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Illegal Genetics Research in India

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ABSTRACT

Genetics offers medical hope. Genetic research is cutting-edge. It's used to develop cancer drugs. It's in our cells and easily shared. This affects privacy and security. What can be done legally or illegally with genetic data? Article 14 and Article 21 also play a huge role here as genetics research is concerned with privacy and health care rights. Genetic discrimination is based on an individual's health, habits, racial genetic history, or other community-based information derived from the gene. Such discrimination is linked to broader social and racial discriminatory practices. India is yet still to cope up with the future of genetics research, its uses, and testing. There are many advantages as well of genetics research and we come to know how it can help us build a better and healthy future for ourselves.

Keywords: Genetics, Privacy, DNA, Insurance

I. INTRODUCTION

Ever since Watson and Crick deciphered the biological code of life, scientists have been busy finding the mysteries of life.² Gregor Mendel, known as the "father of genetics," proposed the law of heredity in the 1850s, and since then the discipline has advanced significantly. Improved crop productivity and reduced risk of catastrophic losses due to droughts, floods, and pests are just two examples of how advancements in genetic engineering are revolutionizing agriculture. They also are offering new solutions for fighting cancer and many hereditary diseases, improving quality of life and life expectancy³. Genetic technologies are also being employed more frequently in the criminal justice system to clear the innocent and punish the wicked. Since the introduction of life insurance firms barring people from policies based on their genetic propensity to any health issue, the topic of genetic discrimination has risen to the forefront of the techno-social conversation. The term "genetic discrimination" refers to instances in which an individual is treated differently due to the person's knowledge that they have a gene mutation that raises their risk of an inherited condition, regardless of the individual's actual level of risk for the disorder. Whether it's based on skin colour, ancestry, or something else that can be determined by DNA testing, racial discrimination is always wrong. Genomic data can be used

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² (The Ethical Considerations of Genetic Screening, 2022)

³ Playing with genes: The good, the bad and the ugly, UN.ORG

to stigmatize entire groups of people. The usage of DNA technology will help lower the annual average of over 60,000 missing kid reports in India. An Indian Law was proposed on a collection of genetic data to tackle crime. India also aims to set up a DNA regulatory board.⁴ The data being collected here is very sensitive and it requires additional security. In the absence of a statutory framework protecting the right to privacy, this bill will cause irreversible damage to individuals' right to privacy if any information is leaked or hacked. Not only the present life will be in front of everyone but one can even find out about the future with DNA.

Genetic records privacy prevents a third party from exploiting someone's genetic records without authorization. Advances in science and technology make it easy to get DNA samples and extract personal information. This contradicts India's constitutional rights to equality (Article 14) and privacy (Article 21). This discrimination is not only recognized by the state but also by individuals. Modern advances in science are in violation of a person's right to privacy. Every time that we take a sip from a cup, brush our teeth or comb our hair, we leave our DNA samples behind. If all the samples are collected and used against us, the world will be in a danger. Humans will be tracked down even without cell phones. We are approaching a new era of genetic study as more affordable and efficient methods for sequencing complete genomes and archiving family trees in databases become commonplace. It's possible that our enemies will utilize this information against us. Knowing the risks of hereditary prejudice is crucial.

Experts in both forensic law and forensic science agree that there should be guidelines for the ethical acquisition and use of genetic data in criminal proceedings. Individuals' right to anonymity is central to these ethical principles, and those with less anonymity need to be afforded additional safeguards. The idea of consent must be incorporated into these guidelines as well. Officers gathering a DNA sample are required by law to get the subject's permission before doing so. These guidelines will ensure that there is a healthy equilibrium between the two. First, there is the issue of criminal law and procedure; second, there is the issue of genetic privacy. Justice may be served and public interests safeguarded through the use of genetic data in criminal prosecutions. However, it has also made persistent attacks on the right to privacy, bodily integrity, and personal autonomy. U.S. citizens already have protections under the Genetic Information Non-discrimination Act (GINA). The bill was officially passed and signed into law on May 21, 2008. Specifically, GINA prevents people from being denied health insurance or being fired because of their genes. Now more than ever, in an era of widespread genetic testing, protecting "equal treatment under the law" from being used as a tool for

⁴ (India's DNA data law could harm minorities, hurt privacy: Experts, 2022)

discrimination prevention is crucial. The same legislation prohibiting genetic discrimination is needed in India. The crucial research question of this paper is should genetic research be allowed and can the genetics data be stored and used to our advantage?

Review of Literature

1. Playing with genes: The good, the bad, and the ugly, FTQ (May, 2019)

This article gives information about genetic technologies and how it works. It explains right from the history of DNA and how it all started. It is very elaborative and tells us how genetic modifications are used in agriculture and other places too, technically we are surrounded by it. It explains the legal, ethical, and moral boundaries of using genetic technologies and tells how it is still unclear and modern science may possess threats creating opportunities for their misuse and abuse.

2. The Ethical Considerations of Genetic Screening, Shaun Christenson

This research article elaborates on the importance of genetic screening and gives two arguments that go against genetic screening. Some feel that the screening would lead to discrimination against those individuals, which possess "inferior" genes. Second, people fear that genetic screening will lead to reproductive decisions being based on the genetics of their child. The main thing which the researcher gathered from this research paper is that some things are just not meant to be known. Advances in science are sometimes dangerous too.

3. Criminalizing Genetic Discrimination in India, Sangita Sharma and Sayan Chandra(Sept 19, 2020)

The primary focus of this paper is to introduce the act prohibiting genetic discrimination. This is even more important than the use of genetic tools for the identification of criminals because many insurance companies and employers will be able to obtain your genetic information and deny health insurance or employment due to the genetic disposition of an individual. This needs to be prevented. This paper focuses more on the Indian context and is now more relevant because it has allowed even more people to get tested.

4. Ethical and Social Issues in Incorporating Genetic Research into Survey Studies, Sharon J Durfy.

This research focuses on the ethical issues in genetic research and whether they are any different from other forms of medical research being carried out. The U.S Human Genome Project (HGP) officially began in 1990, and since that time rapid developments in gene discovery and technical and molecular capabilities have occurred due to the influx of funding to these areas of research.

5. Social, Legal, and Ethical Implications of Genetic Testing

The researcher has understood the legal issues from this research and why numerous decisions took place in court protecting a person's bodily integrity. In the realm of law, the idea of privacy serves as a catchall for the protection of both individual liberty and private information. The right to privacy provided by the U.S. Constitution and state constitutions protects, in part, the right to make choices regarding one's health care. The researcher has used the rules provided by the U.S constitution to draw an analogy and indicate that such laws and provisions are required in India too.

II. ANALYSIS

Status of Genetic Privacy in India

The Supreme Court of India has made it quite apparent that any form of genetic discrimination, especially on the part of insurance companies, is in direct violation of the principles enshrined in Articles 14 (Right to Equality) and 21 (Right to Health and Healthcare). Discrimination in health insurance against people based on their genetic makeup or genetic origin, in the absence of adequate genetic tests and intelligible differentia, is unconstitutional, the court ruled. People are scared regarding the fact that if the insurance companies which have sensitive data leak it. Discrimination is a very real prospect, now that humans possess the technology to analyze genetic content. insurance companies and employers would like to be able to determine insurance rates and employment statuses based on the genetic composition of people.⁵ The order was later partially halted by the Supreme Court. The time has come for India to enact legislation banning all forms of genetic discrimination. In this era of ubiquitous genetic testing, we must respect the principles of non-discrimination and "equal justice under the law." The line of reasoning that most countries have taken is that right to privacy and health are fundamental rights and holding discrimination of any kind against it by an individual, government, or corporation should be met with legal repercussions and reparations. The case of United India Insurance Co. v. Jay Prakash Tayal demonstrates this through a multifaceted examination of relevant factors. ⁶The infringement of this fundamental right due to discrimination is not only actionable against the state, but also non-state actors. A requirement of parliamentary law to protect an individual's privacy against Non-State Actors has arisen in light of the Puttuswamy case, which rejected the idea of direct horizontal application of privacy rights. As the contents of one's genome are personal, any form of genetic prejudice needs to be addressed under privacy

⁵ (The Ethical Considerations of Genetic Screening, 2022)

⁶ (United India Insurance Co. v. Jay Prakash., [2018])

laws. The Delhi High Court's ruling above has kicked off the process, and it is now up to the legislation to ensure that genetic discrimination is prohibited by law. Biometric information, which only includes an individual's DNA and no other genetic material, is already protected by existing legal frameworks. When defining a person's biometric data, the Rules do not take into account other genetic materials, such as messenger RNA (mRNA) and other RNA particles, which have recently been shown to be sources of information, thanks to the development of complementary DNA libraries and advances in sequencing technology. However, while the IT Rules on Sensitive Personal Information forbid the discriminatory use of genetic information, they do not preclude its collection or distribution. This contrast in approach is highlighted in the dissenting opinion of the Canadian judgment, which suggests that the goal of any rule barring genetic discrimination should be made explicit. Apart from the judgment of *United India Insurance Co. v. Jay Prakash*, No other judgments are available in India. This case explicitly prohibits genetic discrimination in India. To protect people's right to secrecy, human dignity, and bodily autonomy in such a situation, it's crucial to argue for making such behavior a criminal infraction on par with racial and caste-based discrimination.

Genetic testing is extremely sensitive and private and to use it for a public purpose falls within the Right to privacy under Article 21. It can also affect the right to good health facilities because the insurance companies will deny giving insurance to people who already have problems in their genes and they will be discriminated against. Adding on to this, The fear of information being leaked is also a major issue and Indian Laws do not protect such information.

Since there are currently no regulations in place in India about genetic testing, organizations like 23andMe in the United States can sell consumer data to pharmaceutical companies without notifying them or other third parties, potentially leading to discrimination based on genetic profiles. The fact that other countries, such as the United States, have also experienced this problem suggests that it is not too far-fetched to assume that it will become a major problem in India in the years to come. As a result, we need to be proactive and adopt the required legal measures to address this issue before it becomes entrenched in the Indian setting. It doesn't matter how insignificant it may seem, discrimination based on a person's genetic composition can set dangerous precedents that endanger people's safety, privacy, dignity, and health.

III. SUGGESTIONS

Even though genetic research is very dangerous and has privacy concerns, it can be very helpful too. A doctor can prescribe an early treatment that would allow the person to live a longer more productive life. A disorder can be predicted way early and many changes can be made which

can save that person's life too. An individual who learns they carry a cancer-causing gene may choose to make lifestyle changes to suppress the gene's expression. Some diseases cannot be found unless one is born but it is possible through genetic research. If one knows that they can make adjustments in their life right now rather than dealing with it at a stage where it is difficult to cope with it, they will choose to deal with it prior. In the medical field, genetic research can be very helpful. Strict laws regarding this should be made in India following the path of the USA. A DNA regulatory board should be set up in India but even before this, a personal protection bill should be brought up so that the citizens of this country know that they can trust the law and that their DNA can be stored without any breach of privacy. Genetic research can also help an individual can study his ancestors and distant relatives. Nowadays humans are using DTC (direct-to-consumer) tests which are not constantly reliable and this allows a third party to access different private records, which may be harmful. If the genetic facts get stolen or a person receives the unauthorized get right of entry to over it then it is probably to affect the privacy of an individual. If such records are revealed, it can have a poor effect on their lives, consisting of unwelcome responses from employers, insurance providers, the government, and others. Such tests from a third party should be avoided as people make decisions based on those findings.

IV. CONCLUSION

It's remarkable how much information about us can be gleaned from a tiny DNA sample. Genetic information poses a serious privacy risk due to its widespread application in sectors such as medicine, science, and the law. Thanks to advances in genetics, we now have the option of having our DNA analyzed using only a little sample of tissue. Because of this, the situation is now more critical than ever. Any party, including insurance providers, employers, or other interested parties, could potentially abuse this information. Genetic data is distinct from other forms of individual data. Thus, it necessitates a heightened level of focus. It's a part of being human that everyone carries at least one genetic tendency. This means that there can be no bias against someone because of their DNA. The concept of insurance evolved as a result of the collective assumption of various hazards. Nobody might be able to get insurance if businesses started requiring testing for everyone. Therefore, the only real option is universal health care. New regulations for direct-to-consumer research are being created to protect people's right to privacy in regards to their genetic information. The user, however, would be wise to study the company's privacy policy before signing up. And if the company does not adhere to its policies, we will take legal action against it in accordance with the applicable laws. Smaller companies may not have a thorough privacy policy, so those who opt for direct-to-consumer testing should

stick with well-known brands. In India, there's no clear regulation governing genetic testing laboratories. They should meet the set of requirements as a scientific laboratory. As a result, it's far essential that the authorities take a move to control 'Genetic Testing' within the country. Genetic research is a concept for the future and it may be an accepted practice right now but, in the future, it will be. Knowledge about genetics will be a great tool for the future and will lead to the elimination of numerous diseases. Individuals will always be uneasy about change because it forces them to reassess who they are and their place in the world, but eventually most people come to terms with the new realities they face. The same thing will most likely happen with genetic research. Despite initial apprehension, the genetic screening will eventually be widely accepted and promoted as a social good, despite its unintended consequences. However, some safeguards must be established for the public. Many people worry that health insurers and potential employers would be able to access their genetic data and use it to decide whether or not to offer them coverage or a job based on their traits. This is something that must be avoided at all costs. Under proper laws and regulations, science can help us cure many diseases and this can even help the forensics field.

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