# Agenda: Evaluating the feasibility of legalising Designer babies

#### **The Committee**

Aiming for the attainment of the highest possible level of health for all people, The World Health Organization (WHO) is the directing influence on international healthcare concerns within the United Nations (UN) system. WHO mediates among six areas of work: the eradication of non-communicable diseases; the provision of assistance to the development of its 194 Member States in their respective health systems; the surveillance, preparedness, and response with respect to international health emergencies; the treatment, prevention, and care for communicable diseases; the promotion of good lifelong health; and the extension of corporate services to the organization's public and private partners. WHO is led by the principle that health is a state of total physical, social, and mental well-being rather than simply the absence of infirmity or disease.

Outlined in the *Constitution of the World Health Organization* (1946), the principle was adopted in July of that same year by the then 51 UN Member States and 10 additional states. After a full analysis of the international health cooperation during the time of the Second World War, an Interim Commission maintained the activities of existing institutions until 26 Member States approved the WHO's constitution. In April 1948, once the constitution had entered into force, the World Health Assembly (WHA), a commission of all WHO the Member States and the organization's decision-making body, convened in Geneva for the first time on 24 June 1948.

Throughout its first decade WHO largely continued as a stimulator for health research, and it's operative programmes progressively extended in the following years. The approval of the WHA resolution 19.16 of 13 May 1966 on a "Smallpox Eradication Programme" noted the organization's first global immunization campaign, ultimately succeeding in eradicating the disease in 1980. The 1978 International Conference on Primary Health Care was yet another defining moment for WHO, as it linked health to economic and social development, and declared access for all to primary health care as the organization's key strategic objectives. *The Declaration of Alma-Ata* (1978) worked as the foundation for WHO's *Global Strategy for Health for All by the Year 2000* (1981), intending to achieve primary healthcare universally. As a whole, the WHO is an association which aims to combat all health issues in regards to the physical, social and mental well-being, making it a committee with the goal to better the world and the people in it.

#### Introduction

Designer babies are defined as "a baby whose genetic make-up has been selected in order to eradicate a particular defect, or to ensure that a particular gene is present." Scientists in the 1960's first discovered that DNA encoded information that determined the processes of replication and protein synthesis. This triggered a series of theoretical advances suggesting that the basic make up of the DNA could be altered and manipulated. Following this the first transfer of Genes from one organism to another took place in 1972 and was pioneered by Herbert Boyer and Stanley Cohen. In 1974 Rudolf Jaenisch created the first genetically modified animal (a mouse). In 1976 the technology was applied to bacteria which yielded somatostatin. In 1948 the same technology was used to produce insulin.

Now it is possible to use CRISPR technology to Alter the genetic make up of Human beings. The question raised is whether it should be used and whether the technology should be legalised.

#### What is CRISPR

CRISPR or Clustered Regularly Interspaced Short Palindromic Repeats technology is a mechanism which allows for the editing of DNA sequences and modification of Gene function.

#### Significant conferences on gene editing

#### Asilomar conference (february 1975)

The first regulations and guidelines for the use of biotechnology were put in place at the Asilomar Conference on Recombinant DNA held in february 1975. The aim of the conference was to set limits for geneticists so they could safely research the implementation of biotechnology without harming public health and safety.

The conference was held by Paul Berg and a set of precautionary principles were introduced. 'The first principle for dealing with potential risks was that containment should be made an essential consideration in the experimental design. A second principle was that the effectiveness of the containment should match the estimated risk as closely as possible.' Biological barriers and physical containment were also suggested to achieve this.

Along with the principles the conference provided specific guidelines about the necessary containment's needed for specific types of research. In addition to the recommendations, the conference also prohibited the cloning of recombinant DNAs derived from highly pathogenic organisms, cloning of DNA containing toxin genes, and large scale experiments using recombinant DNAs that were able to make products that were potentially harmful to humans, animals or plants.

#### **International Summit on Human Gene Editing (December 2015)**

Regulations and guidelines for the scientific, ethical, and governance issues associated with biotechnology and human gene-editing research were put in place at the International Summit on Human Gene Editing held in Washington D.C. in the December of 2015.

The conference was Co-hosted by the U.S. National Academy of Sciences, the U.S. National Academy of Medicine, the U.K.'s Royal Society and the Chinese Academy of Sciences. A closing statement by committee chair David Baltimore encouraged the pursuit of "many promising and valuable clinical applications of gene editing", which was directed at the altering of genetic sequences in somatic cells (cells whose genomes are not transmitted to the next generation). The "intensive" continuation of basic and preclinical research was also recommended.

However, it was also stressed that "it would be irresponsible to proceed with any clinical use of germline editing" (cells whose genomes are transmitted to the next generation), until the technology's efficacy and safety issues were more clearly evaluated, and until there was a broad societal consensus.

### **Countries Stances on Regulating Genome Editing**

**Canada** - strongly influenced by public outcry over the production by British scientists of a cloned sheep called "Dolly", decided to ban and criminalize human cloning research in 2004.

Germany - the creation, use, and harvesting of embryonic cells for basic research are prohibited.

**France** - the modification of the human genome may be undertaken for preventive, diagnostic or therapeutic purposes only.

**United Kingdom** - Allowed in 2016 the application of genetic technology in research on human embryos.

**Republic of Korea -** laws prohibit genetic experimentation with and modification of human embryos, including any product that alters genes.

**Qatar** - adopted a consultative approach to policy making on issues relating to bioethics of new genetic technologies. The Qatar consultations have involved scientists, industry experts, government representatives and scholars in Islamic jurisprudence.

#### **Reasons for gene editing**

The United Nations frontier technology quarterly (may 2019 issue) states the importance of "genetic technologies for improving health and agricultural productivity, two important goals of the 2030 Agenda for Sustainable Development"

Gene editing has the potential to eradicate complex diseases such as heart disease, asthma, diabetes and cancer. This mechanism could also be used to treat genetically inherited diseases. In 2018 the technology was used to identify Dystonia in the USA. The technology could possibly eradicate diseases such as malaria which is one of the most severe public health epidemics in the sub-Saharan Africa, large swaths of Asia and Latin America. It is a leading cause of death, especially in Africa, where a quarter of the population remains at risk of contracting the disease.

The advancement of CRISPR technology also has the potential to advance human genome research and genetic mapping.

#### **Reasons against gene editing**

One of the primary concerns regarding Gene editing are the "off-target effects" of the technology. This means that not all copies of the target gene have been edited and replacing particular genes may have unanticipated consequences and adverse effects. Furthermore, to eradicate a gene mutation in a sick child scientists may have to introduce mutations into a healthy child. This can again cause side effects that may not be detected until later in the child's life. The mutation could also be inherited, removing the mutated gene from future generations may pose challenges. There is also the risk of accidentally terminating the embryo. Furthermore the selection of embryos poses a serious ethical dilemma as embryos that do not fit the specifications of parents will be disposed of therefore ending a potential life.

The threat of the technology being used for superficial purposes such as editing physical appearance (skin colour, eye colour, height) or even intelligence persists. This could lead to adverse social impacts as the repetitive choosing of appealing characteristics from different races for the same child will concentrate and damage the gene pool.

This will go against the darwinian terms of evolution and could endanger the human race. Evolution is only possible if there is a diverse range of genes, concentrating the gene pool will hinder the human race's ability to adapt. In countries where there is a preference for male children over female children the technology could be used to cater to these preferences which could lead to an imbalance between the genders and will not be evolutionarily favourable.

A widening genomics divide in healthcare will cater to the widening social gap. Designer babies are expensive and only the rich will be able to afford it. This will intern lead to the rich being classified as genetically modified and the poor as naturally made. The resulting social gap will pose problems needing to be solved.

December 1987	The CRISPR mechanism first published
March 2002	Term CRISPR- Cas9 published first time
March 2015	Scientists suggest CRISPR/Cas9 used with stem cells could provide human organs from transgenic pigs
2nd September 2015	Leading UK research councils, including the MRC, declared support for using CRISPR-Cas9 and other genome editing techniques in preclinical research
6th October 2015	Unesco's international Bioethics committee called for ban on genetic editing of human germline
1st February 2016	UK scientists authorised to genetically modify human embryos using CRISPR-Cas 9
21st JUne 2016	NIH approves the first clinical trial using gene editing tool CRISPR/Cas 9 to treat patients
February 2017	US national academies of sciences and medicine approves CRISPR in germline experiments
2nd August 2017	Research published demonstrating possibility of editing gene defect in pre-implanted embryos to prevent inherited heart disease
25th october 2017	New CRISPR technology developed for editing RNA

# Implementation, progression and development of the technology

24th November 2018	First Gene edited babies born in china
21st october 2019	New DNA editing technique called ' prime editing ' published. The technology could correct 89% of genetic defects.

## Questions a resolution must answer (QARMA)

- 1. How feasible is the legalisation of designer babies ?
- 2. What are the scientific limitations in gene editing? How can these risks be minimised? Is legalisation worth the risks with the scientific uncertainty ?
- 3. What limits should be set on the manipulation of the DNA ?
- 4. Which characteristics can be manipulated and to what extent ?
- 5. What conditions must be maintained for further research ?
- 6. What are the moral and ethical boundaries for the creation of designer babies ?
- 7. What precautions can be taken to address a potential social gap?
- 8. How will the committee improve on the limits set by previous conferences ?
- 9. Should there be transparency and collaboration amongst the countries on new research?