

Committee: World Health Organization

Issue: The regulation of genetic testing

Student Officer: Chloe-Alexia Galgadas

Position: Deputy Chair

PERSONAL INTRODUCTION

Dear delegates,

My name is Chloe-Alexia Galgadas and I am an IB1 student at Costeas-Geitonas School. I am more than honoured to participate in the very 1st ACGMUN Conference, especially as it is my first-time chairing. The World Health Organization is one of the most interesting committees, but I have also been to other committees such as the Political, Disarmament, ICJ, Humanitarian, and Legal committee as a delegate. Therefore, I have participated in 7 conferences overall and thus I have the knowledge and experience to provide my services in the best possible way to guide you. You will receive correct and accurate instructions during the lobbying but also during the debate process and hopefully, you will be familiarized with the procedures. Prior to the conference, the Study Guides will assist you in gaining information about the topics. However, you should not base your research solely on the Study Guides. Although they provide information about the topic and make a general introduction, you will need to collect in depth information from your own sources. You should do your own exploration and if any question comes up, feel free to contact me. I am excited and looking forward to this conference as I believe there will be great preparation, collaboration, respect and thus a fruitful and inspiring debate throughout these three days.

Feel free to contact me for any queries on: calggs@hotmail.com

Looking forward to meet you all,

Yours Sincerely,

Chloe- Alexia Galgadas

TOPIC INTRODUCTION

As time passes, genetic testing, also known as DNA testing is becoming more common in clinics. There are hundreds of different tests and furthermore, new ones are being created constantly. The tests are beneficial for us, regardless of the result (negative or positive). Through this genetic testing we can diagnose from foibles, which are defined as weaknesses in one's system, to inherited diseases. They can be used as a healthcare tool to discern gene discrepancies connected to a specific condition. Genetic testing can also detect some specific changes that we may have in our chromosomes, genes and proteins that could possibly result in a genetic condition. One of the biggest advantages of genetic testing is that it allows people to test their genes and determine whether they have a disease before any symptoms show. It can also help us prevent the disease from fully developing and thus take the specific precautions.

Even though genetic testing can be extremely useful, there are ethical considerations that surround this topic that need to be considered. Some genetic tests may provide a person with limited information due to inefficient technology, which in turn can cause uncertainties and leave an individual with difficult decisions to make regarding any recommended procedures. Moreover, parents can authorise genetic testing on their newborn babies in order to see if they have any diseases or if they are prone to become sickened from certain diseases. The ethical concern here is if it is moral for newborn babies to be tested for disorders if they cannot be treated when their organs are so immature. Genetic tests are not only used in humans but in animals as well. These tests are used on animals in order to avoid inherited diseases and ensure their health by taking specific measures depending on the disease that each animal has. Animals also have rights and they should be respected. It is completely unethical to use animals in experiments and not only physically harm them but often lead them to death. Genetic testing may provide us with much needed information but still there are some gaps that should be filled in.

DEFINITION OF KEY TERMS

Genetic Testing¹

Genetic testing is a type of medical test that identifies changes in chromosomes, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition or help determine a person's chance of developing or passing on a genetic disorder.

¹ Genetic Home Reference, Your Guide To Understanding Genetic Conditions, "What is Genetic Testing?", 24 January 2017

Genetic Disorder ²

A genetic disorder is a disorder caused by products expressed from a defective genome. It may involve one or more defective genes. Genetic disorders affect only a small percentage of the population. Genetic disorders may be heritable or non-heritable (acquired). A heritable genetic disorder is also one in which the gene defect leading to a disorder is passed down from parent to offspring. The non-heritable type is caused by new changes in the gene(s) causing the disorder. An example of such a disorder is Down syndrome.

Genetic Mutation ³

A change in the chemistry of a gene that is perpetuated in sequence divisions of the cell in which it occurs; a change in the sequence of base pairs in the chromosomal molecule.

In Vitro Fertilization

In Vitro Fertilization is a one assisted reproductive technology (ART) commonly referred to as IVF and is the process of fertilization by manually combining an egg and sperm in a laboratory dish, and then transferring the embryo to the uterus.

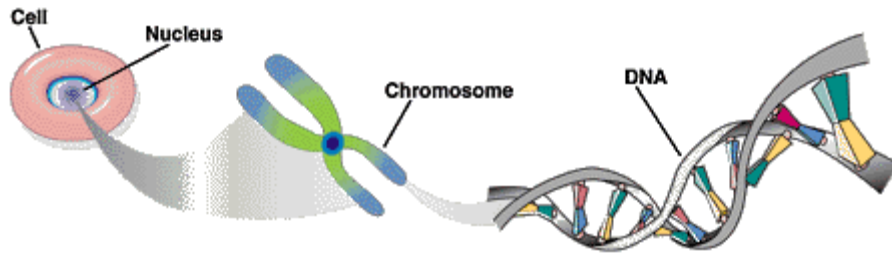
BACKGROUND INFORMATION

Basic Genetics

Genetics is the study of genes which are the main unit of heredity. There are tens of thousands of genes arranged along the chromosomes. In 2003 through the Human Genome Project it was announced that humans have approximately 20,000 to 25,000 genes. Chromosomes contain information that determine the features of living organisms. Genetics also explain how some inherited features may pass from generation to generation and furthermore, how much beings vary from one generation to the next. Chromosomes are made up of DNA. All humans have forty-six chromosomes and thus twenty three pairs.

² "Genetic Disorder." *Genetic Disorder - Biology-Online Dictionary*. N.p., n.d. 23 January 2016

³ "Genetic Mutation | Definition of Genetic Mutation by Medical Dictionary." *The Free Dictionary*. Farlex



#1: Deoxyribonucleic acid (DNA)¹

DNA is an extremely long macromolecule that is the main component of chromosomes and is the material that transfers genetic characteristics in all life forms, constructed of two nucleotide strands coiled around each other in a ladderlike arrangement. The side pieces are composed of alternating phosphate and deoxyribose units and the rungs are composed of the purine and pyrimidine bases adenine, guanine, cytosine, and thymine. The genetic information of DNA is encoded in the sequence of the bases and is transcribed as the strands unwind and replicate.

Types and methods of genetic testing

There are many types and methods of genetic testing. Beginning with the types, some of them are: newborn screening, diagnostic testing, carrier testing, prenatal testing, preimplantation testing, predictive and presymptomatic testing and the forensic testing. For example, newborn screening is used after birth in order to examine any possible genetic disorders so the newborn babies can be treated before there are signs of symptoms.



2: DNA chain

Moreover, there are hundreds of methods of genetic testing and more are developing. Several methods that can be used for genetic testing are: molecular, chromosomal and biochemical genetic tests. The molecular genetic test examines mainly single genes and sometimes a short length of DNA to identify any mutation or abnormality that could lead to a genetic disorder. The chromosomal genetic test examines whole chromosomes or a long length of DNA in order to check if there are significant genetic changes (such as a smaller or larger amount of chromosomes) that could lead to a genetic condition. The third type, a biochemical genetic test, tests the activity of the proteins and abnormalities that could cause any genetic disorder. So, as we can see there are many types and methods of genetic testing although some have not been mentioned here and therefore, they can be included in your individual research.

Animal Testing

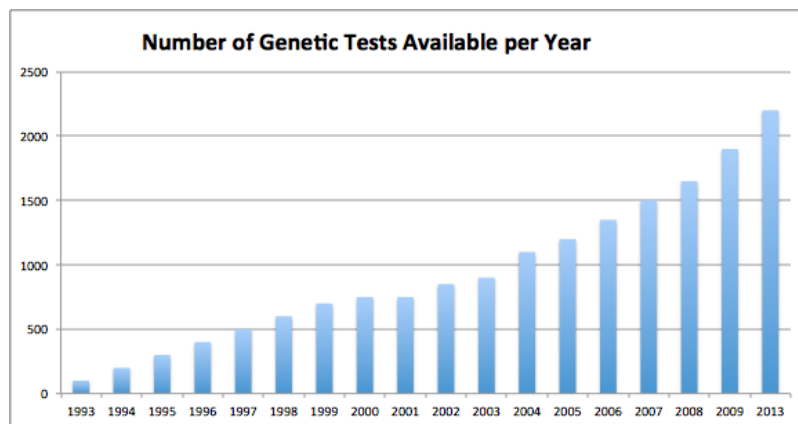
Genetic tests are being conducted in animals not only to avoid any possible inherited diseases but also to make sure that the tests are completely harmless and that they can be used in humans as well. Even though it is important to keep every individual safe there are a lot of ethical issues concerning animal testing in general and also some people claim that data taken from animals cannot be generalized to humans. Moreover, animal testing and more specific genetic testing should only be used in order to keep animals healthy and prevent any disease and not to harm them physically. Supporting animals rights has to do with justice. Even though we can collect important information from animal testing we should still ensure that no animal is physically harmed. However, this is something that not everyone complies with. Animal tests are usually used in sciences such as psychology in order to examine specific cases. In most of those experiments animals are being harmed. If an animal is being harmed then the animal should be immediately euthanized in order to not feel any more pain, so in most cases animals are being sacrificed. The ethical considerations ought to be taken into account by everyone. Animals still have rights and we are not the ones that should violate them.

Benefits and Limitations of genetic testing

Genetic testing has both benefits and limitations. Beginning with the benefits, individuals have the opportunity to check their genes and see whether they have a genetic disorder. Through this testing, someone could even detect a major disease such as cancer. It can be considered to be beneficial no matter the result. A negative result will relieve the individual and it may decrease the need of unnecessary tests when the individual is completely healthy. A positive result could help the patient make some decisions and take some precautions in order to be treated. A positive result may also encourage people to reproduce regardless if there is a potentiality of the genetic disorder passing on to the child, since through screening we are able to see if newborns have any abnormalities and thus appropriate treatment may be provided.

Despite the advantages of genetic testing, there are also several limitations that everyone should be aware before doing such a test. Firstly, even though this is quite rare, the procedures used for the prenatal genetic test may harm and may limit the chances of pregnancy because a small amount of amniotic fluid is needed in order for the test to take place. The other risks are mainly associated with family. Genetic test could arguably increase anxiety and guilt in a parent, since they may pass on a specific genetic disorder to their children. Furthermore, genetic testing is essentially only able to provide limited information and this can lead to a very difficult situation and decision for an individual. Every professional clinician is aware

of both the strengths and the limitations of the genetic testing and every individual that is interested in undergoing a test has to be fully informed.



#3: Number of Genetic Tests Available per Year

Through this diagram we can see that as time passes more genetic tests are being developed. In 2013 there were approximately 2200 genetic tests and thus, analogically, we can understand how many exist currently.

MAJOR COUNTRIES AND ORGANISATIONS INVOLVED

Centre for Medicare and Medicaid Services (CMS)

The Centre of Medicare and Medicaid Services is the largest health insurance program in the United States. It is responsible for improving and providing resources for clinical laboratories that focus on genetic testing. They are guaranteeing their conformity with the Clinical Laboratory Improvement Amendments of 1998 (CLIA). The aim of CLIA is to mainly attest the clinical test quality.

France

Recently, in 2004 and 2011, in France, there were specific laws implemented that limited the use of genetic testing as far as possible. France has made numerous laws concerning this issue since the innovation of genetic testing and has never been completely in favour of legalizing it due to ethical concerns etc.

Germany

In April 2009 Germany accepted the Human Genetic Examination Act. However, it was made legal only under specific circumstances. The tests can only be done from specialized doctors and it demands the assent of all parties tangled. It is

also considered illegal if someone conducts a paternity test, and so conducting one has consequences of large fines. Furthermore, the law prohibits parents to authorise genetic tests on their unborn babies in order to determine their sex. The employees are not allowed to have any access in the information of the tests nor are they allowed to release them publicly. Even though Germany is not openly against genetic testing as a nation, there are many laws which restrict it.

China

Even though the use of genetic testing was quite prevalent in China, the government has recently decided to forbid any use of it. Because of that decision, many U.S and Chinese companies who offered genetic tests have been closed by the government. Currently, genetic tests are used only in specific cases and they have to acquire the permission from the National Health and Planning Commission, the Chinese population authority. They also have to be selected based on the “proper certifications and evaluations”. In China, the most commonly used testing was the prenatal testing. So, China created problems with the people that wanted to undergo the test as they were not allowed to do so. A big impact that also the ban of genetic testing brought was in the economy of the country, since many companies closed which were a big part of the country’s incomes.

TIMELINE OF EVENTS⁴

Date	Description of event
1983	Invention of The PCR (Polymerase Chain Reaction): The polymerase chain reaction is used to amplify DNA and allows researchers to make billions of DNA copies. It was a milestone for genetic testing as it significantly increases the ease and speed of the process.
1987	Discovery of the first Human Genetic Map: The first coherent and accurate map of variations in DNA sequence is created which can be used to identify genes on DNA chromosomes which are responsible for diseases.
1990	Launch of the Human Genome Project: “The Department of Energy and the National Institutes of Health announce a plan for a 15-year project to sequence the human genome. This will eventually result

⁴ "Genetic Timeline ." *National Human Genome Research Institute*. NIH, n.d. Web. Fall 2017.

	in sequencing all 3.2 billion letters of the human genome.” ⁵ This was major in the development of genetic testing since much was essentially discovered about Human DNA.
2003	The Human Genome Project (HGP) was completed and the whole base sequence of the human genome was released. The Human Genome Project has helped many aspects of biology since many important discoveries were made. It also helped medicine to evolve as it allowed for further research and developments.
November 2008	Council of Europe Treaty: Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Genetic Testing: The council of Europe met in Strasbourg in order to discuss the legalisation of genetic testing for health purposes. Important issues such as the quality of genetic services were discussed in this treaty which have immense significance to our issue.

RELEVANT RESOLUTIONS, TREATIES AND EVENTS

Since its innovation, genetic testing has been widely debated about and is a common source of dispute due to possible unethical lines that it crosses. The issue has been debated about in a few UN committees and specialized agencies such as ECOSOC and the World Health Organization. That being said, it is a relatively new topic and there is much yet to be discovered and researched thus resolutions and treaties relevant to the topic are limited.

ECOSOC Resolution on Genetic Privacy and non-discrimination

Although it slightly strays from our issue, it has some relevant clauses on genetic testing such as clause 4. Clause 4 protects the rights of an individual that wants to undergo the test. It firstly states that in order for someone to do such a test they must have given their informed consent. Furthermore, the individual should be fully informed by an expert about the limitations and the consequences of the genetic testing. So, it refers to the humans rights and the specific circumstances that someone is allowed to do a genetic testing.⁶

⁵ "Genetic Timeline, Launch of the Human Genome Project." *National Human Genome Research Institute*. NIH, n.d. Web. Fall 2017.

⁶ "Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes." *Council of Europe*. Council of Europe, 27 Nov. 2008. Web. Winter 2017.

UNESCO

The United Nations Educational, Scientific and Cultural Organization is focused around ethical and moral issues which concern science. It has instruments which have been endorsed by the GA such as Universal Declaration on Bioethics and Human Rights (2005) and the International Declaration on Human Genetic Data (2003). These should be researched and made aware of so as to produce quality resolutions.

Article 4 of the International Declaration on Human Genetic Data (UNESCO)

This article is centralised to the ethical considerations surrounding genetic tests and data due to the impact they may have on family members as well as possible unknown information which may constitute them.

PREVIOUS ATTEMPTS TO SOLVE THE ISSUE

There have been several attempts to solve the issue of genetic testing especially on animals since it is completely unethical. People from the Ethical Treatment of Animals rescued animals that were used in laboratory experiments, in the University of Utah, and they were physically harmed with most of the times being dead at the end of the testing. People that could not take care of their animals any more gave them to the University of Utah with the thought that their pets will have a better home and they will be treated well. Of course they did not know that their pets were used to death for tests. So, the Ethical Treatment of Animals in collaboration with PETA helped as many animals as possible and saved them.

Another really important effort is made by the known cosmetic line, LUSH. Usually, even though not everyone knows it cosmetic lines use animal testing firstly in their ingredients and then in their final products in order to ensure that their products will not trigger any allergies. However, at the same time all those animals are being harmed and used and this is not only unethical but it violates the rights of animals. Such efforts made by famous companies should be continued. Everyone, in order to help to limit the use of animal testing should prefer to use products that do not harm animals.

POSSIBLE SOLUTIONS

Genetic testing is an issue that concerns all, so in order to tackle it some measures should be taken. First of all, all people should be completely informed about genetics in general and specific genetic tests before they undergo the test, this will come

through education and from lectures or a conversation from an expert. The governments should make the use of genetic testing legal only for specific types of genetic tests and under specific circumstances in order to ensure that any person will not be harmed physically or mentally. Animal testing also has to be resolved through means of encouraging alternative means of testing. Finally, such a crucial issue should be discussed more often in committees and it should be proposed regularly for example; to the Humanitarian Committee.

ANNEX

For additional help you should look over the detailed timeline regarding key discoveries in genetics from the following address:

<https://www.genome.gov/pages/education/genetictimeline.pdf>

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