NPSI MUN

WHO

World Health Organisation

Table of Contents

Chairpersons Introduction

Head Chair: Rayna John

She submerged herself into the MUN circuit in 7th grade and hasn't slowed down since. Her initial intention was to be a note passer - perfect for someone with ZERO public speaking skills that wanted to see what the MUN hype was all about. Five years down the line and she can assure you that MUN is nothing but enriching. She has learnt how imperative it is for the youth to strengthen their global awareness, make new connections and provide fresh perspectives. Don't get jealous, but over the years she has compiled numerous feats both as a delegate and as a chair: Accidentally deleting her opening speech seconds before approaching the dias, tripping in front of everyone during the opening ceremony, laughing/crying?? for a minute straight etc. Jokes apart, she understands that most of you might be beginners but fear not - trust her when she says she's been there. She cannot wait to make the committee as memorable as can be!

Deputy Chair: Samud Suhas Shetty

16, NPSI student, looking forward to making this your best ever MUN experience! He doesn't throw around superlatives lightly, so when he says it, he means it. Almost all of you will be quite fresh to the scene in this council, so he's frankly overjoyed to have the opportunity to be a part of your exploration of the world of MUN. It's a world that he dunked himself into 3 years ago, at the 2017 edition of this very event, because it seemed like a "cool time pass". That cool time pass has since taught his ignorant self so much about public speaking, cooperation, international affairs and the whole lot. To be able to chair now, for the first time, he is beyond excited, and in all honesty, a tad bit nervous. But if there's one thing he can promise, it's that wonderful memories will be forged, and the time spent at this MUN will be relished! Now, enough of reading him wax lyrical and talk about himself in third person, go read the study guide!

Deputy Chair: Sindhu Sunkad

Her MUN journey began right here at NPSI so to start off her chairing journey here too is inherently nostalgic. Her inaugural MUN was a result of an impulsive decision upon which looking back, she is so glad to have made. After finding out that lunch was ordered from 'Pastamania', she decided to register for her first MUN, which seemed like a valid enough reason at the time. This allowed her to satiate her curiosity towards MUN as a whole, and thus she embarked on her journey as a MUNner. Through this journey, she has learnt so much about diplomacy, international cooperation and conflict resolution, at the very least. Previously oblivious to international happenings, her awareness has improved so much since her first MUN, and it's only increasing. As most of you are beginner delegates, she hopes to instill in you the same admiration she has for MUN and cannot wait to do so!

Council Introduction

The WHO was established on 7 April 1948 as a specialized UN agency with the goal of maintaining and improving global health. Its mission is stated as, "to promote health, keep the world safe and serve the vulnerable."[1] The WHO was born from a merger of the Health Organization of the League of Nations, the Pan-American Sanitary Bureau, and the Office International d'Hygiène Publique, all previously existing health organizations, to form a unified body under the United Nations.

Firstly, we present the mandate of WHO, i.e. the nature of resolutions and the means at its disposal. All of the WHO's resolutions must address one or more of the key core objectives of WHO[2], as listed below -

- Providing leadership on health related matters and engaging in required collaboration.
- Shaping research agendas hence, stimulating the generation and spread of vital knowledge.
- Setting standards and expectations relating to health, and promoting and monitoring their implementation.
- Encouraging the implementation of ethical and evidence-based policies.
- Providing required support to effectuate change, and building sustainable and sufficient institutional capacity.
- Monitoring the health situation and assessing health trends.

The WHO achieves its goals of improving international health standards in many ways, such as, but not limited to[3] -

- Directing and coordinating authority on international health matters,
- Assisting governments, upon request, in strengthening health systems,

[1] "What We Do." World Health Organization. https://www.who.int/about/what-we-do/.
[2] "The Role of WHO in Public Health." World Health Organization. May 31, 2017. http://www.who.int/about/role/en/.
[3] "Constitution." World Health Organization. https://www.who.int/about/who-we-are/constitution.

- Providing technical assistance and, in emergencies, aid upon the request or acceptance of nations,
- Stimulating and advancing work to eradicate epidemic, endemic and other diseases,
- Promoting, in cooperation with other agencies, the improvement of nutrition, housing, sanitation, recreation, economic or working conditions and other aspects of environmental hygiene,
- Assisting in developing an informed public opinion among all peoples on matters of health, through the means of providing information, counselling and assistance.

In essence, the WHO's main areas of work are those of health systems in the fields of; health through the life-course; non communicable and communicable diseases; preparedness, surveillance and response; and corporate services. From 1990 and 2010, WHO's activities of expanded prevention, diagnosis and treatment have contributed to a 40% decline in the number of deaths from tuberculosis, saving an estimated 53 million lives. WHO has also been maintaining a continually revised Essential Medicines List since the 1980s, which acts as a guide for countries on the core medicines that a national health system needs, one of the many ways WHO acts to advise national healthcare systems.[4]

Currently, the WHO works with 194 countries - the tools at their disposal limited to non-legally binding resolutions, which act as recommendations to Member States, and a funding for the 2020-21 programme of USD 4.84 billion.

[4] "WHO Model Lists of Essential Medicines." World Health Organization. March 23, 2020. https://www.who.int/medicines/publications/essentialmedicines/en/.

Agenda: The Future of Human Gene Editing

Introduction to Agenda

Human gene editing - a tool or a weapon? While there are definitely many advantages that come with the use of genetic editing technology, it has been made clear that geneticists are to, if ever, proceed with much caution in this field.

In the 2016 Worldwide Threat Assessment of the US Intelligence Community, the United States Director of National Intelligence claimed that genome editing was a potential weapon of mass destruction[5], adding that "genome editing conducted by countries with regulatory or ethical standards different from Western countries could likely increase the risk of the creation of harmful biological agents or products". Due to its wide distribution, low cost, and fast paced development, its misuse could result in huge economic and national security implications - whether intentional or not. For example, technologies such as CRISPR could be used to deactivate essential genes, inappropriately activate cancer-causing genes or rearrange chromosomes. "Rogue" geneticists with a strong understanding of vulnerabilities to specific diseases could significantly disrupt entire populations.[6]

Contrary to how genome editing is now viewed, the initial intention behind the ideation of the technology was to further the cause of science through the study of genetics. The possibilities that come with human gene editing are endless, many of which could bring positive societal progress when kept in the right hands. Imagine the selection and deletion of human characteristics for therapeutic enhancement purposes. Capacities that we have never known could be unlocked for the human race - improved

[5] Regalado, Antonio. "Top U.S. Intelligence Official Calls Gene Editing a WMD Threat." MIT Technology Review. April 02, 2020. https://www.technologyreview.com/2016/02/09/71575/top-us-intelligence-official-calls-gene-editing-a-wmd-threat/.

[6] Editor's Notes: National Security Implications of Gene Editing. https://www.nationaldefensemagazine.org/articles/2019/3/26/editors-notes-national-security-implications-of-gene-editing.

cognition, physical abilities, longevity - favorable traits that can be passed down from generation to generation.

As for the WHO's current stance, in a statement issued in July 2019, the WHO Director General agreed with the WHO Expert Advisory Committee's recommendation that it would be "irresponsible at this time for anyone to proceed with clinical applications of human germline genome editing."[7] However, this does not imply that research on the topic cannot be carried out, nor does it rule out future implementation of the technology in clinical applications. Thus, it is crucial that the benefits and downsides of genetic engineering are considered and debated upon, in order to decide whether and how to find a balance between the numerous opportunities and risks that the technology presents.

[7] WHO statement on governance and oversight of human genome editing. https://www.who.int/news-room/detail/26-07-2019-statement-on-governance-and-oversight-of-human-genome-editing.

Key Definitions

- **Gene Editing/Genetic Engineering:** The process by which DNA is altered, inserted, replaced or deleted in the genome of a living organism.
- **Germline Editing:** The process by which the genome of an individual is edited in such a way that the change is heritable, ie, future generations will also possess the altered genome of the edited organism.
- **Somatic Cell Gene Therapy:** Somatic cell gene therapy involves the placement of a human gene into a living person's somatic cells—cells that do not produce the eggs and sperm that in turn produce the next generation.
- **Genome:** The complete set of an organism's genetic material.
- **CRISPR-Cas9:** CRISPR (Clustered regularly interspaced palindromic repeats) is cutting-edge technology that allows geneticists and medical researchers to perform genetic engineering by modifying, inserting or deleting genomes.
- **Zinc Finger Nuclease:** This was the first developed high targeting genome editing technique that helped in promoting backward genetics in which the exact gene causing mutations could be identified. The technique also plays a part in the formation of "genetic scissors" that help to cleave DNA at a specific point.
- **Human Enhancement:** Human enhancement refers to an alteration of the human body in order to ameliorate physical or mental capabilities of the body. This is, in some way or another, the ultimate goal of Human Gene Editing.
- **Gene Therapy:** Gene therapy is a technique in the experimental phase that uses genes to treat or prevent disease. It works by introducing genetic material into cells to compensate for non-functional/abnormal genes, or to make a beneficial protein. This can be considered a basic form of Human Gene Editing.

History and Development

The door to human genetics was opened in 1953 when 3 scientists pioneered the discovery of DNA, the current core around which genetic engineering revolves.[8]

Year	Event Description
1970s	By 1972, researchers had created the first example of recombinant DNA, by cloning the SV40 molecule into plasmid DNA.[9] This decade was full of some of our most promising milestones in the world of genetics, creating multiple stepping stones for future geneticists.
1971	Application of Type II Restriction Enzymes: [10] These were used to map DNA. Three scientists (Werner, Nathans and Smith) were able to separate fragments of viral DNA using gel electrophoresis, all of whom were awarded Nobel Prizes 6 years later.
1974	Moratorium on Genetic Experimentation: Proposed by National Academy of Science after seeing the possible ethical implications of unsafely experimenting with genetics.[11]
February 1975	Asilomar Conference: Arranged by Paul Berg, a leading geneticist. Over 100 others in the field attended the event. Joshua Lederberg drew attention to the potential of recombinant DNA technology for curing disease, his optimism

[8] "Full Stack Genome Engineering." Synthego. https://www.synthego.com/learn/genome-engineering-history.

[9] Berg, Paul, and Janet E. Mertz. "Personal Reflections on the Origins and Emergence of Recombinant DNA Technology." Genetics. January 2010. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2815933/.

[10] Roberts, Richard J. "How Restriction Enzymes Became the Workhorses of Molecular Biology." Proceedings of the National Academy of Sciences of the United States of America. April 26, 2005. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1087929/.

[11] Berg, Paul and Singer, Maxine. “The recombinant DNA controversy:Twenty years later.” Proceedings of the National Academy of Sciences of the United States of America. September, 1995.

	encouraging others to look past the fears of its misuse.
1985	Discovery of the Zinc Finger Nuclease (ZFN): This technique helped to promote backward genetics, in which the exact gene causing mutations could be identified, instead of causing random mutations and guessing which gene was responsible (forward genetics).[12]
1990	The Human Genome Project: This project was formally launched in 1990, 6 years after the idea was thought up by the US Government, and included scientists from 20 institutions in 6 different countries (USA, China, France, Germany, UK and Japan). The project ran over a span of 13 years with the aim to ascertain the base pairs that make up Human DNA, and to investigate the human genome at physical and functional angles. By 1999, they reached the milestone of completely mapping out the sequence for Chromosome 22. However, the project ended up mapping only about 92.1% of the intended and multiple working drafts have since been completed, also with many knowledge gaps. Due to several repetitions and other intractable sequence features, it has been very hard to apprehend the true depth of the heterochromatic part of the genome, leaving us with about 5% to 10% uncertainty.[13]
2011	Discovery of TALENs: The new designer nucleases came about and brought about significant progress in the genetic field as they

[12] Klug, Aaron. "The Discovery of Zinc Fingers and Their Development for Practical Applications in Gene Regulation and Genome Manipulation: Quarterly Reviews of Biophysics." Cambridge Core. May 18,2010.https://www.cambridge.org/core/journals/quarterly-reviews-of-biophysics/article/discovery-of-zinc-fingers-and-their-development-for-practical-applications-in-gene-regulation-and-genome-manipulation/D25ADFAFC0F47D14E52E36BF5A27FCDE.

[13] "What Is the Human Genome Project?" Genome.gov. https://www.genome.gov/human-genome-project/What.

	were able to recognize smaller units than previously possible. They helped to make designing much easier and quicker, allowing for fewer off-target effects and less cytotoxicity than ZFN.
2012	Discovery of CRISPR Genome Editing Tool: Creating the bacterial adaptive immune system in nature was a huge stepping stone in genetics as it allowed geneticists to make precise targeted cuts in DNA. The technology can be engineered to edit eukaryotic DNA by designing guide RNA complementary to the target sequence. This is attributed to the work of Jennifer Doudna, Emmanuelle Charpentier and their teams.
2018	Human Genome Editing Registry:[14] The WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing agreed on bridging gaps in transparency and inclusivity by having a "more structured mechanism for collecting and curating details of planned and ongoing research". WHO was thus requested to commence work on developing a registry, including research on gene editing technology, that would be made publicly accessible.

[14] "Human Genome Editing Registry." World Health Organization. https://www.who.int/health-topics/ethics/human-genome-editing-registry.

Scope of Debate

Germline Editing

The biggest point of contention for this agenda is the ethical concern of harmful mutations. This is because current technology that modifies a person's genotype may produce a change that can be passed down to future generations. Therefore any error, intentional or not, will also be passed down and inherited by offsprings, a process that may continue and propagate greatly. This is a crucial health dilemma that is likely to be divisive. The social acceptability of germline editing is highly dependent on its perceived safety, which is only becoming increasingly ambiguous. While somatic gene editing impacts only the patient it's applied to, germline editing impacts every cell in the organism, including eggs and sperm, and is thus heritable. Should such a technique be ill-implemented, these overlooked off- target mutations may cause children to develop lethal diseases later in their lives.[15] Furthermore, advancements in genome editing can soon open doors to creating 'designer babies', which creates its own ethical issues, regarding whether it is morally correct for people to 'design; their children, and equally pressingly, whether it is fair to have the rich be able to have genetically advantageous offspring, compared to the poor.

There exist multiple reasonings supporting human germline editing as well. For example, embryonic genes can be edited to reduce the risk of disease in offspring that is associated with that specific gene (E.g. BRCA1 and Breast cancer). This may be particularly useful in populations that are at a higher risk of such diseases.

Allowing the development of genetic therapy yields huge financial benefits in the long run, as a lifetime of treatment costs can be spared for an individual. For example, gene therapy seems to be promising for treating a

[15] "What Are the Ethical Issues Surrounding Gene Therapy? - Genetics Home Reference - NIH." U.S. National Library of Medicine, National Institutes of Health, https://ghr.nlm.nih.gov/primer/therapy/ethics.

wide range of diseases like cystic fibrosis, heart disease, diabetes, hemophilia and AIDS.

Risks of CRISPR and Embryonic Research

Several warning signs have been raised about CRISPR. Some studies have found that editing cells with CRISPR-Cas9 could increase the chance of the altered cells becoming cancerous. At this stage, the biggest barrier to change is the uncertainty regarding the safety of the method, as no large-scale or long-term research has been (or currently can be) conducted on humans to assess whether it is safe in the long run, leading to a lack of scientific evidence and data. This has led to a stalemate in this field of science, where for progress to be made, the importance of safety has to be sidelined, and vice versa.

Moreover, before even performing this procedure on any humans, research will have to be conducted first using embryos, some of which may be destroyed in the process. The question of embryonic research is one shrouded in controversy.

Differing Stances of Nations

The general health stances of different countries will undoubtedly create rifts. Given that the commercialization of such treatments is far in the future, a country's stance regarding their openness to healthcare advances will be a determining factor in how likely they are to accept the ideas and required legislations surrounding human gene editing. Strict national legislation is required to combat this transnational problem, but due to the uncertain and evolving nature of the science, countries have not yet openly accepted or rejected germline editing. This makes it more challenging to come to an international consensus on the agenda.

These kinds of arguments against genome editing, and the general uncertainty around the topic are large parts of the reason as to why germline editing is still in its clinical stage as of today, while the promise the technology holds plays an equally large part in the growing support in the scientific and medical communities regarding the subject.

Case Studies

Cardiomyopathy[16]

Cardiomyopathy is a disease that 1 in 500 people are affected by, in which a gene causes cardiac muscle to thicken (especially in the left ventricle), which often leads to heart failure. This is just one among many hereditary illnesses which could be corrected by genetic engineering. The TTN[17] Gene mutation accounts for about 25% of all familial dilated cardiomyopathy and its signs and symptoms may only show themselves in mid-adulthood. While gene correction strategies will have to be extremely specific, a one-time treatment could fix the problem as opposed to a continuous dosage of antisense oligonucleotide drugs. The correction would include the deletion of the problematic gene, which will help to restore protein expressions, while being cautious about altering the mutant allele and avoiding the healthy one. A thorough genetic diagnosis would thus play a huge role in this process.

Lulu and Nana - Shenzhen, China

This was the first ever reported case of human genome editing and was done by Chinese scientist, He Jiankui which led to the birth of genetically edited twins in 2018. Jiankui worked at the Southern University of Science and Technology and began a project directed towards helping couples with HIV-positive fathers, aiming to achieve genetic resistance to HIV. While People's Daily classified this event as a historical breakthrough in the field of disease prevention, Jiankui soon faced immense backlash[18] for ignoring ethical considerations and tarnishing the reputation of Chinese science. All of his research activities were suspended and deemed "abominable in nature". The question of bioethics was thus thrust to the

[16] Ohiri, Joyce C., and Elizabeth M. McNally. "Gene Editing and Gene-Based Therapeutics for Cardiomyopathies." Heart Failure Clinics. April 2018. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5849064/.
[17] "Familial Dilated Cardiomyopathy - Genetics Home Reference - NIH." U.S. National Library of Medicine. https://ghr.nlm.nih.gov/condition/familial-dilated-cardiomyopathy.
[18] Gallagher, James. "He Jiankui: Baby Gene Experiment 'foolish and Dangerous'." BBC News. June 03, 2019. https://www.bbc.com/news/health-48496652.

forefront and issues such as 'designer babies' arose. Using CRISPS-Cas9's technology, he managed to debilitate the CC5[19] gene which typically codes for a protein that would allow HIV to enter a cell. While Jiankui has claimed that the twins are healthy, this has not been confirmed and their parents' reaction have not been published, leaving his statements unsubstantiated.

Figure 1: Scientist He Jiankui speaking at the Second International Summit on Human Genome Editing[20]

Hunter Syndrome or MPS II

The rare genetic disorder is one in which there is a build-up of large sugar molecules known as glycosaminoglycans. This is another inherited affliction caused by the passing down of a defective chromosome from a mother to her child, leaving the child with a missing or malfunctioning enzyme (iduronate 2-sulfatase) which is responsible for breaking down certain complex molecules. Therefore, its absence leads to an accumulation of these molecules. The sickness causes permanent and progressive damage to the heart, brain, nervous system, connective tissue, respiratory system etc. and thus finding a solution for its prevention is imperative. Currently, those with Hunter Syndrome turn to weekly infusions

[19] Regalado, Antonio. "He Jiankui Faces Three Years in Prison for CRISPR Babies." MIT Technology Review. April 02, 2020. https://www.technologyreview.com/2019/12/30/131061/he-jiankui-sentenced-to-three-years-in-prison-for-crispr-babies/.
[20] "China Jails 'gene-edited Babies' Scientist for Three Years." BBC News. December 30, 2019. https://www.bbc.com/news/world-asia-china-50944461.

of the IDS enzyme but this is rapidly depleted[21]. Researchers from Sangamo Therapeutics in Richmond, California have been working towards a more permanent fix but have faced difficulties such as the detection of low levels of the enzyme in the blood. Now they are still in the process of developing gene editing treatments, SB-318 and SB-319, that are currently undergoing testing. Its goal is to use ZFN to insert a functional copy/healthy version of the gene for the missing IDUA (MPS I) or IDS (MPS II)[22] enzyme in the liver. They claim[23] that the liver could then potentially produce large amounts of the missing enzyme inside the body with the hope of improving or curing the disease, and possibly even eliminating the need for lifelong Enzyme Replacement Therapy.

[21] Ledford, Heidi. "First Test of In-body Gene Editing Shows Promise." Nature News. September 05, 2018. https://www.nature.com/articles/d41586-018-06195-6.
[22] "Mucopolysaccharidosis Type II." NORD (National Organization for Rare Disorders). https://rarediseases.org/rare-diseases/mucopolysaccharidosis-type-ii-2/.
[23] "MPS I II." Concrete5. https://www.sangamo.com/patients/mps-i-ii.

Relevant Stakeholders

China

As the nation in which the first and so far, only, recorded case of human gene editing has taken place, China has a lot to answer for. After the He Jiankui affair, the Chinese government had stepped in and condemned his work, giving him a 3 year jail sentence for illegal medical practices. Simultaneously, China's stance on the matter remains legislatively ambiguous, having only implemented basic guidelines to restrict human genome editing.[24]

United States of America

The United States of America has a unique system in place against human germline engineering. Presently, rules are extremely restrictive, and while it may still be possible to conduct research on the subject in the future, as there is no outright ban, the Food and Drug Administration, and National Institutes of Health have implemented a moratorium on human genome editing research at the moment. Furthermore, an outright federal ban is in place in the US on genetically modified babies, which has been voted on by a House Committee as recently as June 2019, largely as a result of the general consensus regarding unknown risks.[25] However, there is widespread dissent over the rule in the scientific community, as it is argued that the ban prevents the studies necessary to determine and improve the safety of the technique in the first place. Given the "superpower" status of the US, and its position as an example for many nations, the state of guidelines and legislation in the country will have great implications for the field, within the country, and internationally.

---

[24] Li, Jing-Ru, Simon Walker, Jing-Bao Nie, and Xin-Qing Zhang. "Experiments That Led to the First Gene-edited Babies: The Ethical Failings and the Urgent Need for Better Governance." Journal of Zhejiang University. Science. B. 2019. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6331330/.
[25] Stein, Rob. "House Committee Votes To Continue Ban On Genetically Modified Babies." *NPR*, NPR, 4 June 2019, www.npr.org/sections/health-shots/2019/06/04/729606539/house-committee-votes-to-continue-research-ban-on-genetically-modified-babies.

Sub-Saharan Africa

With countries like Angola, Nigeria, Uganda, Burundi and the Gambia consistently filling up the lower spots of the R&D expenditure per capita charts, their interests in human genetic engineering is likely to be little to none, especially given that they have much more pressing health issues to deal with. However, in the long run, these developing nations have the most to gain from such technologies since human gene editing can make their populations more immune to communicable diseases like HIV/AIDS and malaria. Their present stances may lead to a dangerous divide in genomics as the technology becomes more widespread in countries where research is stronger. The trade-off between short term stability and long term prosperity will be crucial for these nations.

QARMA (Questions A Resolution Must Answer)

- What must be done in order to make human genome editing a permissible/universally accepted procedure?
- What regulations must countries impose to ensure that human genome editing is being used ethically? Who decides how 'ethics' are standardized globally?
- How can countries prevent a 'genomics divide' that can exacerbate existing inequality in health outcomes between rich and poor nations? How can the healthcare system adapt with the changing priorities in medical research?
- What procedures should be set in place for establishing the consent and privacy of those involved in human genome editing?
- Who owns the information sharing and intellectual property rights of patients' genetic information that must be gathered for research and implementation? Under what circumstances can this information be divulged?
- How can officials regulate illegal testing during the development of human genome editing?
- Who holds the responsibility for the spillover and third party effects of human gene editing research? How will possible foreseen and unforeseen effects be mitigated?

Concluding Remarks

Ethical dilemma or scientific discussion? Dream of the future or concern of today? WHO's future stance on gene editing is uncertain, and hence, it is up to the delegates, and the countries they represent, in this council, to dictate the future landscape of this contentious issue.

Genetic editing is an issue that is completely unprecedented. The first documented case of genetically engineering humans was rife with controversy. Never has there been an innovation in the field of medicine and healthcare that holds such great promise, while also posing such an enormous long-term threat, with the ability to harm families and populations due to unforeseen circumstances.

A topic as new-age as human genome editing does not have an extensive history or list of past events to fall back on, only a blank slate to look forward to. Hence, its debate is not easy. After all, gene editing deals with more than just politics. It addresses ethics, sociology, legal challenges, science, religion and much more. Delegates will be tasked with the challenge of debating and coming up with an effective solution in the form of a resolution for this agenda, with the purpose of determining the future of human genome editing, on both national, and global levels.

Further Reading

- ➔ Gene editing saves girl dying from leukaemia in world first - Michael Le Page
  Acute Lymphoblastic leukemia treated by gene therapy
  https://www.newscientist.com/article/dn28454-gene-editing-saves-life-of-girl-dying-from-leukaemia-in-world-first/
- ➔ New Gene-Editing Tool Could Fix Genetic Defects--with Fewer Unwanted Effects - Tanya Lewis
  Introduces a new technique called 'prime editing'
  https://www.scientificamerican.com/article/new-gene-editing-tool-could-fix-genetic-defects-with-fewer-unwanted-effects1/
- ➔ 1 THE EUROPEAN LANDSCAPE FOR HUMAN GENOME EDITING A review of the current state of the regulations and ongoing debates in the EU - Jeff Kipling
  Highlights key issues of genome editing in the EU
  https://acmedsci.ac.uk/file-download/41517-573f212e2b52a.pdf
- ➔ Understanding Our Genetic Inheritance: The First Five Years
  5-year goals of the Human Genome Project
  https://web.ornl.gov/sci/techresources/Human_Genome/project/5yrplan/index.shtml
- ➔ The Ethics of Human Genome Editing - Giulia Cavaliere
  Talks about the areas of controversy in genome editing
  https://www.who.int/ethics/topics/human-genome-editing/WHO-Commissioned-Ethics-paper-March19.pdf
- ➔ The recombinant DNA controversy: Twenty years later - Paul Berg, Maxine F. Singer
  Addresses the ramifications of recombinant DNA technology
  https://www.pnas.org/content/pnas/92/20/9011.full.pdf
- ➔ Did CRISPR really fix a genetic mutation in these human embryos? - Ewen Callaway
  Evaluates whether fixing a disease causing mutation in human embryos using CRISPR is possible
  https://www.nature.com/articles/d41586-018-05915-2

Bibliography

Council Introduction

- "Constitution." *World Health Organization*, World Health Organization, https://www.who.int/about/who-we-are/constitution.
- "The Role of WHO in Public Health." *World Health Organization*, World Health Organization, 31 May 2017, https://www.who.int/about/role/en/.
- "What We Do." *World Health Organization*, World Health Organization, https://www.who.int/about/what-we-do.
- "WHO Model Lists of Essential Medicines." *World Health Organization*, World Health Organization, 23 Mar. 2020, https://www.who.int/medicines/publications/essentialmedicines/en/.

Agenda: Human Genome Editing

- Berg, Paul, and Janet E. Mertz. "Personal Reflections on the Origins and Emergence of Recombinant DNA Technology." Genetics. January 2010. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2815933/.
- Berg, Paul and Singer, Maxine. "The recombinant DNA controversy: Twenty years later." Proceedings of the National Academy of Sciences of the United States of America. September, 1995.
- Brad Plumer, Eliza Barclay. "A Simple Guide to CRISPR, One of the Biggest Science Stories of the Decade." Vox. July 23, 2018. https://www.vox.com/2018/7/23/17594864/crispr-cas9-gene-editing.
- "China Jails 'gene-edited Babies' Scientist for Three Years." BBC News. December 30, 2019. https://www.bbc.com/news/world-asia-china-50944461.
- Editor's Notes: National Security Implications of Gene Editing. https://www.nationaldefensemagazine.org/articles/2019/3/26/editors-notes-national-security-implications-of-gene-editing.
- "Familial Dilated Cardiomyopathy - Genetics Home Reference - NIH." U.S. National Library of Medicine. https://ghr.nlm.nih.gov/condition/familial-dilated-cardiomyopathy.
- "Full Stack Genome Engineering." Synthego. https://www.synthego.com/learn/genome-engineering-history.
- Gallagher, James. "He Jiankui: Baby Gene Experiment 'foolish and Dangerous'." BBC News. June 03, 2019. https://www.bbc.com/news/health-48496652.
- "Human Genome Editing Registry." World Health Organization. https://www.who.int/health-topics/ethics/human-genome-editing-registry.

- Klug, Aaron. "The Discovery of Zinc Fingers and Their Development for Practical Applications in Gene Regulation and Genome Manipulation: Quarterly Reviews of Biophysics." Cambridge Core. May 18,2010. https://www.cambridge.org/core/journals/quarterly-reviews-of-biophysics/article/discovery-of-zinc-fingers-and-their-development-for-practical-applications-in-gene-regulation-and-genome-manipulation/D25ADFAFC0F47D14E52E36BF5A27FCDE.
- Ledford, Heidi. "First Test of In-body Gene Editing Shows Promise." Nature News. September 05, 2018. https://www.nature.com/articles/d41586-018-06195-6.
- Li, Jing-Ru, Simon Walker, Jing-Bao Nie, and Xin-Qing Zhang. "Experiments That Led to the First Gene-edited Babies: The Ethical Failings and the Urgent Need for Better Governance." Journal of Zhejiang University. Science. B. 2019. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6331330/.
- Moulds, Josephine. "How Is the World Health Organization Funded?" World Economic Forum. https://www.weforum.org/agenda/2020/04/who-funds-world-health-organization-un-coronavirus-pandemic-covid-trump/.
- "MPS I II." Concrete5. https://www.sangamo.com/patients/mps-i-ii.
- "Mucopolysaccharidosis Type II." NORD (National Organization for Rare Disorders). https://rarediseases.org/rare-diseases/mucopolysaccharidosis-type-ii-2/.
- Ohiri, Joyce C., and Elizabeth M. McNally. "Gene Editing and Gene-Based Therapeutics for Cardiomyopathies." Heart Failure Clinics. April 2018. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5849064/.
- Regalado, Antonio. "He Jiankui Faces Three Years in Prison for CRISPR Babies." MIT Technology Review. April 02, 2020. https://www.technologyreview.com/2019/12/30/131061/he-jiankui-sentenced-to-three-years-in-prison-for-crispr-babies/.
- Regalado, Antonio. "Top U.S. Intelligence Official Calls Gene Editing a WMD Threat." MIT Technology Review. April 02, 2020. https://www.technologyreview.com/2016/02/09/71575/top-us-intelligence-official-calls-gene-editing-a-wmd-threat/.
- Roberts, Richard J. "How Restriction Enzymes Became the Workhorses of Molecular Biology." Proceedings of the National Academy of Sciences of the United States of America. April 26, 2005. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1087929/.
- Stein, Rob. “House Committee Votes To Continue Ban On Genetically Modified Babies.” NPR, NPR, 4 June 2019, www.npr.org/sections/health-shots/2019/06/04/729606539/house-committee-votes-to-continue-research-ban-on-genetically-modified-babies.

- "What Are the Ethical Issues Surrounding Gene Therapy? - Genetics Home Reference - NIH." U.S. National Library of Medicine, National Institutes of Health. https://ghr.nlm.nih.gov/primer/therapy/ethics.
- "What Is the Human Genome Project?" Genome.gov. https://www.genome.gov/human-genome-project/What.
- WHO statement on governance and oversight of human genome editing. https://www.who.int/news-room/detail/26-07-2019-statement-on-governance-and-oversight-of-human-genome-editing.