cure diseases such as Alzheimer's, cancer and AIDS. Although the prospect of creating "designed" baby seems far and away, scientists from China, during a conference in April 2015, informed the scientific world that they had tried using CRISPR/CAS9 to edit the genes of human embryos, which however, unlike the macaque embryos mentioned above, were not able to develop to full term. This revelation has prompted numerous reactions from scientific circles. One of the inventors of the CRISPR/CAS9 method, proposed a ban on editing germ line cells, that is, those cells that can give rise to subsequent cellular generations, thus carrying the same genetic mutations their parent cell was endowed with.

The America's National Academy of Sciences has already held a meeting to discuss all the possible ethical implications of the CRISPR/CAS9 technique. The ethical concerns are of two types: one is a pure practical one, the other is a philosophical kind of concerns<sup>8</sup>.

The practical concerns arise because CRISPR/CAS9 is not risk-free yet. In fact, it may even take one generation before it could be safely applied

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<sup>8</sup> [http://www.nationalacademies.org/gene-editing/gene\\_167925](http://www.nationalacademies.org/gene-editing/gene_167925)

to humans: in the meanwhile couples carrying genetic diseases can rely on methods such as in vitro fertilization to give birth to healthy babies. CRISPR/CAS9 technology still has some flaws. As well as cutting or modifying the intended pieces of DNA, CRISPR/CAS9 sometimes goes off target, editing the wrong sections of genetic material along with the right ones. This does not really matter in the laboratory, nor would it matter in the case of a patient who wanted to fight a terrible disease, as they might be willing to run the risk. However, most people would not accept the correlated risk factor, thus before CRISPR/CAS9 can become mainstream, the technique must achieve sharper and more precise capacities. The danger is even higher in cases where the targeted cells are germ-line cells, as the effect would be quickly felt in all the body.

The philosophical concerns are, of course, no less complex. Some say CRISPR/CAS9 technology lets humans play the role of God, but such objections are easily dismissed: medicine already and repeatedly interferes with the natural order of things with vaccines, drugs, surgery and so on. Harder objections to address are editing germ-line cells, and the thin veil between therapy and enhancement. The first case (editing germ-line cells) has already been banned in about 40 countries, and many others have severe restrictions in place. The latter case, enhancement, that is, modifying a person's characteristics not to compensate defects but to confer above-average abilities or features, needs much more discussion and thought, and it is the topic of this thesis and of this part in particular.

When CRISPR/CAS9 will finally be declared safe for humans, the ethical issues connected with it will no longer be ignored, and values such as equality, or consent, will have to be taken into consideration in order to have a public conversation about the practice. For example, parents might want to make choices that are not in the best interest of their child, such as wanting to confer him or her an impressive intelligence, perhaps compromising other aspects of the child's personality, or, as it already has happened in a case of artificial insemination, deaf parents wanting their child to be deaf too. Another question is, if significant enhancement will really be possible, should it be limited to those who can economically afford it, or should the option be made available to anyone who so desires?

To address the practical concerns about the consequences that might follow a wrong modification of germ-line cells, researchers have already made a significant proposal, a sort of *kill switch* which would allow to deactivate the modification made to a cell and its descendant cells. Animal species which use sexual reproduction have two versions of each gene stored in two different chromosomes, that can be quite different from each other.

Normally, with reproduction, offspring inherit only one gene version out of the two that each parent has, and end up with a set of two versions for each gene themselves, one from the mother and one from the father. This means that the odds of getting each version of the gene are fifty-fifty. CRISPR/CAS9 technology has developed a system, called a *gene drive*, which has the ability to copy itself from one chromosome to the other, so that whichever chromosome the offspring will inherit, it will contain the gene with the modification, which will then copy itself again to the other chromosome inherited by the other parent.

The implications of this system are extraordinary. Normally, under the process of natural selection, genes spread through a population only if they confer an advantage for survival (natural selection) and/or reproduction rate (sexual selection). The gene drive bypasses natural and sexual selection and spreads the modified gene much faster than it normally would. Researchers have already expressed their desire to apply these discoveries to mosquito populations, changing the genes responsible for carrying malaria in a few individuals, and then waiting for the genes to quickly spread through all the population thanks to the gene drive<sup>9</sup>.

As positive as it may sound, the gene drive technology carries huge risks with it. In fact, the modified genes would spread even if they are undesired genes. If a specimen with a modified gene and a gene drive escaped from a laboratory, its new characteristics would immediately spread even if no one wanted to. This is why many workers in the field have called for some solution to the problem. One idea would be to create *reverse drives*, tools that would allow to undo the changes brought about by the drives. Another would be to design the drives so that they require the presence of an exogenous chemical, only present in the laboratory, in order to work.

Gene therapies that can be done *ex vivo*, that is, outside of the patient's body, are the easiest of all and the safest ones. In fact, after the cells have been extracted, they can be worked on and later, before putting them back into the body of the subject, the modified genes can be tested to make sure the therapy had a good result. The stage at which to intervene for gene editing, and the one which presents the most powerful impact (and the most controversial) is the very beginning, when the patient is still an embryo. This is due to the characteristic totipotency of the embryonic cell. In fact, the cell will later divide and all the cells of the future body of the patient will descend from the initial embryonic cell. Therefore they will all inherit the

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<sup>9</sup> <http://www.economist.com/news/leaders/21661651-new-technique-manipulating-genes-holds-great-promise-but-rules-are-needed-govern-its>

modifications brought to the embryo. The modifications, most importantly, will also be present in the gametes, and this is what makes this type of interventions controversial, as all the modifications made to a person will be passed on to the future generations.

Although there is no plan for a clinical application of this kind of editing operation, there has already been at least one instance of gene editing on embryos of the human species. In fact, in April 2015 a team of Chinese researchers announced that they had tested the CRISPR/CAS9 technology on a sample of non-viable human embryos. Junjiu Huang, the leader of the team, said that the sample consisted of eighty-six embryos which were the result of in-vitro fertilization at a local fertility clinic, and were going to be discarded anyway, because they had an extra set of chromosomes, since they were fertilized by two sperms: this prevents the embryos to proceed to full term, although they do undergo the first few stages of development.

The experiment did not have a positive result: in fact, after 48 hours, of the 86 embryos which received the Cas9 enzyme, 71 survived, and 54 of them were tested to verify how they had responded at a genetic level. Of the 54 embryos which were tested, only the DNA of 28 had successfully spliced (the first of the two steps of the CRISPR/CAS9 procedure), of which just a tiny fraction had reached the second stage, that is, the replacement of the removed genes with genetically modified genes. The experiment proved that the world will have to wait some years before being able to apply CRISPR/CAS9 on humans safely and cure dangerous diseases<sup>10</sup>. But it also proves that research on humans is underway and going fast, and safe application on embryos of our species might soon be viable.

A few days ago, in February 2016, as I was writing this, the United Kingdom allowed CRISPR/CAS9 application on human embryos<sup>11</sup>. The *UK Human Fertilisation and Embryology Authority* was the first in the world to openly permit the technique on embryos of our species on February 1st, 2016. The request to consider the case came from researchers from the Francis Crick Institute in London, in particular from the team of Kathy Niakan. Niakan asked permission to apply CRISPR/Cas9 on healthy human embryos, to be destroyed seven days later. The application for the permission came five months after the Chinese scientists announced the experiment we mentioned above. Sarah Chan, bioethicist from Edinburgh, has declared that she thinks

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<sup>10</sup> <http://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378>

<sup>11</sup> <http://www.nature.com/news/uk-scientists-gain-licence-to-edit-genes-in-human-embryos-1.19270>

this decision will send a powerful signals to other nations, and will embolden scientists everywhere.

### **3. The Asilomar Conference, 1975**

The Asilomar Conference on Recombinant DNA in 1975 was an interesting example of a meeting of researchers and experts in the field who met in order to discuss the possible ethical implications and biohazards of biotechnology. Its importance is fundamental for the history of bioethics, because for the first time the government of the United States of America actively promoted a meeting of the finest minds and field expertise of the time, with the explicit mission to discuss the ethical implications of Recombinant DNA, (a technology arisen with the progress in biology made during the 1950s and 1960s), and to lay down guidelines for its use, which the government committed to follow<sup>12</sup>.

The conference, held in February 1975 in Asilomar State Beach, California, saw the participation of 140 professionals, among whom there were biologists, lawyers and physicians, and had the goal to draw some voluntary guidelines for the use of recombinant DNA technology. The relevance of the meeting put the scientific issues of the time in the spotlight and set an example for future initiatives of the same kind. The guidelines set by the conference are still followed today. The model of this conference has since been followed because of the way it managed to unite scientists in the pursuit of an ethical way to do science, and it showed that it is possible to encourage progress while at the same time share a common concern for bioethical issues.

According to the analysis of Paul Berg and Maxine Singer in 1995, the conference had a great significance because it marked the beginning of a public discourse on science and public scientific policy. Furthermore, the conference set an important precedent about how to respond to new discoveries and progress in the scientific realm of knowledge: the conference's conclusion was that the proper reaction is to form guidelines to regulate it.

The example set by the Asilomar conference was emulated in December 2015, when nearly 500 scientists and other professionals in the field, forty years after the historic predecessor, reached the conclusion that research on genome editing technology should not be hindered or hampered,

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<sup>12</sup> [https://en.wikipedia.org/wiki/Asilomar\\_Conference\\_on\\_Recombinant\\_DNA#cite\\_note-asilomar-2](https://en.wikipedia.org/wiki/Asilomar_Conference_on_Recombinant_DNA#cite_note-asilomar-2)

but encouraged, provided that no effort be made to create modified human embryos for a pregnancy. Ephrat Levy-Lahad, from the Hebrew University of Jerusalem, has declared that the State of Israel will most likely welcome embryo genetic modification, as it already promotes preimplantation genetic diagnosis for newlywed couples in an effort to encourage large demographic growth of its population. Among the issues raised in the conference, there were suggestions that genome editing may cause discrimination and inequality, for example in the case of parents selecting children with certain characteristics. Also, according to the sociologist Ruha Benjamin of Princeton University, frictions will be created over which traits should be considered undesirable traits or handicap, as is the case with deafhood, considered a culture and not a disability by many Deaf people.

#### **4.1 Genetic enhancement and ethics**

Trying to address the bioethical challenges associated with a world where human genome enhancing will be available to the population by means of a more accessible and ready technology is essentially a matter of justice.

In fact, justice is that branch of ethics which deals with the equal and right distribution of resources to the population. Such resources can be economic resources, cultural resources, power resources, health resources, physical resources, etc. The way such resources are distributed affects the lives of individuals and their opportunities in the society where they live in. Justice is not necessarily a synonym of equality, although equality is a value that must always be taken into account, in order to assess when inequality is *just* and when it is *unjust*. Genome enhancing entails questions of justice because it affects the core asset of every human being: their genetic makeup. The genetic makeup of a person is not based on his or her merit, it is not the fruit of their decisions, and at the same time it determines, probably more than any other factor, the opportunities that life will present to the individual and the success of his or her endeavours, and his or her happiness and fulfilment.

Is it possible to live in a just, post-genomic world? *Post-genomic world* is how we will call a world where genome-editing technologies will be available for safe application on humans. Will such a world be an inherently unjust place for human beings or will it be possible to ensure justice for all? What would an unjust post-genomic world look like? This is the question that we will try to address in this section of the present work.

Firstly, I feel that a point has to be addressed: the relationship that our species has with enhancement. Enhancement, as defined by the *Oxford Dictionary*, is «an increase or improvement in quality, value, or extent»<sup>13</sup>: it is an enrichment of the default capacities and characteristics of a subject. Our species has a particular relationship with enhancement: in fact, enhancing ourselves is part of our very nature, and has proved to be a trait which has insured our survival as a species and our perpetuation on this earth. Enhancement is very human. Without enhancement, humans would be just like all other animals: naked, illiterate, and relying solely on their natural physical characteristics. Needless to say, *Homo Sapiens* would be a pretty miserable creature. Furless, weak, unable to digest most food, with very poor eyesight, hearing, and sense of smell. But natural selection has endowed humans with a trait able to trump all the deficiencies of our body: the ability to enhance ourselves through the manipulation of the outside world. As we learned to take advantage of the resources we found around us, clothing replaced fur, fire permitted us to digest otherwise inedible foods, and spears and arrows allowed us to hunt preys that we simply could not compete with if we relied solely on our bodies. Enhancement therefore, far from being something modern or something alien to our species, is the very characteristic that makes us men. It is the evolutionary strategy that, so far, permitted us to enjoy reproductive success and populate most of the planet's mainland. And no one cares to refuse the multiple forms of enhancement that we use everyday: education, housing, tap water, heating, medical progress, roads: these are all things that - very few disagree - made our lives better. Enhancement is neither new nor inhuman: quite the contrary, it is the most human of endeavors.

Why, then, does the prospect of altering our genomes in order to improve our condition scare so many people and raise so many contrary voices? Well, for one, genome enhancing is unexplored territory, a path that we just recently have started to set foot on. We know so much about all its potential, but still so little to put it into concrete, safe use with humans, and the risks are, as of now, much greater than the good it could accomplish. So, people are scared because we do not know the real risks yet. Secondly, genome enhancing is particularly controversial because it touches the most intimate part of a person: their DNA. DNA is what makes John John and Jane Jane. If John happened to have a different genetic makeup, would he still be John, or would he be Jake? DNA is the very identity of a person, and deliberately modifying it scares us because it triggers our self-preservation

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<sup>13</sup> <http://www.oxforddictionaries.com/definition/english/enhancement>

instinct. One thing is enhancing ourselves by improving the tools available to us, another is to change the molecule in the nucleus of every single cell of a human body that contains, so to say, who you really are. The mere thought of it provokes vertigo and stomach knots. Moreover, genome enhancing is scary to many because of the consequences of modifying our DNA. As i wrote above, DNA determines everything in our life, who we are, how we think, our physical and mental abilities. The prospect of modifying it deliberately, causes the fear that we may not know all the consequences, and we may cause irreparable damage in the life of a person (and their descendants).

*Playing with fire:* this is among the most common accusations made to those who encourage the exploration of this new and exciting frontier. Men have always had an innate fear of daring to cross some metaphorical border, perhaps set by God, or daring to take that additional step which may lead to some divine wrath for wanting to *play God*. The temptation to employ too much prudence is as strong in man as the temptation to challenge that prudence and explore more. This archaic game between fear and want for knowledge was expressed in many of the myths of the ancient world. Adam and Eve partaking of the forbidden fruit is the most famous example which links knowledge together with the fear of disastrous consequences:

*But of the tree of the knowledge of good and evil, thou shalt not eat of it: for in the day that thou eatest thereof, thou shalt surely die. (Genesis 2:17, King James Version).<sup>14</sup>*

The story of the Tower of Babel is another biblical account of Man *daring too much*, and being chastised for it:

*And they said, "Come, let us build ourselves a city, and a tower whose top is in the heavens; let us make a name for ourselves, lest we be scattered abroad over the face of the whole earth." But the LORD came down to see the city and the tower which the sons of men had built. And the LORD said, "Indeed the people are one and they all have one language, and this is what they begin to do; now nothing that they propose to do will be withheld from them. Come, let Us go down and there confuse their language, that they may not understand one another's speech." So the LORD scattered them abroad from there over the face of all the earth, and they ceased building the city. Therefore its name is called Babel, because there the LORD confused the language of all the earth; and from there the LORD scattered*

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<sup>14</sup> King James Version of the Bible, 1611 – Genesis 2:17  
(<https://www.lds.org/scriptures/ot/gen/2?lang=eng>)



*them abroad over the face of all the earth. (Genesis 11:4-9, King James Version – emphasis mine).*<sup>15</sup>

Equally famous in the western world are the myth of Prometheus, who dared to steal from the gods the knowledge of fire and metalwork to give them to humankind, and was for this reason eternally punished by having his liver eaten by an eagle and grown again every day<sup>16</sup>; or that of Daedalus and Icarus, who after building wings with wax and osier to escape from the Labyrinth of Knossos, dared to fly too close to the Sun, melting the wax in their wings and ending forever their flight<sup>17</sup>.

Despite our insecurities, progress has never stopped. The desire to know and be more has overcome our ancestral fear, and man has grown from an ape-like biped running through the plains of Africa to an *enhanced* creature enjoying a long life span thanks to medicine and about to take the greatest leap ever taken so far.

#### **4.2 Genetic enhancement and ethics: justice**

As mentioned above, justice deals with the resources that have an impact on the quality of life and how they are distributed. We can draw a first distinction between resources that are inherently good, and resources that are *positional*, that is, derive their value depending on how much of that resource other people have. For example, health is a resource that is always good, no matter how many people enjoy it. School grades, in contrast, are a resource that derives its value from a comparison with the grades of other people.

Bioethics does not address the enhancement of all the resources, but only those of the scientific and biomedical fields. Examples of enhancements of this kind, could be for example, the extension of memory of university students, or the enhancement of some physical characteristics. These are cases that already exist in our time, although not in a genetic form. *Modafinil*, a molecule whose official function is to cure narcolepsy and ADHD, is widely used in American campuses to boost students' cognitive faculties and attention capacities. Growth hormone, used when it is deficient in a person's body, acts also in normally tall individuals, and it is in fact used by many

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<sup>15</sup> *King James Version of the Bible*, 1611 – Genesis 11:4-9  
(<https://www.lds.org/scriptures/ot/gen/11?lang=eng>)

<sup>16</sup> <http://www.theoi.com/Titan/TitanPrometheus.html>

<sup>17</sup> <http://www.island-ikaria.com/about-ikaria/Ikaros-Myth>

parents to improve their children's stature: 40% of the use of this hormone is without a medical prescription in the United States.

In his work *Remaking Eden: How genetic engineering and cloning will change the American family (1998)*<sup>18</sup> Lee M. Silver has foreseen a scenario of genetic castes, a future where society will be divided into those few who can afford genetic enhancement and their offspring, and all the other *normal* citizens, with little intermarriage between the two groups. Those who endorse a free-market system argue that the problem of inequality of access to such technology is not a serious problem and, just like free market, is compatible with principles of justice.

Presently, four main objections to genetic enhancement have been raised<sup>19</sup>.

The first argues that the role of medicine is curing diseases and restoring sound health, not potentiating our faculties.

The second complains that enhancement would essentially be a waste of precious resources that could otherwise be directed to more useful goals, such as therapies themselves.

The third states that enhancement would bring about more and more inequality and for this reason should just be avoided.

Finally, the fourth objection argues that enhancement is inherently immoral.

The first argument can be easily dismissed: in fact, one must first assume that enhancement is, in fact, medicine, in order to demonstrate that it offends the medicinal tradition.

To the second argument, which states that enhancement would waste resources, we can respond that it is normal that society, or the State, moves a part of its resources in order to develop ways and strategies to make the life of its members better. It is in fact its primary goal. Furthermore, progress is not a zero-sum game. Employing resources for a goal does not necessarily subtract them from other efforts.

The third objection brings the attention to a legitimate risk, that inequalities may be accentuated with genetic enhancement. Let us examine this claim and the likelihood of this risk. First of all it should be recalled, that inequality is not always unjust. Sometimes, imposed equality is unjust. There are many theories of egalitarianism that are compatible with some forms of inequality. One of them is *luck egalitarianism*, which postulates that society should strive to provide circumstance equality (which does not depend on the

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<sup>18</sup> Loi, M. (2011)

<sup>19</sup> Ibid.

choices of individuals), while leaving people free to develop inequality based on their decisions. Another theory which leaves space for some form of inequality is the so-called *leximin*. *Leximin* prescribes to improve the condition of the individuals that are the worst off, and, if that is not possible, the ones immediately above them, and so on. Thirdly, *sufficientarianism* believes that for justice to be satisfied, it is enough to guarantee to everyone a certain degree of quality of life, after which all inequalities cease to be unjust. These theories demonstrate how simply arguing that enhancement could bring inequality does not imply that it will bring injustice with it.

Finally, to respond to the fourth objection, that enhancement is inherently immoral, suffice it to say that no one objects to other types of enhancement, as those we mentioned before, such as clothing, reading and writing, gym, meditation, vaccines etc.

As we already explained elsewhere in this work, there can be two types of intervention with genetic enhancement - let's recall them here. One is a somatic intervention, after the birth, which modifies just the DNA of cells on which it operates and their children-cells: this is currently already habitually done. The other is an intervention on the germinal line, made before the birth of the subject: this type of intervention modifies the DNA of totipotent cells, therefore affecting all the future cells of the body, including the gametes, which will pass the modification to future generations. This second type of intervention has never been tested on humans yet (apart from the experiment on embryos - who were discarded - by Chinese scientists) and this section deals with the implications for justice of the above-mentioned methodology.

There are many reasons why parents might choose to consider genomic therapy. Perhaps the zygote carries some genetic abnormality or illness, perhaps the parents do; perhaps there are age-related risks for the pregnancy, or risks stemming from the pregnancy of a couple of blood-related people; or perhaps there were many previous spontaneous abortions. One way parents can assess the genetic fitness of an embryo who was conceived *in vitro* or whether it has any genetic diseases, is the so-called *pre-implantation genetic diagnosis*. This form of eugenics is currently legal and practiced in some countries, like the State of Israel, as we mentioned elsewhere. In Italy no form of pre-implantation selection is legal. It is important to notice that recurring to abortion after a pre-implantation genetic diagnosis is not an option for those who raise objections that concern the dignity and the right to life of a human embryo.

One of the greatest obstacles is tracing a line between therapy and enhancement. Oftentimes, enhancement has received criticisms of being

similar to abortion. But it should be noted, and this is important, that there is a vast difference between modifying the genetic makeup of an embryo and suppressing him or her. Genetic enhancement is perfectly compatible with pro-life positions and with those who consider the human embryo as having the same dignity as an already-born human being.

Another question in order to understand whether a certain human trait constitutes an undesired trait, or a disease, or not, is the definition that we give to *pathology*. Boorse, who formulated *Bio Statistical Theory*<sup>20</sup>, offers the following explanation: «a pathology is a deviation from species-typical functioning»<sup>21</sup>. Bio Statistical Theory observes that many genes of our makeup are neither positive nor negative. They are simply the result of an evolutionary adaptation to a habitat where we no longer live in. As a species, we evolved to live with a very limited pool of resources. The current epidemics of heart attacks, diabetes, obesity etc. is a symptom of the fact that our body is simply not well adapted to live in our current environment. Should therefore the genes responsible for such diseases be considered defective genes?

Since clearly the definition of pathology is not as clear as many might think, the therapy/enhancement spectrum could be thought of as composed of three levels. The first is pure therapy to cure diseases, the second is something in between a therapy and an enhancement, aimed at giving better health expectations; finally, the third level is constituted by actual enhancement, whose objective is to improve an otherwise normal characteristic of an individual.

Having established what constitutes outright enhancement, we need to ask ourselves the question: which human faculties are worth enhancing? Is it courage? Or intelligence? Aggression? Physical strength? Some characteristics may be more important for some people, whereas totally irrelevant or even undesirable for others. Others have a universal appeal and everybody would like to have more of it. Who would not like to be more intelligent, for instance? One criterion to establish whether enhancement is a positive idea and which traits should be sought more, can be offered by the notorious *A Theory of Justice* (1971) by American philosopher John Rawls. In his work, Rawls identifies what he calls *primary goods* - goods that «every rational man is presumed to want», according to his own definition. The philosopher then introduces a first distinction within these *primary goods*. He calls the first group *natural primary goods* and the second group *social*

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<sup>20</sup> Abhaya Indrayan (2012)

<sup>21</sup> Ibid.

*primary goods*<sup>22</sup>. *Natural primary goods* are goods bestowed by nature, or chance: they are bodily and mental abilities such as intelligence, memory, strength, creativity and so on. *Social primary goods* include all those goods bestowed by laws or the wider society, such as rights, liberties and opportunities. Natural primary goods are an effective key to assess the goodness of genetic enhancement. Does enhancing the genome improve natural primary goods, or does it make them worse? Asking this question may help giving a first tentative judgement to the technique.

### 4.3 Genetic enhancement and ethics: eugenics

A more serious obstacle for public acceptance of genome enhancing technologies is its association with eugenics (from Greek *eu-genes*, *well-born*)<sup>23</sup>, a word that has gained a very bad reputation due to the racial theories promoted mainly by the Anglo-Saxon world and Nazi Germany in the Twentieth Century. The aim of eugenics is to improve the quality of the genetic makeup of a population and ultimately, of humanity. The preferred method to achieve this goal, at least before the possibility of modifying our DNA, is to promote higher rates of reproduction between people carrying the desired traits and lower reproduction (sterilization was unfortunately used or promoted) between those carrying less desirable characteristics. The contention, of course, lies mainly in who gets to decide what is desirable and what is not (often the group that holds political power), and the fact that it was often forced upon individuals. The right to reproduce, in fact, is often cited among the list of human rights.

Eugenics in itself is not a modern invention. The philosopher Plato suggested the idea of selective mating to produce members of the Guardian Class, one the castes of his *Republic*<sup>24</sup>. In Sparta, to give an historical example, deformed babies were suppressed if so deliberated by the council of the Elders - and the Laconian *pòlis* was certainly no exception at the time, since the same happened throughout the ancient world. But eugenics received its modern name and identity in Great Britain (the birthplace of modern racist theory<sup>25</sup>) in 1883, with Sir Francis Galton's interpretation of the theories of his half-cousin Charles Darwin, who, by the way, strongly refuted the

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<sup>22</sup> Rawls, *A Theory of Justice, Revised Edition* (Harvard University Press, 1999)

<sup>23</sup> <http://www.etymonline.com/index.php?term=eugenics>

<sup>24</sup> *Stanford Encyclopedia of Philosophy* (Stanford University, 2014).

<sup>25</sup> <http://discoveringbristol.org.uk/slavery/after-slavery/wider-world/black-white-in-britain/racist-ideas/>

conclusions of Francis. Eugenic ideas were quickly adopted in many countries and started being taught in most universities, which hosted numerous congresses on the subject. The United States of America espoused eugenic thought and, incidentally, employed it also against Italian immigrants during the first two decades of the Twentieth Century, among other groups.

The popularity of eugenics started to decline in the 1930s when its role in National Socialist thought (and, unfortunately, actions) became clear to all, but surprisingly survived well into the second half of the century, the last eugenics program being discontinued in Sweden in 1975<sup>26</sup>. Today, most modern democracies have abjured the practice, at least officially. Liberty of procreation, defined as freedom to choose whether or not to have descendants, and freedom to control the use of one's reproductive capacity, is by now recognized by all liberal societies. The Charter of Fundamental Rights of the European Union declares «the prohibition of eugenic practices, in particular those aiming at selection of persons»<sup>27</sup>. In 2013, the State of Israel finally acknowledged giving orders to its Health Department to administer shots of long-term contraceptive drug *Depo-Provera* to Ethiopian Jewish Israeli women without informing them about the consequences of the treatment, in an attempt to control the birth rate of the Ethiopian community in the country (now numbering around 130,000 members). The birth rate of the Beta Israel Jews had in fact plummeted by 20-50% in the previous decade<sup>28</sup>.

The newly-developed technologies in genomic engineering and their applicability on human beings have obviously raised numerous accusations of resurrecting the practices of eugenics. Troy Duster, a sociologist at the University of California Berkeley, has blamed modern genetics to be a «backdoor to eugenics»<sup>29</sup>. Other scientists expressed different opinions, such as renowned British militant atheist Richard Dawkins, who noted that modern discussion about eugenics is inhibited by its Nazi reputation, and suggested that perhaps enough time has passed since World War II to start exploring the subject again. He also invited to think about the ethical differences between breeding humans with certain abilities and training sport athletes or forcing children to take lessons of particular skills<sup>30</sup>.

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<sup>26</sup> <http://www.wsws.org/en/articles/1999/03/euge-19m.html>

<sup>27</sup> <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT>

<sup>28</sup> <http://www.haaretz.com/israel-news/israel-admits-ethiopian-women-were-given-birth-control-shots.premium-1.496519>

<sup>29</sup> <http://www.nejm.org/doi/full/10.1056/NEJM199112193252520>

<sup>30</sup> <http://www.theguardian.com/commentisfree/belief/2014/aug/29/nobody-better-at-being-human-richard-dawkins>

Does modern genetics necessarily lead to eugenics? And, if so, is eugenics inherently bad? The *reductio ad Hitlerum*<sup>31</sup> which associates any form of eugenics with Nazist ideology has been opposed by many. For one, Tania Simoncelli, White House Assistant Director for Forensic Sciences, opined that modern genetics advances are moving society towards a new era of eugenics but that, contrary to the National-Socialist kind of eugenics, the modern one is going to be consumer-driven and market-based<sup>32</sup>. Johns Hopkins University professor Nathaniel C. Comfort also noted this shift from state-led reproductive decision-making to individual choice, claiming that moving the responsibility from the State to the patient helps moderating the worst abuses so typical of past eugenics<sup>33</sup>. Stephen Wilkinson, bioethicist at Keele University, has stated that some aspects of modern genetics can undoubtedly be classified as eugenics, although this does not make it automatically immoral<sup>34</sup>.

Following the remarks of the above specialists, we can draw a distinction between eugenics as it was intended in the past and eugenics as it may be going to be intended in a near future. Whereas the goal of past eugenics was to intervene in the reproduction of the general population by limiting the reproduction of less-fit individuals, modern, liberal eugenics tends to be carried out on an individual basis by private citizens and couples, and has a more egalitarian flavor, as it tries to give equal opportunities to the members of future generations. This kind of liberal egalitarian eugenics can only be pursued as a collective result of free individual exercise of reproductive freedom, not planned by the State.

#### **4.4 Genetic enhancement and ethics: example of an unfair society**

Rawls' theory prescribes that institutions follow two main principles in their pursuit of justice. The first is that everyone is entitled to as many fundamental freedoms as compatible with the same freedoms for others («First: each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others.»). The second is that social and economic inequalities be a) of advantage to everybody, and b) available to everyone

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<sup>31</sup> The expression was invented by philosopher Leo Strauss in 1951

([https://en.wikipedia.org/wiki/Reductio\\_ad\\_Hitlerum#cite\\_note-Strauss1951-1](https://en.wikipedia.org/wiki/Reductio_ad_Hitlerum#cite_note-Strauss1951-1))

<sup>32</sup> [http://genetics.live.radicaldesigns.org/downloads/200303\\_difftakes\\_simoncelli.pdf](http://genetics.live.radicaldesigns.org/downloads/200303_difftakes_simoncelli.pdf)

<sup>33</sup> <http://www.biopoliticaltimes.org/article.php?id=8741>

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<https://www.keele.ac.uk/media/keeleuniversity/ri/risocsci/eugenics2013/Eugenics%20and%20the%20ethics%20of%20selective%20reproduction%20Low%20Res.pdf>

(«they are to be of the greatest benefit to the least-advantaged members of society; offices and positions must be open to everyone under conditions of fair equality of opportunity»).

Is genome enhancing compatible with these two requirements for a just society? Could it even offer opportunities to achieve more fully the model envisioned by Rawls?

Dworkin's theory was the first one to be called *luck egalitarian* (although its inventor has rejected the name)<sup>35</sup>: its basic premise, as already mentioned a few pages above, is that inequalities caused by individual choices are just, while those caused by sheer luck are unjust - and society should work to minimize the latter when possible. In Dworkin's view a just distribution should be *ambition-sensitive* and *talent-insensitive* (where *talent* is intended as natural talent). A person's genetic makeup (genotype) is without a doubt a matter of luck, completely independent of the individual's choices. Theories such the one of Dworkin can help develop a fairer distribution of resources, included in the health department. But compensating someone's genetic deficiencies with mere medical treatments will be but a *second best* option. Modern genetic technologies, like CRISPR/CAS9, would allow to aim at the *first best* option: endowing someone with natural resources, right from the start. Genomic enhancement allows us, using Rawls' terminology, to act not only on what he defined as *social primary goods*, but also *natural primary goods*, until now considered the realm of sheer luck and completely outside the sphere of our control.

Of course, a *post-genomic society* - a society where genomic engineering on man will be possible and regularly put into action - does have risks of developing into an utterly unfair world, even when trying to stick to the guidelines for a just society that we surveyed before. We must know what a post-genomic future might look like in order to best avoid unintended consequences. What follows is a hypothesis of how a world which regularly puts into action genomic enhancement might degenerate into an unfair society.

Let us assume that in the coming generations our community will have enough knowledge and technical expertise to modify the genome of a person before their birth, both as a way to cure and repair potentially defective genes and to actually enhance characteristics like memory, intelligence, strength, hearing, eyesight and conventional beauty. Let us also assume that these services are provided by private companies operating under free market rules (the state can provide public genetic therapy in case of a serious monofactorial

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<sup>35</sup> Magro M. *Is Dworkin a luck egalitarian?* (LUISS thesis, 2014)



disease. In this environment, families that wish to and that have the means to afford it, can decide to buy certain genes and use them to give birth to children with desired enhanced characteristics, like a better memory or a higher intelligence.

The society we are trying to picture functions under the *fair equality of opportunity* axiom devised by Rawls (the first part of the second rule of justice in his theory), according to which, assuming that two people have the same natural equal talents and the same willingness to work, they should have the same likelihood to attain a position regardless of whether one of them is richer than the other. Now, in such a society, although differences in income are irrelevant to attain a position or be promoted to a certain office, wealthier families can still afford to breed children with enhanced capacities. And these children, if Rawls' rule is interpreted literally, will more likely have more success than normal children, because they will have better natural talents.

Following the trail of this hypothesis we can attempt to make a prediction<sup>36</sup>. If genetic enhancement will remain for enough time inaccessible to poorer families, in the long run, children of wealthy families will tend to be healthier, more intelligent and more talented; they will therefore reach higher and better paid positions; this will allow them to be wealthy enough to improve even more their children's genetic makeup, who, by being more talented than the others will reach higher positions and will therefore be able to improve again their offspring's genome... and so on. Although initially there may be a high social mobility and a great percentage of genetically-enhanced people might pair off with non-enhanced partners, as generations go by this trend will tend to reduce more and more, as the differences between those enhanced and the others become more pronounced and eventually social mobility becomes virtually absent. Every more generation would accentuate the result that citizens who can afford genetic enhancement will come from richer families, that are richer because they are already genetically enhanced. The correlation between social status and natural talent would eventually become so high, that it would be possible to know with certainty that someone coming from a richer family has also much greater natural talent.

Today, our democratic institutions try to create opportunities of social mobility because we know that a person coming from a poor family might actually be smarter or more ambitious than someone coming from a rich family. Therefore, *discovering* them can benefit all society, and so the State provides opportunities for them, such as free schooling or scholarships, in order to form them. However, in a post-genomic society, the correlation

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<sup>36</sup> Loi M. (2011)

between wealth and talent would in the long run be so high that it will be statistically proven that poor people have no natural talent, and there will be zero social mobility even in a perfectly meritocratic, Rawlsian-just system. The result of our hypothetical world will be the creation of a new aristocracy, led by the enhanced-wealthy class, that will occupy power positions, and will therefore tend to promote policies that are not in the best interest of everyone, despite complying with Rawlsian justice requirements.

One objection to this picture could be that a society organized in the way described above would stop respecting the *fair equality of opportunity* principle. However, the *fair equality of opportunity* principle is concerned with *equal opportunities* for individuals with the same natural talent and willingness to work. In our post-genomic society, natural talent will be strongly correlated with social extraction (and more so with every new generation), resulting in a system which favors wealthier classes while still maintaining the *fair equality of opportunity* principle.

Another objection could point that a post-genomic world would be no different than our current state of things, where people tend to pair off with partners from the same social environment. In our current world, however, when a society is well-ordained, there will always be some exception to the general rule, and a certain degree of genetic mixing will always be present. In contrast, in a post-genomic world, mixed-class reproduction would become rarer and rarer with each generation, as genetic differences grow together with economic ones.

A third objection could criticize the hypothesis that assumes that members of the enhanced-wealthy class would be perfectly rational in their mating choices, pointing to the fact that cross-class mating would happen frequently, as people are often blind and irrational in their sexual behaviors. Let us note, though, that the phrase *people are often blind and irrational in their sexual behaviors* refers to people as we currently know them, that is, non-enhanced humans. Future genomic modifications could very well remove, or at least significantly reduce, the irrational element currently characterizing sexual behavior.

In his work *Justice and Genetics* (2011), author Michele Loi, analyzing how Rawls' theory would fit in the context of a post-genomic world, points that Rawls' principle of *fair equal opportunity* is actually designed for a world, our world, where natural talents are really natural, not modifiable, and they are really the product of sheer luck. In a society such as the one we described above, this assumption is no longer valid. Considering the starting talents of people as something coming from nature, and thus impartial, is not accurate. Loi then proposes to readjust Rawls' principle to fit

this new post-genomic world as follows: *if the probability of success of two individuals are different, the explanation of this difference should not depend on their social class of origin*<sup>37</sup>.

## 5. Interview to Marco Crescenzi

During my research for this work, I personally conducted an interview with Professor Marco Crescenzi at the *Istituto Superiore di Sanità* (Higher Institute for Health). I have decided to include the most salient parts of the interview below:

Professor Marco Crescenzi, what is your role and what does your research consist in?

*I am a researcher at the Istituto Superiore di Sanità. I also have an institutional role: I give technical opinions on proposals for experimentation on animals, which is under a strict ethical control after a law passed in Italy last year. In the past I was in the committee for the creation of guidelines for the Phase 1 of new drugs (when they are first used on humans). As a researcher I study regenerative medicine. Our goal is to regenerate cells that normally do not, such as neurons. I also study the insurgence of tumors.*

At what stage of the research with CRISPR are we in this moment?

*The state of Crispr is excellent: it is a method that I would almost call revolutionary. What Crispr does could be done with other methodologies, but Crispr is so much easier, inexpensive and quick that it really changes the way we operate in the sector, and it allows to a huge number of people and laboratories to employ the technique.*

How was CRISPR received in the academic world?

*Very well, with open arms, because it is a technology that changes the way we act and think. It allows to imagine projects that were previously almost impossible to realize. On the other hand, the availability and democratization of Crispr has a downside: it puts in the hands of many people a technique that can have potentially*

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<sup>37</sup> Loi M. (2011, 120-122)

*controversial applications or outright illegal uses, like the modification of the germline, which is against the law in most countries.*

I mentioned in my work the Asilomar Conference. Why was it so important and what can we learn from it?

*The role of the Asilomar Conference was highly debated. It is a very important historic event, one of the rarest, most brilliant examples of an attempt of self-regulation of Science for the safety and ethics of experimentation. It also provided an opportunity to show the public the responsibility of scientists, which, honestly, is not always present. The Conference, that discussed the Recombinant DNA technologies that had just been developed, ended with a common position and set of guidelines.*

What were the fears at the time, and, were they eventually realized?

*The fear was that theoretically a dangerous DNA could be created, a DNA which codifies a dangerous organism, for example a virus. At the time a few viruses were produced, by mistakenly recombining together two cancerogenic viruses in a laboratory. So some fears are justified. There was and there is a real dangerous potential. But so far there were no intentional episodes where Recombinant DNA was used to make damages.*

Do you think the Asilomar Conference can be taken as an example for how to act today with CRISPR?

*This is a tough question and the answer will be very personal. The recent conference held by the American Academy of Sciences in December 2015 could be considered as a successor of the Asilomar Conference. The conference set non-binding guidelines that however constitute a reference point for scientists and future legislators on the matter. The conference was undoubtedly needed, for legislators, scientists and the wider society. On the other hand I think that in the long run it is not enough to modify the course of events. But we will deal with them accordingly at the right time.*

Does this mean you see any attempt to control science as useless?

*Well, not completely useless, although I believe that whatever knowledge we acquire will eventually be used. The history of humankind teaches that a newly-acquired technological capacity does not remain unutilized for long. Quite the opposite: somebody, somewhere, will put it into practice with one goal or another, legally or against the law and the common will. Man has never allowed the fear of producing environmental disasters or weapons of mass destruction with his inventions and his technology. Nor has he ever succeeded in refraining from colonizing Antarctica or extraterrestrial space to gain more power, as it had solemnly been promised. There always is a strong interest, often on the part of the State, a noble cause or an unstoppable social force that leads to opening*

*Pandora's Box. It would therefore be good that we start to debate about the genetic engineering of man, in order to bring to the light all its implications, to better control and channel it or, should we decide so, to try to ban it with as many probabilities of success as possible. Burying our heads in the sand to ignore the future that is rushing towards us will not keep dangers away: it will only make us unprepared<sup>38</sup>. It is possible to maneuver the natural course of the events, or to reduce the impact of certain consequences. To give an historical example, this happened with nuclear weapons: once we were able to produce them we did use them, but we have also been able to reduce as much as possible their use and production.*

What is the relationship between bioethicists and scientists?

*It is quite a complex relationship. Many bioethicists are also scientists. But generally, as Bioethics has a function of control over science, its influence annoys many scientists, and I think that it is natural that whoever is subject to a degree of control in their activity can perceive it as a restriction. I believe that science and research should not be left on their own to go wild, so to speak. Society must verify that their activity is pursued within certain limits. On the other hand we must contrast a certain tendency of bureaucratization that often, although in part inevitably, create formalizations and obstacles, that, frankly, are not always necessary.*

Are your moral values important in your personal work?

*Yes, certainly. My therapeutic goals have a moral value and are also a means to apply my knowledge and capacities for the good of humankind. In my work I also require that all the animals be treated as ethically as possible. Finally, the relationship with my coworkers and colleagues is an important part of my work.*

I mentioned in my work the accusation against genome editing technology of resurrecting eugenics. Do you think that accusation is justified?

*This requires a complex and multifaceted answer. It is a matter of borders; borders that are not always clear and well defined. Now, technically the elimination of mutations that produce diseases is eugenics, but ethically the matter is quite simple: we have always been fighting diseases; if we have the possibility of removing a disease forever from a family there are no ethical objections. Now, the problem arises when we deal with characteristics that are undesirable but non-pathological, like the tendency of developing diabetes, because we cannot foresee all the consequences of editing certain genes. On the end of the spectrum we have outright enhancement, where we try to create characteristics that are desirable, even if just on the esthetic side, or features that do not exist in humans: these are*

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<sup>38</sup> Crescenzi M., *Cosa Rimarrà* (2015)

*things that eugenics could not even conceive in the past, and they certainly raise enormous ethical concerns.*

Does our DNA determine our destiny?

*Not entirely. This is the great debate in biology between genetic determinism and environmental influence. There are cases where genes cause the disease 100%: in that case the genetic influence is at its maximum. In other situations, such as diabetes, genetics have an influence because they create a tendency, but lifestyles, diet, and other stimuli can modify the immune system.*

Thank you for your time and for your interesting insights.

## **7. Conclusion**

Genome editing on humans is not an hypothesis. It is not a dream or the theme of a science-fiction book. It is reality, and research for the safe modification of the human germline is well underway, and may be ready before we can even expect it. Next year an article might be published on *Nature* or *Science* informing us of the successful delivery of the first genetically enhanced baby.

The prospect of enhancing our species gives us hope of overcoming our greatest handicaps and making humanity a little better. There is no question that a world without diseases and all the suffering they bring would be a better world. On the other hand, genome editing carries with it many risks. Practical risks and risks linked with justice and equality. It is our responsibility to ensure that this great opportunity we have in our hands can serve us instead of creating more evil and suffering.

I am very optimistic about our future: so far, all the technological advancements we made have in the end benefited all humankind, regardless of social class or background. Although fear is natural, there are no reasons to think genetic enhancement will be any different.

The topic of genomic enhancement greatly fascinates me. In this work I tried to first give the reader a general sense of how this technology works, and of its significance for our future. I also tried to explore two great objections to it: that it would resurrect eugenics and that it could create heavy inequalities. But I also tried to express my optimistic view for our future and my belief that human progress cannot be stopped.

After all, what makes us human is our desire to know more and work together to improve our condition.

And this will never be edited out of mankind.

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