

Forum:	Commission on Science and Technology for Development (CSTD)
Issue:	The question of Boundaries in Genetic Engineering and Eugenics
Student Officer:	Phaedra Valetta
Position:	Deputy President

PERSONAL INTRODUCTION

Dear delegates,

My name is Phaedra Valetta and it is an utmost honor and pleasure to serve as your Deputy President for the Commission on Science and Technology for Development in the 13th PSMUN. I am 16 years old and an 11th grade student at HAEF Athens College. Model United Nations has provided me the opportunity to broaden my horizons on topics of global importance whilst collaborating with people of my age, as well as proudly watch others flourish into capable delegates. This will be my second and last time chairing and I am very glad to finish my MUN journey with the topic of boundaries in genetic engineering and eugenics since it is one that I wish to study in depth as a university major.

I understand that this can be a complex topic to study individually, especially seeing as the Commission on Science and Technology for Development is a less known sub commission of the United Nations Economic and Social Council (ECOSOC). In brief, our committee examines questions of scientific and technological nature as well as their impact on global development, particularly pertaining to developing countries and the UN Sustainable Development Goals. After discussing advancements on science and technology, we analyze relevant problems that may concern the UN and recommend policies and actions on regional and global levels¹. Having said that, I would strongly encourage you to use this study guide as a starting point to conduct your own research before the conference. Of course, I am at your disposal to discuss all your inquiries concerning this topic or your preparation. Do not hesitate to contact me via email: fvaletta@athenscollege.edu.gr

I'm looking forward to meeting and working with you all!

Best Regards,
Phaedra Valetta

¹"Mandate and Institutional Background." *UNCTAD*, United Nations Conference on Trade and Development, unctad.org/topic/commission-on-science-and-technology-for-development/mandate. Accessed 26 Oct. 2023.

INTRODUCTION

Deoxyribonucleic acid, commonly known as DNA, is a chemical compound that contains all instructions for the development of most living organisms. The entirety of an organism's DNA, meaning the combination and the order of all molecules within the DNA, is called a genome. When the information within the DNA, also known as genetic information, is properly translated to create proteins in the cells, those proteins direct all procedures and activities within an organism for its creation and growth. In sum, the genome of an organism foresees a vast majority of its traits.²

Cancer and genetic disorders, such as Huntington's disease and certain types of anemia, may appear in the human organism and disrupt its standard processes for various reasons. Thankfully, technological advancements in the field of medicine and molecular biology have made it possible for scientists to change the DNA of an organism by modifying pairs of DNA molecules, deleting and adding other sections of it within the organism. The total of these laboratory-based technologies is known as genetic engineering and can be used to alter and ameliorate living organisms.

However useful genome editing may seem for the human race and the progress of our world and species, it is important to utilize it with great caution and moral integrity. Genetic engineering can easily be deemed unethical if used to create humans inspired by racist, ableist or colonialist ideologies. Using molecular biology and medicine for such means opens the door to a new era of scientific racism, known as modern eugenics.

Based on the aforementioned observations, it is quite comprehensible that genetic engineering is at the same time one of the greatest advancements of humanity and a serious threat to modern moral principles. It is, just like the theme of this year's PSMUN conference, a paradox of progress.

DEFINITION OF KEY TERMS

Deoxyribonucleic acid (DNA)

"Deoxyribonucleic acid (DNA) is the molecule that carries genetic information for the development and functioning of an organism. DNA is made of two linked strands that wind around each other to resemble a twisted ladder — a shape known as a double helix. Each strand has a backbone made of alternating sugar (deoxyribose) and phosphate groups. Attached to each sugar is one of four bases: adenine (A), cytosine (C), guanine (G) or thymine (T). The sequence of the bases along DNA's backbone

²"A Brief Guide to Genomics." Genome.Gov, National Human Genome Research Institute, 16 Aug. 2022, www.genome.gov/about-genomics/fact-sheets/A-Brief-Guide-to-Genomics.

encodes biological information that the organism used to perform the basic functions of life.”³

Embryo

“The developing human individual from the time of implantation to the end of the eighth week after conception”⁴

Enzymes

“An enzyme is a biological catalyst and is almost always a protein. It speeds up the rate of a specific chemical reaction in the cell. The enzyme is not destroyed during the reaction and is used over and over. A cell contains thousands of different types of enzyme molecules, each specific to a particular chemical reaction.”⁵

Eugenics

“Eugenics is the scientifically erroneous and immoral theory of “racial improvement” and “planned breeding,” which gained popularity during the early 20th century. Eugenicists worldwide believed that they could perfect human beings and eliminate so-called social ills through genetics and heredity. They believed the use of methods such as involuntary sterilization, segregation and social exclusion would rid society of individuals deemed by them to be unfit.”⁶

Forced Sterilization

“Forced sterilization is the involuntary or coerced removal of a person’s ability to reproduce, often through a surgical procedure referred to as a tubal ligation. Forced sterilization violates the human rights of bodily autonomy and reproductive choice, and can constitute an act of genocide, gender-based violence, discrimination, and torture.”⁷

Genetic engineering

“Genetic engineering (also called genetic modification) is a process that uses laboratory-based technologies such as CRISPR to alter the DNA makeup of an organism. This may involve changing a single base pair (A-T or C-G), deleting a region of DNA or adding a new segment of DNA. For example, genetic engineering may involve adding a gene from one species to an organism from a different species to produce a desired trait. Used in research and industry, genetic engineering has been

³“Deoxyribonucleic Acid (DNA).” Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/Deoxyribonucleic-Acid.

⁴“Embryo.” Merriam-Webster.com Dictionary, Merriam-Webster, <https://www.merriam-webster.com/dictionary/embryo>.

⁵ “Enzyme.” Genome.Gov, National Human Genome Research Institute, 24 Oct. 2023, www.genome.gov/genetics-glossary/Enzyme.

⁶“Eugenics and Scientific Racism.” Genome.Gov, National Human Genome Research Institute, 18 May 2022, www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism.

⁷“Forced Sterilization.” International Justice Resource Center, 10 Jan. 2021, ijrcenter.org/forced-sterilization/.

applied to the production of cancer therapies, brewing yeasts, genetically modified plants and livestock, and more.”⁸

Genetic screening

“Genetic screening is the process of testing a population for a genetic disease in order to identify a subgroup of people that either have the disease or the potential to pass it on to their offspring.”⁹

Genome

“The genome is the entire set of DNA instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes located in the cell’s nucleus, as well as a small chromosome in the cell’s mitochondria. A genome contains all the information needed for an individual to develop and function.”¹⁰

In Vitro Fertilization (IVF)

“In vitro fertilization, also called IVF, is a complex series of procedures that can lead to a pregnancy. It's a treatment for infertility, a condition in which you can't get pregnant after at least a year of trying for most couples. IVF also can be used to prevent passing on genetic problems to a child. During in vitro fertilization, mature eggs are collected from ovaries and fertilized by sperm in a lab. Then, a procedure is done to place one or more of the fertilized eggs, called embryos, in a uterus, which is where babies develop.”¹¹

Mitochondrial DNA

“Mitochondrial DNA is the circular part of DNA found inside the cellular organelles called mitochondria. Located in the cytoplasm, mitochondria are the site of the cell’s energy production and other metabolic functions.”¹²

Mitochondrial replacement therapy

“Mitochondrial replacement therapy (MRT) is a new form of reproductive in vitro fertilization (IVF) which works on the principle of replacing a woman's abnormal mitochondrial DNA (mt-DNA) with the donor's healthy one.”¹³

⁸Smith, Mike. “Genetic Engineering.” Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, [www.genome.gov/genetics-glossary/Genetic-Engineering#:~:text=Genetic%20engineering%20\(also%20called%20genetic,a%20new%20segment%20of%20DNA](http://www.genome.gov/genetics-glossary/Genetic-Engineering#:~:text=Genetic%20engineering%20(also%20called%20genetic,a%20new%20segment%20of%20DNA).

⁹“Genetic Screening.” Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/Genetic-Screening.

¹⁰“Genome.” Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/Genome.

¹¹“In Vitro Fertilization (IVF).” Mayo Clinic, Mayo Foundation for Medical Education and Research, 1 Sept. 2023, www.mayoclinic.org/tests-procedures/in-vitro-fertilization/about/pac-20384716.

¹² “Mitochondrial DNA.” Genome.Gov, National Human Genome Research Institute, 24 Oct. 2023, www.genome.gov/genetics-glossary/Mitochondrial-DNA.

¹³Sharma, Hitika, et al. “Development of Mitochondrial Replacement Therapy: A Review.” Heliyon, U.S. National Library of Medicine, 14 Sept. 2020, www.ncbi.nlm.nih.gov/pmc/articles/PMC7492815/.

Neurotypical

“The word ‘neurotypical’ refers to people who have a brain that functions in a similar way to most of their peers. Individuals who are neurotypical develop skills, such as social or organizational skills, at around the same rate as others their age. They can also tolerate change, disruption in routines, and distractions without too much difficulty.”¹⁴

Preimplantation Genetic Diagnosis (PGD)

“Preimplantation genetic diagnosis (PGD) is a reproductive technology used along with an IVF cycle to increase the potential for a successful pregnancy and delivery. PGD is a genetic test on cells removed from embryos, to help select the best embryo(s) to achieve pregnancy or to avoid a genetic disease for which a couple is at risk.”¹⁵

T4 Program

“T4 Program, also called T4 Euthanasia Program, was a German effort—framed as a euthanasia program—to kill incurably ill, physically or mentally disabled, emotionally distraught, and elderly people. Adolf Hitler initiated the program in 1939, and, while it was officially discontinued in 1941, killings continued covertly until the military defeat of Nazi Germany in 1945.”¹⁶

BACKGROUND INFORMATION

Predecessors of Genetic Engineering

Before we delve into the editing of the genome, it is essential that we understand the genome itself, as well as DNA-related discoveries that enabled the initiation of genetic engineering.

The study of molecular biology and genetics began in the 1950s, after Rosalind Franklin managed to diffract DNA proteins using X-rays. James Watson and Francis Crick used Franklin’s work -without her permission- to discover the aforementioned structure of DNA, the double helix. Knowing the structure of the DNA, scientists in the following decades managed to study the nucleic acid in greater depth, including its enzymes that keep the organism’s DNA intact while others cut down any foreign DNA. With the use of these two types of enzymes, after many years of experimentation and research,

¹⁴Villines, Zawn. “What Does Neurotypical and Neurodivergent Mean?” *Medical News Today*, MediLexicon International, 4 Feb. 2022, www.medicalnewstoday.com/articles/what-does-neurotypical-mean#neurodivergent.

¹⁵“Preimplantation Genetic Diagnosis (PGD).” *What Is PGD?*, Genetics & IVF Institute, [www.givf.com/geneticservices/whatispgd.shtml#:~:text=Preimplantation%20genetic%20diagnosis%20\(PGD\)%20is,a%20successful%20pregnancy%20and%20delivery](http://www.givf.com/geneticservices/whatispgd.shtml#:~:text=Preimplantation%20genetic%20diagnosis%20(PGD)%20is,a%20successful%20pregnancy%20and%20delivery).

¹⁶ Berenbaum, Michael. "T4 Program". *Encyclopedia Britannica*, 25 Feb. 2023, <https://www.britannica.com/event/T4-Program>. Accessed 26 October 2023.

scientists achieved what was once believed to be impossible: a deoxyribonucleic acid made from the combination of DNA strands from two different organisms.

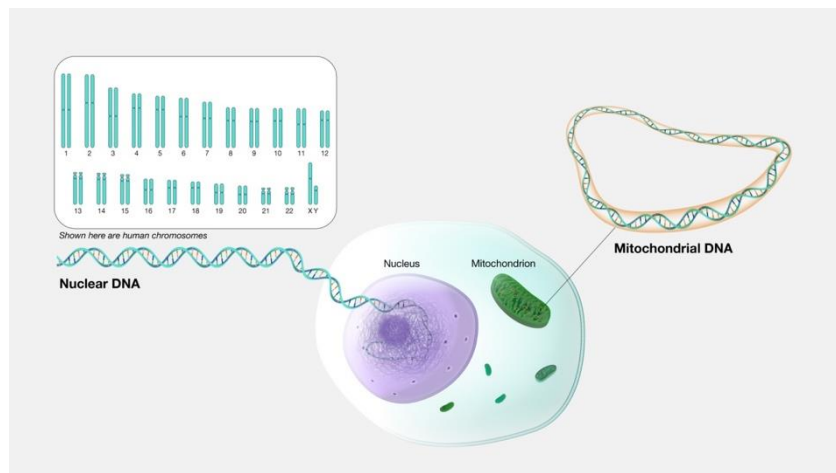


Figure 1: Visual representation of genetic information within the human cell¹⁷

This came to be known as recombinant DNA (rDNA) and was officially created in 1972. This discovery played a major role in the ability to edit genetic information of organisms. It is important to note here that after the discovery of rDNA, a US National Academy Moratorium on Genetic Engineering Experiments was held in 1974. Ethical concerns about the use of rDNA and the experimentation on the genetic information of multiple organisms to cure disease had arisen even from that time, so it is not surprising that the scientific community is morally troubled to this day.¹⁸

Of course, genetic engineering cannot be discussed without mentioning the Human Genome Project. Initiated by a group of researchers from around the world in October 1990 under the direction of Dr. James Watson, its goal was to decode the human genome, as its name proposes. The project was completed in April 2003 and deemed successful, after it managed to analyze the components of the human genome (what is widely known as sequencing) for the first time in history.

¹⁷ "Genome." Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/Genome.

¹⁸ "History of Genetic Engineering and the Rise of Genome Editing Tools." Synthego, www.synthego.com/learn/genome-engineering-history.

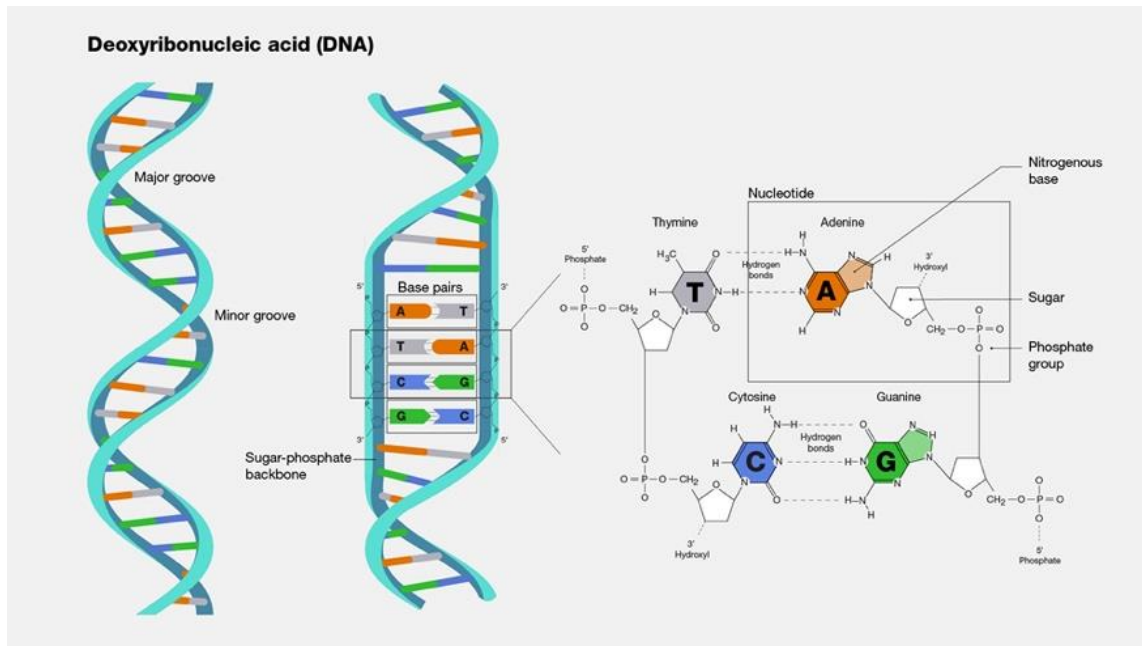


Figure 2: Visual representation of DNA and its contents¹⁹

Genetic Engineering Today

There are numerous ways in which genetic engineering is utilized in our times. The two greater categories would be its use for plants and animals alongside genome editing for humans. Concerning the former, many producers use genetic modification to enhance the taste and quality of their products and subsequently maximize their profit. The Food and Drug Administration of the United States as well as numerous respective offices of other countries have deemed certain genetically modified organisms (GMOs) safe for consumption, including but not limited to fruits, vegetables, cattle etc.

Regarding the latter, humans undergo genetic engineering as a part of gene therapy to cure multiple diseases, from cancer to mental illnesses. There are two types of gene therapy: germline and somatic. Germline gene therapy alters, among others, the genetic information of reproductive cells, such as sperms and eggs. Modifications in reproductive cells are passed down to future generations, thus preventing the inheritance of diseases to a great extent. That is why germline genome editing is more controversial than somatic genetic engineering, which does not involve any alteration of reproductive cells and is usually preferred for slowing the spreading of diseases within the organism.²⁰

¹⁹ "Deoxyribonucleic Acid (DNA)." Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/Deoxyribonucleic-Acid.

²⁰ "What Is Genome Editing?" Genome.Gov, National Human Genome Research Institute, www.genome.gov/about-genomics/policy-issues/what-is-Genome-Editing.

The prevailing tool for genetic engineering utilized by the scientific community that followed the steps of rDNA is the CRISPR (Clustered regularly interspaced palindromic repeats), a mechanism that uses enzymes to collectively modify genomes. The idea was first conceived in 1993, yet the CRISPR Genome Editing Tool was not developed until 2012 by Jennifer Doudna. Nowadays, it is the prevalent form of genetic engineering, utilized for diagnoses, as well as multiple treatments, from cancer to obesity.²¹

Although gene therapy has been discovered, it remains laboratory based and has not entered the clinics, since the techniques used have not been perfected yet, even with the use of CRISPR. If any of all the possible unfortunate scenarios involving CRISPR were to take place when clinically treating a patient, the patient's condition would most likely not be treated and, even worse, it could be exacerbated, hence the restriction of genetic engineering in experimental laboratories. Tools for genetic engineering are still being developed to tackle relevant issues and make gene therapy safe for clinical applications, so unless scientists discover more on the function of certain cells or create more precise tools to use for genetic engineering, gene therapy has still a long way to go.

The scientific community, apart from finding ways to enhance genetic engineering's security and accuracy, has been cooperating with multiple organizations to use genome editing ethically. Starting from moratoriums such as the one in the United States in 1974²², numerous ethical codes and legal regulations have been put in place, with the most commonly known being the Universal Declaration on the Human Genome and Human Rights and the European Union's Oviedo Convention, which will be discussed later on.

Advantages and ethical aspects of Genetic modification

One of the greatest advantages of genetic engineering is that it can assist in treating, if not curing, numerous diseases that were once considered incurable. Notably, genetic engineering is used in CAR-T cells to attack cancer cells and cure tumors and terminal cancers such as leukemia and myeloma. Furthermore, mental illnesses, neurodegenerative disorders (diseases that occur when nerve cells gradually lose their ability to function properly and die), acquired diseases and chromosomal anomalies can all be significantly treated with the help of genetic modification and CRISPR. While disease prevention using genetic engineering has comparably not been as developed in our times, correcting defective genes does assist in preventing the deterioration of

²¹Smith, Mike. "CRISPR." Genome.Gov, National Human Genome Research Institute, 8 Sept. 2023, www.genome.gov/genetics-glossary/CRISPR.

²²"History of Genetic Engineering and the Rise of Genome Editing Tools." Synthego, www.synthego.com/learn/genome-engineering-history.

a disease to an extent. Whether somatic or germline, gene therapy has undoubtedly changed the course of medical history and the battle against multiple illnesses and disorders. As a result, a great number of lives can be saved in the future. Humanity can expand its lifespan drastically with the use of genetic engineering, leading in a healthier and stronger human race.

Pharmacogenetics is an emerging research field as well. It involves the utilization of information about a patient's genetic make-up and the way their genes indicate how they respond to medication to tailor a specialized therapy that meets the individual needs of the patient. Administering personalized medicine or customizing genetic modification to each person protects their genetic identity and promotes their individuality instead of forcing them to make do with common and oftentimes less effective medication. Pharmacogenomics and personalized treatment, however, still have a long way to go, as they are still being researched and developed.

Of course, let us not forget that genome editing is able to help childbearing people safely deliver children to term. If a couple decides to conceive through In Vitro Fertilization, during Preimplantation Genetic Diagnoses, parents are able to consult geneticists and doctors to discuss the possible characteristics of their offspring, possible chromosomal anomalies or inherited diseases, and choose the healthiest embryo. By choosing the healthiest embryo and examining it in a safe manner for both the child and the carrier, a pregnancy is more likely to be carried out successfully, allowing all people to form their own family. A healthy heterosexual couple has the same chances of creating a family as an infertile one, a homosexual one and even single parents. No matter the parents' fertility levels, sex or sexual orientation, science will be able to assist them in founding a family.

Introduction to Eugenics

The main reason that there are numerous concerns about the use of genetic engineering is that it might signify the dawn of a new era of eugenics. Eugenics drew inspiration from sexist, anti-LGBTQ, xenophobic, anti-Semitic and colonialist values. As a result of generally misinterpreting scientific theories of the time, eugenicists believed that intangible qualities such as intelligence or mental illness were purely a manifestation of genetic information and their inheritance to future generations could easily be avoided by planned breeding, segregation or sterilization. It is inextricably connected to scientific racism, the misapplication of medical theories to prove the superiority of the white European race against people of color and minorities.

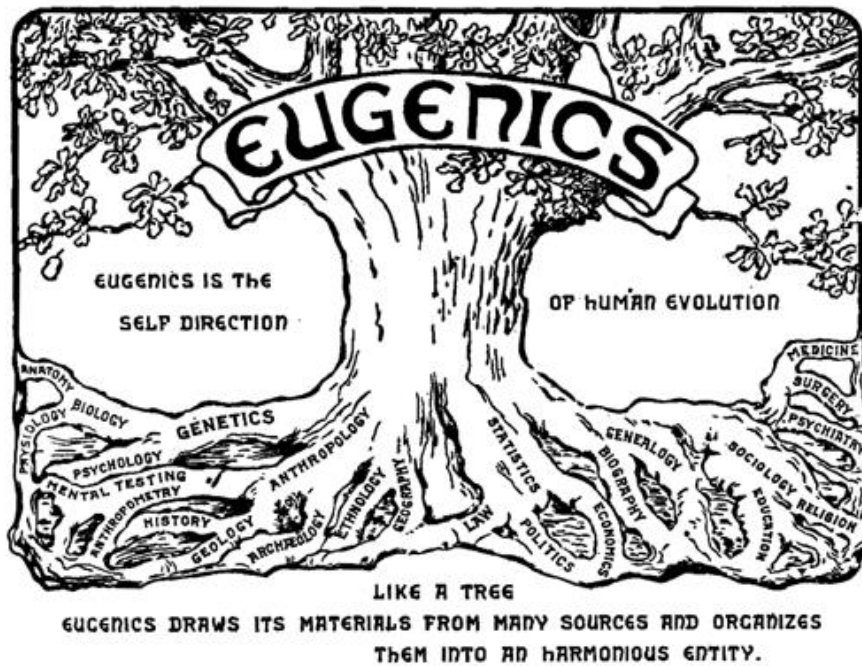


Figure 3: The most prevalent illustration of eugenics, representing eugenics as a multidisciplinary theory²³

The theory of eugenics was conceived in the late 19th century. English statistician, demographer and ethnologist Francis Galton was the first to use the term “eugenics” to describe the aforementioned theory in 1883, explaining it was “the study of agencies under social control that may improve or impair the racial qualities of future generations either physically or mentally.”²⁴

By the second decade of the twentieth century, eugenics had become a globally acclaimed movement, with large conventions being held and eugenics societies being formed to discuss “racial biology” and promote “racial hygiene”. In 1907, the state of Indiana was the first one to pass a compulsory sterilization law. That law and many others that followed prevented the spreading of “feeble-minded”, “promiscuous”, even criminals and alcoholics. The first International Eugenics Congress was held in London in 1912, followed by one in New York City in 1921 and the third and final one in 1932.²⁵

²³ “Introduction to Eugenics.” Genetics Generation, 16 Aug. 2023, knowgenetics.org/history-of-eugenics/.

²⁴ “Eugenics and Scientific Racism.” Genome.Gov, National Human Genome Research Institute, 18 May 2022, www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism.

²⁵ “Eugenics: Its Origin and Development (1883 - Present).” Genome.Gov, National Human Genome Research Institute, 30 Nov. 2021, www.genome.gov/about-genomics/educational-resources/timelines/eugenics.

Case Studies

Canada²⁶

A great example to describe the methods and aftermath of eugenics would be the case of Canada, since actions such as sterilizations were imposed on citizens in order to ameliorate the Canadian populations. In 1928 and 1933, the Canadian provinces of Alberta and British Columbia respectively passed laws to create eugenics programs. The original laws targeted the mentally deficient and others with mental disorders. Canadian reformers deemed immigrants inferior to Anglo-Saxon families and Eastern Europeans allegedly performed lower in intelligence examinations and public health surveys, leading them to being institutionalized and, in certain cases, sterilized. Gradually but unnoticeably at the time, the target of sterilizations shifted from immigrants to orphans, disabled youth and indigenous people, especially indigenous women. It is worthy to mention that aboriginal women became the population with the highest sterilization rate, whereas males were slightly less sterilized by the time the sterilization laws were repealed in the 1970s.

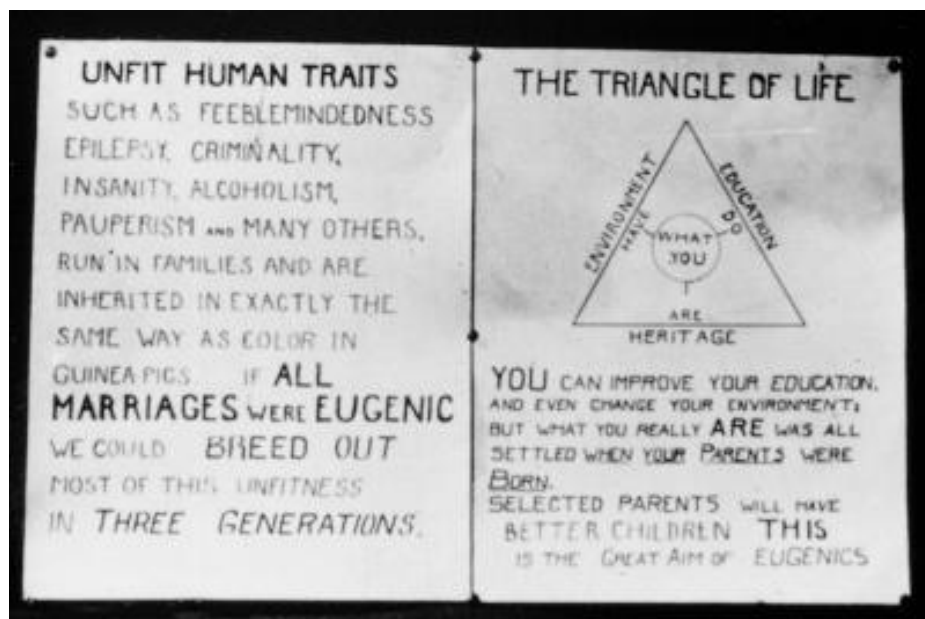


Figure 4: Charts explaining the beliefs of eugenics²⁷

²⁶Dyck, Erika. "Canada." Eugenics Archive, www.eugenicsarchive.ca/around-the-world?id=5233c9085c2ec50000000093.

²⁷ Kevles, D J. "Eugenics and Human Rights." *BMJ (Clinical Research Ed.)*, U.S. National Library of Medicine, 14 Aug. 1999, www.ncbi.nlm.nih.gov/pmc/articles/PMC1127045/.

Germany (1939-1945)²⁸

Perhaps the most memorable case of national eugenics because of its racist and bigoted ideologies which led to extreme cruelties, around 400,000 people were sterilized during the prevalence of the National Socialist German Workers' Party (around 3,000 were sterilized in Alberta and British Columbia combined²⁹). As it is well known, Adolf Hitler believed that, in order for Germany to stay strong, a “master race” - that of the Aryan people - should prevail. Tall, blonde and blue-eyed people were, according to supporters of the party, far superior to other minorities, including, among others, people of the Jewish religion and the disabled population. To promote their ideology – what came to be known as Nazi racism - on July 14th 1933, the far-right party introduced the Law for the Prevention of Hereditarily Diseased Offspring, or Sterilization Law. The law stated that people suffering from certain diseases were to be forcibly sterilized to prevent their inheritance in future generations. Not only did the Sterilization Law remain in effect during World War II, Nazi racism and eugenics became stricter with the introduction of Aktion T4, also known as T4 Program, a German Reich policy and euthanasia program that commanded the death of the physically and mentally ill, the incurables and the elderly.³⁰ Throughout the Second World War, sterilizations and related experiments took place in concentration camps, mainly in Auschwitz.

Post-World War II, Germany was profoundly stigmatized from the party's eugenics, and many have sought compensation for what they had suffered in Germany of that time period and concentration camps since. Not once has eugenics not been used with bigoted and discriminatory principles as its foundation, which is why people in our days do not wish for genetic engineering to instigate a new age of modern eugenics.

Ethical Considerations of Genetic Engineering.

The main concern the global community has referring to genetic engineering is that it might provide opportunities for the beginning of a new era of eugenics. Regarding designer babies, the traits that their parents will choose to have will inevitably be based on the time's expectations. They would most probably be intelligent, able-bodied, neurotypical and strong. Consequently, designer babies and modified people could, in the long run, become a modern “master race” with so-called superior abilities

²⁸Shaw, Laura. “Germany.” *Eugenics Archive*, www.eugenicsarchive.ca/around-the-world?id=51c2795697b8940a5400000f&view=reader%27.

²⁹Dyck, Erika. “Canada.” *Eugenics Archive*, www.eugenicsarchive.ca/around-the-world?id=5233c9085c2ec5000000093.

³⁰Berenbaum, Michael. “T4 Program”. *Encyclopedia Britannica*, 25 Feb. 2023, <https://www.britannica.com/event/T4-Program>.

and characteristics. While that by itself might not be explicitly deemed unethical, its consequences could easily be seen as such. Indubitably, not all people would be able to financially afford genetic engineering and/or gene therapy or even want to be genetically modified. A healthcare disparity, therefore, could occur between socioeconomic classes, and those at the higher rankings will be “super-humans”, while the ones lower or refusing to edit their genome would be frowned upon as “suboptimal human beings”. The unmodified will possibly be victims of a new sort of racism and an era of “modern eugenics” might dawn. There is also the possibility of gene doping, editing the human genome of an athlete to enhance their performance. It is needless to say that not all athletes can afford this; therefore, athletes of families of lower income would have an inevitable disadvantage to those of wealthier families.

Even if all people could afford to be genetically altered, they would all opt for the same characteristics, as long as that did not impact their health negatively. Of course, in certain cases, if people were to change some of their traits, they would suffer catastrophic consequences. For example, if people who lived near the equator genetically reduced their melanin levels, their skin would be severely damaged from the direct UV emissions of the sun. Having said that, human biodiversity inside each race could easily run the risk of ceasing to exist. Millennia of human evolution could be erased for the purpose of “fitting in” and avoiding becoming an outcast. The example of the perfect human being would naturally be set by more economically developed countries, whereas less economically developed countries would have to catch up with the technological and scientific advancements of the developed nations.

It is important to state that, throughout the genetic engineering process, the embryo is not able to consent to the parents’ selection of its characteristics. Hence, the baby loses its freedom to self-identify even before its birth. Should the child wish to reverse or change some of their characteristics given to them by their parents, they would not be able to, or, at best, they would have to undergo procedures and modifications of high risk and price, which is not guaranteed they could afford. Genetically modified children would have to live with the burden of their parents’ decisions.

[Ethical concerns of genetic engineering regulation](#)

Genetic engineering can be humanity’s greatest weapon, but it can also cause great chaos. Based on the aforementioned possibilities, regulation and boundaries on the use of genome editing are deemed vital. A global ethical code should be established for all countries, scientists, and medical experts to obey. It is obvious that different countries have reached different levels of scientific development and medical advancements. Moral codes and positions on the topic of genetic engineering also vary depending on each culture’s beliefs. This begs the questions: which countries’ positions have greater gravity on the matter? Should the new regulation endorse cultural relativism - the relativity of ethics due to differences in history, traditions and creed - or should a global set of ethics be established despite cultural objections? If

the latter option is chosen, which culture’s ethical system ought to be followed as the foundation of the international regulations?

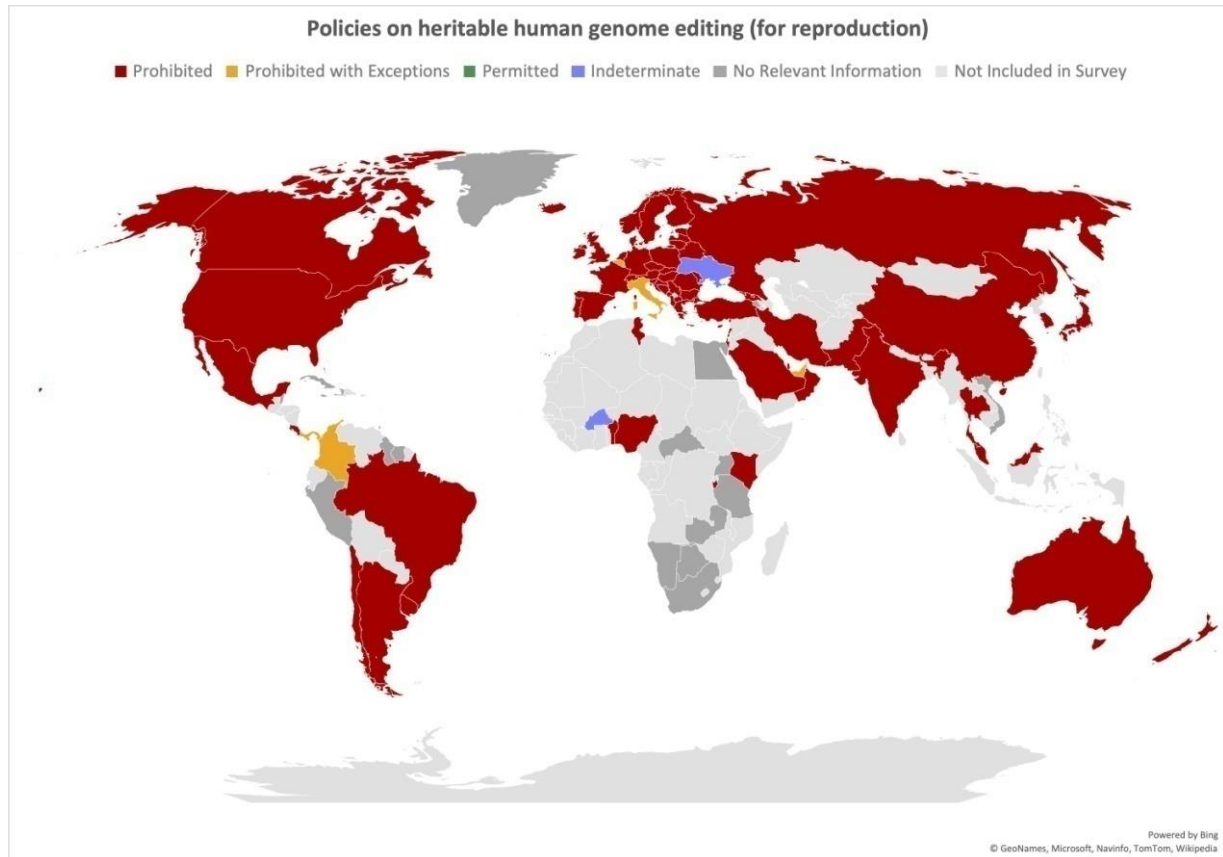


Figure 5: Map of the world that shows national policies on heritable human genome editing as of 2020³¹

MAJOR COUNTRIES AND ORGANISATIONS INVOLVED

People’s Republic of China³²

In China, germline gene editing is allowed solely for research purposes and requires permission from an ethics committee, a hospital or an IVF clinic, not from national regulatory agencies. Regulation is still very lax and penalties and enforcement mechanisms of any related laws are still unclear. China is one of the most active countries in the area of genetic engineering research. In 2015, the Sun Yat-Sen University in Guangzhou was the first one to edit human embryos using CRISPR, an action deemed immature for its time. Scientist He Jiankui, under the surveillance of

³¹Hasson, Katie. “Assessing the Global Policy Landscape for Human Germline and Heritable Genome Editing.” *Center for Genetics and Society*, 11 Feb. 2020, www.geneticsandsociety.org/biopolitical-times/assessing-global-policy-landscape-human-germline-and-heritable-genome-editing.

³²“China: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/china-germline-embryonic/.

the Southern University of Science and Technology in Shenzhen, edited the genome of two twin girls that were carried to term, in an attempt to make their organisms HIV-resistant. This action caused great outrage from the global scientific community and the Chinese government condemned the project and charged the scientist. The National People’s Congress Standing Committee has been drafting a code for stricter regulation and legislation ever since.

Canada³³

Since 2004, Health Canada has been enforcing the Assisted Human Reproduction Act (AHRA), after a Royal Commission’s report urged the Canadian government to regulate all issues surrounding Assisted Human Reproduction more than a decade prior³⁴. The act dictates that all types of germline genetic engineering are strictly prohibited. Canada is the country with the strictest policy concerning genome editing, to the point that the Consortium of scientists and bioethicists requested a reform of AHRA, explaining that research on genetic engineering could provide promising results for future reproductive mechanisms.

Japan³⁵

Japan has one of the loosest regulations on genetic engineering worldwide. There are restrictions on genome editing for reproduction purposes, though they are not punishable by law. As far as research is concerned, however, draft guidelines were issued in 2018 stating that research on human embryos to treat genetic diseases was allowed. Embryonic stem cells left over from fertility treatments are offered to universities, something that does not happen in many other countries due to it being considered widely controversial. In 2019, the Japanese science ministry allowed the insertion of human cells in an animal embryo to be transferred inside an animal’s uterus in an attempt to create human-compatible organs from animals.

United Kingdom (UK)³⁶

The United Kingdom has a much more organized approach to the practice of genetic engineering compared to most countries in the world. The Human Fertilization and Embryology Authority (HFEA) is responsible for licensing gene editing research using

³³“Canada: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/canada-germline-embryonic/.

³⁴ “Regulating Creation: The Law, Ethics, and Policy of Assisted ... - JSTOR.” *JSTOR*, ITHAKA, www.jstor.org/stable/10.3138/j.ctv1005dgv.

³⁵“Japan: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/japan-germline-embryonic/.

³⁶“United Kingdom: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/united-kingdom-germline-embryonic/.

embryos, as provisioned in the 1990 Human Fertilization and Embryology Act. Genetic engineering for reproductive purposes remains illegal. In 2015, the United Kingdom became the first country to allow mitochondrial replacement therapy, also known as “three-parent IVF”, seeing as it is performed for the child’s best interests and is therefore “morally permissible” and is not considered genetic modification. The separate regulation of mitochondrial replacement therapy renders the UK’s policy on genetic engineering even more complex.

Republic of India³⁷

The regulation in India, albeit not legally binding, is severely critical of genetic engineering. All sorts of gene editing are prohibited, with the only exception being genome alterations to embryos that will not be carried to term. Any other type of genetic engineering is prohibited by the National Guidelines for Stem Cell Research. Legal ambiguity and the country’s uncontrollable rise of the population still remain problems for scientists in India, leading to malpractice and misuse of genetic engineering. The Indian Council of Medical Research is working on laws to unambiguously ban genome editing.

European Union (EU)³⁸

The European Union is one of the few entities to have blatantly made the connection between genetic engineering and eugenics. Specifically, the 1997 Convention on Human Rights and Biomedicine, popularly known as the Oviedo Convention, promotes genetic identity and uniqueness and prohibits genome editing for clinical and reproductive purposes as well as “eugenic practices, in particular those aiming at the selection of persons”. The convention, however, is not clear on the regulations concerning non-clinical research. This is why 15 of 22 Western European countries have further regulation on a national level. The Oviedo Convention has been ratified by 29 of the 47 European States. Countries that have not ratified the convention include Italy, Sweden, Germany, Austria, Russia, and The Netherlands, due to its restrictions on gene editing research.

World Health Organization (WHO)³⁹

In December 2018, just a month after He Jiankui’s experiments on the genomes of the twin sisters that were carried to term, the World Health Organization’s Director

³⁷“India: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/india-germline-embryonic/.

³⁸“European Union: Germline / Embryonic.” Global Gene Editing Regulation Tracker, Genetic Literacy Project, crispr-gene-editing-regs-tracker.geneticliteracyproject.org/eu-germline-embryonic/.

³⁹“Human Genome Editing: As We Explore Options for Global Governance, Caution Must Be Our Watchword.” World Health Organization, 8 Nov. 2019, www.who.int/news/item/08-11-2019-human-genome-editing-as-we-explore-options-for-global-governance-caution-must-be-our-watchword.

General Dr. Tedros Adhanom Ghebreyesus announced the creation of an Expert Advisory Committee on Human Genome Editing, comprising of an international group of 18 scientists. The committee’s objective is the development of international standards for governance and the supervision of all progress on human genetic engineering. Ever since its creation in February 2019, the committee has been advocating for a global registry on human genome editing to ensure the accessibility to all information concerning genetic engineering. It has clarified its opposition to any and all research on heritable genome editing and is encouraging oversight bodies in all countries to renounce any relevant project.

International Bioethics Committee (IBC)⁴⁰

In 1993, the United Nations Educational, Scientific and Cultural Organization (UNESCO) created the International Bioethics Committee, a body of 36 specialists tasked to promote human dignity and moral integrity in life sciences. The IBC, basing its beliefs on the Universal Declaration on the Human Genome and Human Rights which will be discussed later on, as well as other documents drafted and adopted in the years since, is still conducting research concerning the ethical dilemmas of genetic engineering. The main conclusion to which the IBC has been led, as stated in the 2015 Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights⁴¹, is that a global-standard setting on governance mechanism is preferable to nations individually imposing legislation and governmental policy.

TIMELINE OF EVENTS

DATE	DESCRIPTION OF EVENT
1883	Francis Galton is the first person to write about improving organisms and to use the term “eugenics”.
1907	The state of Indiana passes the first compulsory sterilization law.
24 July - 29 July 1912	The first international Eugenics Congress takes place in London.
14 July 1933	The far-right German party introduces the Sterilization Law.
28 February 1953	DNA’s double helix is discovered by James Watson and Francis Crick, initiating studies of molecular biology.
1972	Recombinant DNA (rDNA) is officially created.

⁴⁰“International Bioethics Committee (IBC).” UNESCO.Org, UNESCO, 11 May 2023, www.unesco.org/en/ethics-science-technology/ibc.

⁴¹Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights, unesdoc.unesco.org/ark:/48223/pf0000233258/PDF/233258eng.pdf.multi.

1974	The US National Academy Moratorium on Genetic Engineering Experiments is held after ethical concerns over the use of rDNA arise amid the scientific community.
13 September 1983	The International Centre for Genetic Engineering and Biotechnology is created.
July 1990	The declaration of Inuyama was adopted by the Council for International Organizations of Medical Science (CIOMS) in a conference cosponsored by the World Health Organization and UNESCO.
October 1990	The Human Genome Project is launched, with its main mission being the comprehensive study of DNA.
1993	Francisco Mojica discovers the principles of CRISPR.
1993	The International Bioethics Committee is created by UNESCO.
November 11 th 1997	The Universal Declaration on the Human Genome and Human Rights is adopted unanimously at UNESCO's 29 th General Conference.
April 2003	The Human Genome Project is completed, with its main accomplishment being the generation of the first sequence of human genome.
2004	Health Canada enforces the Assisted Human Reproduction Act (AHRA) that strictly prohibits all types of genetic engineering.
28 June 2012	The CRISPR Genome Engineering Tool is developed.
2015	The Sun Yat-Sen University in Guangzhou, China, is the first one to edit human embryos using CRISPR.
2017	The first CAR-T therapy for cancer is approved.
29 May 2018	Japan announces the provision of embryonic stem cells for research on gene editing.
November 2018	Scientist He Jiankui edits the genome of two twin sisters carried to term, stirring controversy among scientists worldwide.
February 2019	The WHO Expert Advisory Committee on Human Genome Editing is created.
1 March 2019	The Japanese government allows the creation of human-animal hybrids using genetic engineering for the creation of organs compatible to humans.

PREVIOUS ATTEMPTS TO SOLVE THE ISSUE

Universal Declaration on the Human Genome and Human Rights⁴²

The Universal Declaration on the Human Genome and Human Rights, as aforementioned, was put forth by UNESCO in 1997. It is a fundamental document that addresses the ethical, legal, and societal implications of genetics and genomics. It stresses the principle that human rights should apply universally, regardless of one's genetic makeup, and it forbids discrimination based on genetic traits. The declaration highlights the importance of informed consent and the protection of privacy in genetic research and healthcare. It also encourages equal access to its benefits and the recognition and respect of diverse cultural and ethical perspectives. The primary goal is to make sure that rapid advances in genetics benefit society, preserve human dignity, and uphold individual rights. As stated in the declaration, the human genome is, according to the United Nations, “the heritage of humanity”. The most recent advancements in the field of genetic engineering, such as the ability to select an embryo’s characteristics, compromise fundamental ideas of the declaration. This is why any and all relevant regulation that is to be drafted should be in accordance to the declaration.

The Declaration of Inuyama⁴³

The Declaration of Inuyama was adopted in July 1990 by the Council for International Organizations of Medical Science (CIOMS) in a conference titled “Genetics, Ethics, and Human Values: Human Genome Mapping, Genetic Screening, and Therapy” held in Tokyo and Inuyama City, Japan, cosponsored by the World Health Organization and UNESCO. Just months before the commencement of the Human Genome Project, the Declaration deemed the project completely ethical and demanded that Less and More Economically Developed Countries benefit equally from it. As far as genetic engineering is concerned, the Declaration permits gene therapy solely for medical and therapeutic purposes. Germline gene therapy should only be used after assuring its absolute safety. Finally, the Declaration of Inuyama promotes the education of the public so as to disprove any misconceptions on the matter, as well as extensive dialogue and cooperation of multiple sectors and cultural backgrounds to decide on transnational policies.

⁴²Unesco. “Universal Declaration on the Human Genome and Human Rights.” UNESCO.Org, UNESCO, 2 Oct. 2015, www.unesco.org/en/ethics-science-technology/human-genome-and-human-rights#the-declaration.

⁴³Yim, Seon-Hee, and Yeun-Jun Chung. “Introduction to International Ethical Standards Related to Genetics and Genomics.” *Genomics & Informatics*, Korea Genome Organization, 31 Dec. 2013, genominfo.org/journal/view.php?doi=10.5808%2FGI.2013.11.4.218.

International Centre for Genetic Engineering and Biotechnology⁴⁴

The International Centre for Genetic Engineering and Biotechnology (ICGEB) was initially established under the United Nations Industrial Development Organization (UNIDO) in 1983. Autonomous since 1994, ICGEB shares information gathered from extensive experimental research in Italy, India and South Africa with over 70 Member States of the United Nations. Its utmost goal is to assist in the achievement of the UN Sustainable Development Goals through advanced research, expert training and public engagement.

Personalized treatment⁴⁵

In order to assure that there is informed consent from any individuals wishing to undergo genetic modification or gene therapy, genetic counseling has been established, in which genetic counselors inform patients of any genetic disorders they might have and provide them with the appropriate guidance to make a conscious decision for their medical situation, whether it be expert knowledge or psychological support. Presently, genetic counseling is mainly available in the United States, Canada, certain European countries and Cuba.⁴⁶ However, screenings and diagnostic tests are also available and rapidly spreading globally.

POSSIBLE SOLUTIONS

Establishment of a regulatory framework and oversight mechanisms

As it was repeatedly stated above, the need for proper regulation and standard-setting in the field of genomics is dire. An international context of laws and regulations in which local scientists and governments shall be able to act ought to be established. It should foresee access to genetic engineering for MEDCs as well as LEDCs and respect the cultural and socioeconomic backgrounds of all peoples. For this to be achieved, the involvement of expert scientists and their input on the advancements of genetic engineering tools is fundamental, to understand whether somatic or germline gene editing can be legal at this point in time at a clinical level, or if they shall remain strictly in the laboratory. The regulation should adhere to previously adopted documents such as the Universal Declaration on the Human Genome and Human Rights or the

⁴⁴ "What We Do." ICGEB, 17 Jan. 2022, www.icgeb.org/about-us/what-we-do/.

⁴⁵ Venditti, Charles P. "Genetic Counseling." Genome.Gov, National Human Genome Research Institute, 7 Sept. 2023, www.genome.gov/genetics-glossary/Genetic-Counseling.

"Pharmacogenomics." National Institute of General Medical Sciences, U.S. Department of Health and Human Services, 5 Apr. 2022, nigms.nih.gov/education/fact-sheets/Pages/pharmacogenomics.aspx#:~.

⁴⁶ Ormond, Kelly E et al. "Genetic counseling globally: Where are we now?." American journal of medical genetics. Part C, Seminars in medical genetics vol. 178,1 (2018): 98-107. doi:10.1002/ajmg.c.31607.

Declaration of Inuyama, and, therefore, should not only promote genetic identity and human biodiversity, but also set concrete international boundaries on the use of both somatic and germline genome editing, in research as well as in clinical use. Organizations such as the World Health Organization and the International Bioethics Committee could assist in this endeavor.

Once the regulatory framework is established, oversight bodies and the appropriate mechanisms need to be created so as to ensure that every country and all scientists work in accordance with the newer framework. Whether it is organizations or offices in every nation that record and oversee any progress done in genetic engineering and relevant research, educative programs for all scientists, worldwide conferences or campaigns to inform the people and promote transparency, the scientific community and the public need to be informed and engage with the issue of genetic engineering, as well as ensure that they understand and consent to any procedure they might undergo that relates to it. Equal benefits of genetic engineering for all as well as transparency and easy access to new information are fundamental for the ethical utilization of genome editing.

Investments in Research

Numerous people, even countries, seem to be skeptical about genetic engineering and similar sectors, such as pharmacogenomics, due to their limited development. A reasonable solution would be for nations and organizations (e.g. the World Health Organization) to invest in all kinds of research concerning genome editing and provide scientists globally with the appropriate equipment to further study the subject and even make progress towards new medical advancements. Of course, all conducted research should be overseen by corresponding mechanisms and be transparent to the international scientific community and the public to make sure it follows all ethical guidelines. The more knowledge that is gathered by the scientific community and shared globally regarding the issue of genetic engineering, the easier it will be for governments and international organizations to draw the line on its utilization and application.

Support of Genetic Uniqueness and Personal Identity

To safeguard human biodiversity and ensure that genetic engineering is only used for medical and therapeutic reasons, the global community needs to rid itself of any prejudice towards people with genetic disorders or chromosomal anomalies. A great step towards that direction would be the creation of a more accessible world and the decrease of stigma that follows people with genetic anomalies. An adequate start would be the increase of infrastructures that acknowledge and support this group of people, from local support groups to educational programs and seminars. Awareness through pieces of media pertaining to genetic anomalies and representation of people with chromosomal disorders in all lines of work would not only assist this branch of

the global population, but also aid people without genetic disorders become familiar with this phenomenon. Government-appointed experts in every country that can offer genetic counseling services as a means of public health service or social workers that can provide life guidance would discourage people from opting for heritable genetic engineering or designer babies solely for the purpose of fitting in or being deemed valuable and respectable by societies. A safe environment for people with genetic disorders would lead to more ethical and meaningful use of genetic engineering.

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