Chapter 5

Human Genome: Legal Issues

“One by one the eggs were transferred from their test-tubes to the larger containers; deftly the peritoneal lining was slit, the morale dropped into place, the saline solution poured in ... and already the bottle had passed, and it was the turn of the labellers. Heredity, date of fertilization, membership of Bokanovsky group-details were transferred from test-tube to bottle. No longer anonymous, but named, identified, the procession marched slowly on; on through an opening in the wall, slowly on into the Social Predestination Room.”

-Aldus Huxley

Introduction

Aldus Huxley's Brave New World of 1946 paints a dark picture of a future society that defies scientific progress. In this novel, Huxley expresses his concerns about a future society which is over-automated, and people are produced in factories according to the type of work they will be trained to do. The situation is shown to be extreme when factory-produced people show their disgust towards those who were born in a non-mechanical way, with words such as "father" and "mother" being considered swearwords. In addition, Huxley expresses concern in "Brave New World" over the use of drugs as a method of escape from reality.2 Sadly, Huxley's Utopia has become more than a mere story of science fiction. From the eugenics movement o Hitler's obsession with a "master race," to the more recent interest in race-based theories of intelligence, and completion of Human Genome Project3, genetic determinism has waxed and waned in popularity

1 Aldus Huxley, Brave New World: A Defence of Paradise-Engineering, at 123, (1946).
during the past century. The completion of HGP is expected to give a boost to the genetic determinism again, which will have detrimental effect on various aspect of life.\textsuperscript{4}

With the completion of the Human Genome Project, an international, collaborative scientific endeavour to determine the locations and functions of human genes that code for inherited genetic traits, we have overcome the psychological barrier of cracking nature’s code and now face the more daunting responsibility of having power over the genetic destiny of our own species. At the same time it has revived the old concerns raised by Huxley about the uses of scientific knowledge and the limitations of scientific inquiry. Since science, with its new complexity and extensive ramifications, always presents a dark side or a bright side according to how it is used. HGP brings with it a host of legal issues for medical and health practitioners’ lawyers and sociologists concerning the priorities of medical science and the character and quality of human life.\textsuperscript{5} These include both benign use and intentional misuse of genetic information by employers and insurers for commercial interests, genetic privacy and possible breaches of discrimination. This chapter analyses the major legal issues raised by the Human Genome Project.

**Fairness and Equity in Genetic Services**

Technologies are not value-neutral; they usually embody the perspectives, purposes, and political objectives of powerful social and political groups dominating at that time.\textsuperscript{6} But western ideology tends to believe that science and technology are value-neutral, and the only concern regarding them is raised by its abuses. But, since the technologies are the result of

\textsuperscript{4} Ibid.
\textsuperscript{6} By Philip Bereano, Does Genetic Research Threaten Our Civil Liberties? Available at <http://www.uwtc.washington.edu/people/faculty/pbereano.php> (last visited on 21-08-2007).
human interventions into the otherwise natural progression of activities and not acts of God or of nature, they are themselves actually imbued with human intentions and purposes. Current technologies do not equally benefit all segments of society and indeed are not even intended to do so,7 Human Genome Project with all the promises it holds for the humanity is no exception.

One of the major expectations of the Human Genome Project was that it will be possible for scientists to identify the genetic bases for human disease and even traits and raised hope for the early detection and treatment of serious illnesses, through genetic testing and genetic interventions. The availability of genetic testing in society brings along with it issues of fairness and accessibility of these services.8 Equality of opportunity and access is a fundamental social value which is especially damaged where a society is divided.9 The genetic testing existing today can not be accessible to common people and even various countries in the near future due to its enormous costs. The genomics era may create a divide known as the “genomic-divide.” between north and south. In this scenario various questions arises in relation to access of genetic services which consists of, who should be able to make use of genetic tests and interventions if they are developed? And who should bear the cost of the tests and interventions? A standard and most prevalent view is that the state has only an obligation to improve the health and prevent major health threat and has no obligation to provide techniques for improving intelligence or athleticism or changing behaviours, these interventions may not be provided as part of a public healthcare system.10 Public provision of new tests and interventions, especially when accompanied by further

7 Ibid.
10 Ibid.
efforts to prevent the formation of an underclass, would, of course, require considerable resources. Nonetheless, it may also be argued, that within a free society and a free market, these techniques should be available for purchase. But then the anxiety, however is that if such tests and interventions were available for private purchase, the access to these tests will be limited to only more affluent members of society leading to even greater inequalities and increase social and economic polarization. From an egalitarian perspective, if these resources are not available to general public, then the tests and interventions should not be introduced at all. However, libertarians argue that there is no moral basis for this they believe that if a trait like athleticism is desirable and there is an intervention that will increase the likelihood of it occurring, the correct response is to ensure that it is available as widely as possible. While this may entail that, for at least a limited period of time, there will be some who do not have access; the overall goal should be to raise everyone to the highest level. It is difficult at this time to adjudicate in the abstract between these two viewpoints. It is only once some effective intervention is under consideration that the costs and benefits of full public availability versus limited private availability for a privileged few can be assessed seriously.  

Implications for Human Right and Dignity

Human dignity, as a concept, is open to varied interpretations. Sometimes, dignity is thought of as a claim for a basic degree of respect as individual human beings, and is accordingly a driving or defining force in shaping well-being. It is also understood as a concept which protects self-respect, self-consciousness and self-identity. Dignity as a concept is always at the crux of defining and advancing human well-being, which, in turn, requires the promulgation of rights. This is the basic reason that dignity is

11 Ibid.
often seen as the primary source of human rights. No wonder it is viewed as but a species of it or a framework for defining the subject of human rights. In other contexts human dignity defines objects to be protected; it has been asserted that "any violation of human rights implicitly violates human dignity."\textsuperscript{13} The completion of HGP brings a host of human right issues like possible breaches of genetic privacy, discrimination, reproductive questions, etc undermining the underlying human dignity. The problem with these issues is that they try to breakdown human beings into a conglomeration of genes ignoring the underlying dignity of human beings.

The Human Genome Project brings forth fearful condemnation and enthusiastic speculation. In the positive side, prospects and possibilities of genetic testing and availability of human genetic engineering remain tantalizing, even if they are still largely the stuff of science fiction, in the flip side eugenic past brings fears of revisiting discrimination and forcible sterilization and loss of privacy. However, the near-term legal challenges of the human genome project lie neither in private forays in human genetic improvement nor in some state-mandated program of eugenics. They lie in the grit of what the project will produce in abundance: genetic information. They centre on the control, and diffusion of information.\textsuperscript{14} As one scholar has noted, "the revolution in molecular biology that is producing a human DNA map and sequence of genetic material is fundamentally a scientific information revolution in the arena of personal identity or genetic privacy.\textsuperscript{15}

\textsuperscript{13} Ibid.
\textsuperscript{14} Mikulas Teich, \textit{Nature and Society in Historical Context, Mapping the Human Genome}, at 325, (1997).
\textsuperscript{15}http://international.westlaw.com/result/documenttext.aspx?rp=%2FWelcome%2FWorldJournals%2Fdefault.wl&effdate=1%2F1%2F0001+12%3A00%3A00+AM&rlt=CLID_QRYRLT9561147&crt=DC&vce=2.0&fclr=0&rlti=1&ss=CNT&fn=_top&rs=WLIN7.06&eq=Welcome%2FWorldJournals&bl LINKEDCITELIST=FALSE&db=WORLD-JLR%2cLAWREV-PRO%2cCLMLR%2cHVLRL%2cYLJ%2cMELULR%2cCUSLJ%2cUTORLJ%2cHKLJ%2cUKHR-LJI&cnt=D
Genetic Privacy: Balancing Conflicting Interests

The race to find genetic information and apply genetic technology through HGP has unleashed a fierce battle in public health law regarding individual rights to privacy. Various questions arise in regard to it, is there a right to refuse treatment, or testing, as a part of genetic privacy regarding medical decisions? Is there a right to keep the "magic gene" that will cure someone else's ailment for oneself, one's family or the highest bidder? Will people who are tested and refuse treatment for themselves or their children be held liable in tort for the subsequent consequences of their refusal? Even if the refusal is part of their religious beliefs. The questions are unlimited.

The words "private" and "privacy" come from the Latin *privates*, meaning "withdrawn from public life, deprived of office, peculiar to oneself", and the generally negative sense is continued into the early understanding of the word "private" whose first recorded appearance goes back to 1450. By the end of the 19th century, "privacy" had become related to legal and political rights, associated with modernity and advanced civilization, and attributed relatively or very high value. Privacy in modern sense is the right to control your own body, as in the right to have an abortion. Privacy is the right to control your own identity, as in the right to be known by a name of your choice and not by a number, Privacy is the right to control information about yourself, as in the right to prevent disclosure of private facts or the right to know which information is kept on you and how.

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it is used.19 The notion of a right to be left alone is deeply embedded in popular and political culture. There is no information more personal and private, than an individual’s genetic information. Which defines who we are as individuals both physically and mentally?20

Objectively, a society should respect individual privacy rights because a violation of privacy rights may cause harm to the person.21 The legal systems have historically looked at privacy in four ways: private information, private relationships, private decisions, and private places.22 Further the genetic information which will become accessible upon the completion of the HGP will cover all these traditional areas of privacy. Genetic information is inherently private since it is distinctly individual and disclosure may harm a person in all the above areas. These extremely sensitive particulars are frequently revealed in confidence to physicians or health care providers or to close friends and family members. The outcome of genetic testing are normally disclosed in private places, such as a laboratory, physician’s office. Finally these decisions lead to personal and confidential decisions on the part of the individual.23

Genetic technology give rise to a unique form of violation of privacy, defined as the inappropriate or involuntary disclosure of the information coded in an individual’s genome. As the accessibility and affordability of genetic tests increases, as the figure of social institutions depending on genetic examination increases, as the quantity of genetic information stored in computer databases increases and as more individuals find about their unique genetic profile through genetic tests, the threat to genetic privacy will became grave. Additionally genetic data poses

20 Supra note 16, See llise at 19.
22 Supra note 15, Westlaw.
23 Ibid.
significant privacy issues because it can serve as an identifier and can also convey sensitive personal information about the individual and his or her family. At the same time, smaller and smaller tissue samples are required for testing. In some cases tests can be performed with as little as the root of a single hair or saliva left on a glass from which an individual drank. The ability to derive more information from less and less material creates increasing challenges to privacy because it permits analysis of tiny traces that all humans leave behind unconsciously, such as cells left on computer keys or saliva left on a drinking glass.

The ability of genetic information to provide both identification and sensitive information related to health and other predisposition has led to a lively debate about appropriate privacy protections. Proponents of “genetic exceptionalism” claim that genetic information deserves explicit and stricter protection under the law. They base their argument on the special qualities of genetic material.24

- Ubiquity, i.e., the ability to derive genetic profiles from small physical traces and the longevity of material from which genetic profiles can be derived
- Ability to reveal information not just about the individual but also about the individual’s family
- Predictive nature that can point to someone’s future health and traits25

Opponents of “genetic exceptionalism” take the position that genetic information is much like other personal information and should be protected in the same way. They point to the fact that “genetic information” is difficult to define because it includes information like family medical history, which has been collected and used by doctors long before the

sequencing of the genome. Therefore, they emphasize the importance of context in which genetic information is obtained and used. For example, if genetic information is obtained as part of health care research or treatment, it should be subject to the same privacy and anti-discrimination protections as all other health information.²⁶

An absence of appropriate protection would allow outcomes that challenge existing ideas of privacy in various areas. Without privacy protection, an individual’s right to know, their right not to know, and their right to make autonomous decisions about the disclosure of highly sensitive and consequential information is at risk. It may happen in various fields like medical and research settings.

In medical settings, in the case of consensual genetic testing privacy issues are less since informed consent can be obtained from the patient. This informed consent can address all issues of disclosure whether to family members or social agents. The only privacy problem in this area may be regarding the need to maintain secrecy, regarding storage and the use of genetic material taken from him. But this problem can be easily solved through incorporating these fears and regulations into the existing doctrine of informed consent. Major threats to privacy arise in case of mandatory genetic testing and screening since informed consent can not be part of this procedure. The state has certain compelling interest in requiring mandatory genetic testing to maintaining public health. The question which will be hotly debated in the coming years will be can the state permit mandatory genetic testing specially when we have not developed therapeutic cure for these diseases and whether such initiative threaten the individuals right “not to know” about his genetic make up or infirmities. The questions also arise regarding the use for which this information’s will be put like disclosure to family members and who can have access to this information. The question also arises whether

²⁶ Ibid.
individual has a right to get back the genetic material supplied by him in the test. This concern is also quite understandable considering the fact that genetic materials are the property of an individual and the possible misuse and storage of genetic data.

With regard to research settings the issues of privacy are more. Every year in the world over, tens of thousands of people participate as subjects in genetics research. Consensual donation of genetic matter for the purposes of research either for the acquisition of pure knowledge or commercial application raises numerous privacy issues. While individuals who participate in research can derive health benefits and new knowledge from such involvement, they also put themselves at risk of third-party access to sensitive health information. In this arena, privacy concerns focus on standards of informed consent, the physical security and anonymity of information, standards of non-disclosure, and the maintenance and use of stored tissue samples.27 From the viewpoint of personal privacy, it would be desirable for genetic samples used in research to be identified in a way that does not involve the name of the donor—for instance, by an alphanumeric designation—and which would prevent the research team from immediate knowledge of the identity of the person whose genetic material is the subject of research. But this system may not be preferred due to a number of reasons. It happens that researchers may need additional data from the donor for completing and proceeding with the research. Even from the point of view of donor he may prefer to know the result of the genetic testing.28

The question of the status of genetic material taken from the individual also raises some privacy concerns whether in terms of medical settings or clinical settings. Persons unquestionably have property rights in their own DNA, and should enjoy privacy rights over it. But those rights may be

28 Ibid.
subject to greater societal and governmental interests. If we take the judicial response as guide they are contradictory. For instance in USA the Supreme Court of Indiana has ruled that a rape suspect "had a legitimate expectation of privacy in his body and blood samples" when they were taken in a rape prosecution for which he was acquitted on the basis of a consent defence. 29 But in some other case, the court held that once his DNA has been collected under a particular statute "the profile becomes the property of the crime lab." And the defendant had no expectation of privacy in the sample in the database. But the most important controversial aspect of genetic privacy revolves around whether the genetic information is individual or familial.

Genetic Information: Individual or Familial

Another controversy point in the way of providing privacy protections to genetic information stems from the fact that genetic information differs from other forms of medical information because it pertains to a range of people and not solely to one individual. While one might choose to locate control of a genetic sample with the person from whom it has been taken, one cannot ignore the fact that genetic information derived from the sample also reveals information about the relatives of the sample source.30 Question arises whether doctor needs to disclose this information? Are the doctors bound by the confidence and trust of their patients to keep the data confidential?

In the controversy regarding whether genetic information is individual or familial two separate view points have emerged. It treats genetic information akin to property rights. First view treats: Genetic information innately belongs to any one individual because it is personal and medical

in nature. Second view supports the point that genetic information is the common inheritance of mankind. In their support they point out that genetic inheritance is shared within families, whole races or ethnic groups, as such genetic information is owned by the society as a whole. If we accept the second view this has implications for the testing and use of seemingly personal genetic information, and for the determination of ownership of "discoveries" and patentable inventions based on manipulation of genetic material. The inherent conflict in these two positions clearly explains the problem facing the legal system while enacting laws for privacy.\

Thirdly, regarding qualifications for social benefits, the availability of genetic information may restructure qualification systems, who will have access to information and on what basis will individuals be required to grant releases of this information? Lastly, in the realm of social control and public policy, with the advent of genetic technology, the standards for government programs and operations will change since such information may aid with disease control and criminal justice programs.

**Genetic Privacy Violations: Relevant Social Contexts**

**Public Health and Health Care.**

To effectively deliver health services, doctors and other providers depend on access to medical records. Patient information regarding health conditions, drug sensitivities, past medical procedures, and other matters must be carefully maintained and exchanged when necessary to ensure appropriate care. Likewise, in the public health setting, specialists depend on aggregated personal medical data to monitor and analyze the health of populations. The computerization of health files and the creation of medical databases have greatly enhanced these capacities. However, by

31 Supra note 16, See Ilise at 14.
32 Supra note 21, See Jennifer, at 210.
increasing the circulation of genetic and other health information, these technologies also increase the potential for unwarranted invasions of privacy.\textsuperscript{33}

**Law Enforcement:** DNA evidence plays a growing and beneficial role in violent crime investigations. Forensic scientists analyze biological evidence collected from crime scenes to include or exclude individuals suspected of involvement in a criminal act. The success of this analysis has driven the collection of DNA samples from increasing numbers of violent and non-violent criminals, suspects and whole communities, as well as the creation of large-scale forensic DNA databases. As DNA collection and data banking expand, many are concerned by the intrusions into privacy involved in these law enforcement practices.\textsuperscript{34}

**Work Place:** Employers have a long history of interest in their employees' health status, driven by both legitimate and illegitimate motivations. Surveys indicate that 77\% percent of medium-to large firms conduct medical examinations on either employees or new hires. Employers may screen employees for the purpose of monitoring job-related injuries, gauging physical and mental fitness characteristics related to job performance, or protecting other employees from communicable diseases. While genetic information can be put to beneficial use in safeguarding the health and safety of the workplace, it can also be used to stigmatize and discriminate against current and prospective employees.\textsuperscript{35} The same principles and issues are applicable in the field of insurance also

In all contexts, privacy protections require striking a balance between individual rights and other competing values such as public health and safety, law enforcement, and national security.

\textsuperscript{33} Id., at 212
\textsuperscript{35} Ibid.
Genetic Privacy and National Genetic Data

The threat to privacy gets more complicated in the case of national genetic databases established for genetic research. Several countries are developing such large databases, Iceland being an example. In 1998, the government of Iceland passed the Act on Health Sector Database (HSD), which authorized the creation of a database that includes genetic information about the country's entire population of 285,000 people. The database is being used to combine genetic, disease and genealogical data to identify genes linked to specific diseases, the proteins encoded by these genes, and drugs that can be used to treat the diseases.36

At the start of the project, consent for the participation in the database was assumed to be implicit after the concern raised by various societies regarding possible violation of privacy individuals were given the right to have their data excluded from the database by notifying their physicians. Several other national databases and large research projects are being carried out.37

Genetic research databases raise the following privacy concerns:

- Whether or not individuals choose to participate in genetic research, they may be affected by the results of such research. For example, if research identifies an association between an illness and a particular ethnic group, all individuals within that group may be presumed to be affected, whether or not each of them had been tested. An individual's privacy will, in effect, be violated simply

36 Iceland Human Genes Research Act Passed 13 December 2000 According to the Human Genes Research Act, the biological material of gene donors in Estonia will be maintained anonymously, and by the issuance of DNA to the researchers the confidentiality and protection of the personal data of the gene donors is kept. For the research taking place within the framework of these projects, clearance has been given by the Ethics Commission of the Estonian Genome Foundation and by the University of Tartu Human Research Ethics Committee.
37 Ibid.
through the existence of the link between the individual and the group.

- Benefiting from results of research: One of the inducements for participation in genetic research is the promise that the individual will benefit from therapeutics derived from the research. This means that researchers must find a way of communicating research results to individuals who might benefit from them or to doctors who treat them. In some cases this may compromise an individual’s desire not to know about a particular genetic predisposition.\(^{38}\)

Without greater protections for genetic privacy, and amidst the growing surveillance of our genes and genomes, these fears are likely to continue, inhibiting the full realization of promising scientific advances. Despite over a decade of legislative activity, the world continues to lack a broad minimum standard of protection for genetic privacy. As a result, individuals must rely on a mixture of statutes and guidelines that regulate access to genetic and other health information by specific entities—such as hospitals, employers, and forensic laboratories — and for specific purposes — such as insurance, underwriting, criminal identification, and newborn disease diagnosis. Most observers agree that these protections are both woefully limited and under-enforced. Remedying this problem will require political will.

Whilst there is a general consensus on the need to protect genetic privacy, designing effective and equitable policies for the protection of genetic privacy is exceptionally difficult to achieve because there are many situations where one agent’s right to genetic privacy conflicts with another agent’s equal and opposite right to genetic information. Indeed there are many situations in which the right to genetic privacy is not absolute. In the context of insurance, fund managers have a responsibility

\(^{38}\) Ibid.
to other policy-holders and thus, genetic privacy may be violated to ensure the viability of an insurance fund and to maintain actuarial fairness. In the context of education, a child’s right to privacy may be violated by parents if a learning problem is suspected and a remedial program is available to assist the child.

The genetic privacy of immigrants may be violated to protect public health, maintain the fiscal integrity of the health system and to avoid fraudulent claims of consanguinity and finally, in forensic investigations, the right of victims to justice and retribution and the collective right of society to safety and security trumps the privacy rights of suspects and criminals. Whilst acknowledging that genetic privacy is not an absolute and inalienable right, protecting genetic privacy is an important goal for genetic policy. It is important for upholding the intrinsic value of preserving the integrity, dignity and autonomy of individuals and because it provides one of the most effective mechanisms for protecting against genetic discrimination. 39

One of the prominent authorities of bio-ethics law George Annas believes that countries should come up with a privacy protection such legislation which should guarantee the individual’s right to: determine who may collect and analyze DNA; determine the purposes for which a DNA sample can be analyzed; know what information can reasonably be expected to be derived from the genetic analysis; order the destruction of DNA samples; delegate authority to another individual to order the destruction of the DNA sample after death; refuse to permit the use of the DNA sample for research or commercial activities; and inspect and obtain copies of records containing information derived from genetic analysis of the DNA sample. 40

Genetic Discrimination

Mark Rothstein see it as "differential treatment based on genetic status." 41 Larry Gustine defines the term as "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests." 42 The United States Equal Opportunity Commission describes genetic discrimination as "using genetic information to judge an individual with predisposition to a certain disease or condition based on the possibility that he or she might one day develop that disease or condition." 43 Without arguing which of the above definitions is the best, it is important to note that they all emphasize differentiation in granting a benefit based on genetic makeup.

The completion of HGP has given a boost to the possible genetic discrimination. Individuals identified at risk of victims of genetic discrimination are:

1. those . . . who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease,
2. individuals who are heterozygote's (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic,
3. individuals who have one or more genetic polymorphisms that are not known to cause any medical condition, and
4. Immediate relatives of individuals with known or presumed genetic conditions.44

44 Supra note 3 See George at 143.
There are, indeed, extensively changeable reasons for wanting or rejecting to have such influential pinpointing tests performed. However, following the maxim, "if you build it, they will come," social institutions like insurance companies, employers, already are budding a market for genetic testing; this requirement and knowledge is likely to assist discrimination against those who tests for genetic defects.

**Possible Areas of Genetic Discrimination: An Overview**

**Genetic Discrimination in Employment**

Imagine you are a twenty-six year old female who always wanted to become a teacher. You have graduated from the University, passed all of the professional tests, and are now on the verge of getting a permanent position to teach in University. Just one medical test and your dreams will be fulfilled. Part of the medical test is a questionnaire that seeks information about family health history. You mention that your father has Huntington's disease. You clear the medical, but are still denied a teaching position by the University. Because you have a high chance of carrying the Huntington's gene and therefore have a high probability of developing an untreatable disease that may compel you to ask for premature retirement.

While this sounds like a fictional story from George Orwell or Aldus Huxley, this was the reality faced by a young woman in Germany, and it could happen in any country where medicine and research has advanced enough to enable testing for inherited diseases. Other instances of genetic discrimination by employers have been reported by researchers collecting case studies of genetic discrimination. In one instance, a 24-year-old social worker claimed that she was discharged shortly after her employer

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45 George Orwell is one of the most admired English-language essayists of the twentieth century, and most famous for two novels critical of totalitarianism in general (Nineteen Eighty-Four), and Stalinism in particular (Animal Farm).

46 Supra note 1, See Brave new World at 125.
learned that one of her family members had Huntington's disease. Although the employer alleged that she was discharged for poor performance, she had been given three promotions and outstanding performance reviews in the eight months preceding her discharge, and no examples of poor performance were given by the employer.\(^47\)

In the workplace context, genetic testing can be implemented in two basic forms: screening and monitoring.\(^48\) Genetic screening involves predictive genetic examinations or the examination of an individual's genetic code in order to determine if that individual may be prone to disease or even to certain behaviours such as laziness, violence, depression, alcoholism, and so on. Sometimes misunderstood, however, is that most of human behaviour and disease are not the result of a single mutation or gene, but instead "the culmination of lifelong interactions between our genome and the environment. Unlike genetic screening, genetic monitoring is potentially useful to the person monitored. It involves testing over time to assess if an individual's genetic structure has been altered or damaged due to exposure to certain risks.\(^49\) In the employment context this might involve monitoring employees to determine if their exposure to a hazardous environment (due to chemical or other toxin exposure) is adversely affecting their health, and whether a change of position should be made as a result. This is a legitimate use of genetic testing because the objective of monitoring is the prevention however, there is still a danger to employees that without appropriate legal safeguards employers will use these and genetic screening tests to discriminate against employees.\(^50\)

\(^{49}\) Id., at 554.
\(^{50}\) Supra note 47, See Camille, at 77.
Genetic testing in the form of screening and monitoring is generally used by employers to achieve two different aims. First, testing prospective or incumbent employees for disease genes may be used to reduce the financial costs of absenteeism and lost productivity and the administrative cost of recruiting and training temporary or permanent replacement staff. A survey carried out by the Institute of Directors in the UK in August 2000 recorded that 2 out of 353 directors reported that their companies routinely used genetic tests. A further 4 directors stated that genetic tests were used by their companies, but only if they were concerned about specific employees. The particular types of genetic tests used were not recorded.

To the extent that genetic screening for susceptibility to occupationally-related diseases can actually determine the likelihood of an individual contracting an occupational disease, employers can take steps to avoid exposing susceptible employees to hazardous substances. Second, screening employees for genes that confer a hyper susceptibility or hypersensitivity to workplace allergens, toxins, mutagens or teratogens may be used to promote occupational health and safety and to reduce the volume and cost of compensation claims for workplace acquired injury or illness. For instance Sickle-cell anaemia is an incurable and debilitating disease, prevalent in African-Americans. In an age of ever-increasing health care costs and fiscal concerns governing medicine, employers that provide comprehensive health care coverage to their employees may be tempted to reduce costs for everyone by only hiring people without potential or obvious genetic diseases causing genetic discrimination.

Additionally, genetic monitoring, with the capability of detecting genetic injury in employees before disease has manifested itself, allows the employer to implement measures to avoid future or further harm.

Employers can use information disclosed by genetic testing in a number of ways to avoid or prevent genetic harm or occupational illness. Employers who learn that particular individuals are susceptible to sustaining injury from workplace chemicals or that particular employees have sustained genetic harm may inform those employees of the dangers of workplace exposures so the employees may make intelligent choices about their continued employment in positions involving such exposure. Employers can also use information obtained from genetic monitoring to assess the dangers posed by workplace substances; employers who learn that those substances have caused genetic harm to exposed employees may decide to reduce the amount of exposure through the use of protective equipment or engineering controls or by the removal of the offending substance from the workplace.55

Thomas H. Murray thinks that "genetic testing in the workplace was a putative public health measure in its old form and now is used as a means of saving money or promoting health." He opines that access to genetic testing involves considerations of justice since genetic testing competes with other scarce resources and it may emphasize racial and ethnic difference.56

The major problem of having or conducting genetic testing in the field of employment is that like practically all service tests, genetic testing has some scope of slip-up. It may be possible that in future more accurate genetic testings are developed till then those tests are likely to result in the

55 Ibid.
misidentification. 57 If employers rely on the results of genetic testing to exclude individuals from particular jobs, a number of individuals will be unnecessarily excluded from employment. 58

Moreover, even if genetic test results are accurate, most of those tests cannot calculate with any degree of firmness which genetically disposed employees will in fact contract disease. While genetic tests will indubitably turn into advanced and more prognostic in the future, existing tests by and large supply only a warning that a few individuals may be more inclined to contract disease than other individuals. Many individuals disqualified by the results of genetic testing may by no means develop the disease for which they were barred. As the saying goes one medical professional has indicated, "If we know enough about a person's genetic profile, we could exclude him or her from almost any job."59

In addition to the possible economic and social consequences of exclusion from employment based on genetic testing, these individuals will also undergo the individual humiliation of being barred from employment opportunities merely because of misfortune of birth. It is against all ethical and moral principles that individual be made to go through these consequences over a matter on which persons have no power or control since they did not choose their genes.

It is a commonsense fact that employees who had submitted to genetic testing may suffer emotional hurt from the test results if their results

57 Studies cast doubt on the accuracy of genetic tests as used. A team of researchers from Johns Hopkins University in Baltimore reported that in their study of the clinical use of a commercial test to identify a gene that causes colon cancer, the physicians had misinterpreted the test results in 31.6 percent of the 177 cases. In addition, in only 16.9 percent of the cases had the test subjects given informed consent for tests and in only 18.6 percent of the cases had the test subjects received pre-test genetic counselling. See Clinical Use of Tests Reveals Pitfalls, 6 Employment Testing Law & Policy Reporter 65-66 Apr., (1997).
58 Ibid.
indicate any genetic predisposition to diseases. It is quite possible that even when the tests result shows no genetic infirmity people may get seriously troubled by genetic testing. The distress associated with learning such information, traumatic in any situation, should not be forced upon unwilling employees in the context of employment.60

Such worries have already deterred many people from having beneficial predictive tests, says Barbara Fuller, a senior policy adviser at the National Human Genome Research Institute (NHGRI). For example, one third of women contacted for possible inclusion in a recent breast cancer study refused to participate because they feared losing their insurance or jobs if a genetic defect was discovered. A 1998 study by the National Centre for Genome Resources found that 63 percent of people would not take genetic tests if employers could access the results and that 85 percent believe employers should be barred from accessing genetic information.61

**Genetic Discrimination in Insurance**

A woman took a genetic test for breast cancer based on numerous cases among her family members and learned that she carried the gene. She decided to have a prophylactic double mastectomy and petitioned her insurer to cover the procedure without sharing the genetic information. When her insurance company denied her request, she revealed to them that she had the breast cancer gene. Upon learning this information, the insurer not only denied her request for coverage, but cancelled her policy as well.62 If that could happen in the United States where there is a claim of respect for human rights and long history of anti-discrimination laws and policy, the dangers are that it could routinely happen in world with

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impunity. This is more so the case in this era of globalization where multinational corporations continue to expand and exert their influence on developing countries in the guise of foreign investment.

The insurance industry’s attraction to genetic science raises suspicion among the general public and various scholars around the globe who point to the dangers of possible discriminatory practices resulting from genetic testing and/or the use of genetic information. Even though systematic testing does not currently seem to take place and the use of genetic information by insurance companies and other institutions is quite limited as expressed by some scholars. 63 Thus, "in the future, more and more reliable risk information will become available on a variety of diseases. Increased accuracy of genetic risk calculations combined with cheaper and faster genetic detection of mutations will constitute a significant incentive to conduct genetic testing outside the medical context." 64

Many insurance providers, particularly those that rely on individual underwriting, select and classify individuals in terms of risk to determine insurance eligibility and premiums. Personal health information, including records of medical diagnoses, tests and operations, drug prescriptions and family health histories are routinely gathered by health, life, and disability and long-term care insurers. The increasing exchange of health information, through such avenues as the Medical Information Bureau, may improve the quality of insurance underwriting but also places many at risk of losing insurance coverage and having sensitive records in the public domain. 65

64 Ibid.
From the insurance point of view on the possible use of genetic testing and information as part of health information, the argument hinges on underwriting, on the economic side the argument is that if genetic testing is not allowed in insurance the proportion of high risk individuals will thus systematically increase; insurance will enter a spiral of price increases and eventually, the industry will collapse." 66 On the moral angle, the ethical concept of equity or fairness is invoked to the effect that insurers have to distinguish people on the basis of individual risk for reasons of fairness to policyholders. For private insurance assessors, the major benefit of using genetic testing is the ability to protect the viability of the insurance fund.67 This may be achieved by excluding high risk individuals from the fund, thus avoiding excessive claims on the fund, or by adjusting individual premiums to reflect individual risk, thus maintaining the principle of actuarial fairness that states that low risk people pay less and high risk people pay more.68

The prospect of refusing to provide insurance to individuals because of a genetic trait is inequitable and contrary to public policy.69 First, carriers of defective genes may never develop symptoms that affect their ability to function. In effect people will be denied insurance on the basis of a mere fact that they may develop a particular disease in the future. More

69 <http://international.westlaw.com/result/documenttext.aspx?p=%2fWelcome%2fWorldJournals%2fdefault.w1&efftdate=1%2f21%2f20001+12%3a00%3a00+AM&rt=CLID_0_QRYRLT9561147&cxt=DC&v=2.0&fc=1&it=1&ss=CLID&fn=top&rs=WLIN7.06&eq=WeltJournals&blinkedcitelist=False&db=WORLD-JLR%2cLAWREV-PRO%2cCLMLR%2cHLR%2cYLYJ%2cMELULR%2cCUSLJ%2cUKHLJ%2cUKHR-LJ&cnt=19&scxt=WL&cld=1&docsample=False&67db=CLID_DB3561147&mt=WorldJournals&service=Search&query=%22HUMAN+GENOME+GENETIC+PRIVACY%22&method=W%2fFN%2fF24%2fFN%2fF24>
important, however, such disparate treatment and resulting risk minimization vitiates the purpose of traditional private insurance as a risk-spreading mechanism.

In insurance the use or misuse of genetic information will adversely impacts on a person's ability to access healthcare which has a direct effect on the person's right to human dignity and life. 70 The foundation of human rights is anchored in the age-long and universal notion of the intrinsic worth of human beings. The right to access to health has been acknowledged as a basic right in various human right conventions. In Article 12 of the International Covenant on Economic, Social and Cultural Rights, state parties recognize the right of every one to the enjoyment of the highest attainable standard of physical and mental health. 71 Various other international and regional treaties include similar provisions. 72 In other words, people's dignity is at stake when they do not have access to healthcare, and insurance roadblocks based on genetic considerations may just result in debased human beings.

Besides this the use of genetic information will gradually lead to genetic discrimination. People will be denied insurance cover on the basis of their genetic makeup on which they do not have nay control. It is to be noted

70 For instance World Health Organization ("WHO") Const. Preamble ("Health is a state of complete, physical, mental and social well-being and not merely the absence of disease and infirmity."). This remarkably broad definition bespeaks the basic human need for health. For this reason, it has been the undisputed benchmark of many practical standards as well as a host of national health laws. This definition is so encompassing, however, that it has been criticized as making virtually any human endeavour a matter of health jurisdiction. It encompasses vaccines and preventive strategies as well as medical programs.


that insurers has managed to do just fine for many years without having
access to genetic information. In case you have not noticed, the insurance
industry is highly profitable, and has been for decades. On the basis of
these there is no justification existing for the use of genetic information in
Insurance

Genetic Discrimination in Education

The actual and potential use of genetic testing in a school environment
raises a different set of problems to those encountered in employment and
insurance because the testing is administered on minors and because
unlike employment and insurance, school attendance is compulsory.  
Genetic tests may be used in education for four reasons. First, they may
be used to diagnose learning disorders such as dyslexia or fragile X
syndrome and thus to provide a child susceptible to these conditions with
early remedial teaching. Second, the tests could diagnose behavioural or
disciplinary problems such as Attention Deficit Hyperactivity Disorder
(ADHD) and thus to commence a behavioural management program or
course of drug therapy to assist an affected child’s learning potential.
Third, the tests may assist public health researchers and genetic
epidemiologists determine the frequency and geographical distribution of
specific gene mutations, thus providing essential empirical data for
policymakers, whose role is to plan for the future health needs of society.
Finally, genetic screening for recessive or X-linked mutations may be
offered to senior students as part of a genetics awareness campaign
designed to educate young students about the risks and benefits of gene
technology.  

Despite these potential benefits to students and to public health, genetic
testing in a school environment carries an especially high risk of labelling,

74 Ibid.
stigma and altered expectations. Children are especially vulnerable to the negative social and psychological effects of labels and stigma, either imposed on themselves or by others.75

Paediatrics “does not support the broad use of carrier testing or screening in children or adolescents” Finally, the Clinical Genetics Society in the United Kingdom has advised that “formal genetic testing should generally wait until the ‘children’ request such tests for themselves, as autonomous adults” Once a child has been tested, s/he is exposed to the future possibility of genetic stigmatization and discrimination in employment, insurance, immigration and marriage.76

Genetic Discrimination in Adoption

“The little girl awaiting adoption appears hale and hearty now. But what surprises may be preset in her DNA? Are there defective genes that influence her to serious psychological and substantial physical problems—later in life, that would not only obscure her life, but put a severe burden on her adoptive parents?” These are some of the anxieties raised by HGP in the field of adoption "Thousands of children are adopted each year,” Considering the significant consequences flowing out of adoption like the formation of new familial relationships states have always tried to bring legislations giving due attention to the needs and interests of the adoptee, the adoptive parents, and the biological parents during the adoption process.77 One such requirement generally relates to granting the medical information known and obtainable of the adoptee to the adopted parents.78

Since the Human Genome Project has increased our ability to determine

75 Id., at 791
78 Id., at 143.
genetic-based disease or disease susceptibility, geneticists are reporting requests from prospective adoptive parents and adoption agencies to perform a series of genetic tests on the adoptee during the adoption process, which include testing these children for adult-onset diseases where no current treatment or prevention exist. This has led to the heart of a growing legal debate as to whether an adoptee should undergo genetic testing at the request of the prospective adoptive parents and has raised the fears of possible genetic discrimination.

Like any other phenomena different views and opinions prevail here also. Many adoption agencies hail these genetic tests in the hope that it will encourage more adoptions and diminish unfair adoption suits caused by a defect or lack of medical information supplied at the time of adoption. Besides these there is a moral base to this debate, adoptive-parents are entitled to complete disclosure of a child's medical conditions given the fact that they will be accountable for the child for the rest of time. Further state also has an interest in permitting potential adoptive parents to carry out these genetic tests to thwart possible fiscal and emotional tension on the family later on in life. These points presents a argument for strong carrying out genetic tests satisfying the interests of all parties involved in adoption process, one may still ask what is the child's best interest in having a genetic test to determine the child's predisposition for an untreatable, adult-onset genetic disease?

A closer look at the situation makes it clear that whatever may be the advantages in having a genetic testing; these benefits are not strong enough to support a violation of an adoptee's basic rights and dignity.

The consequences of allowing such a test can be devastating on the child psychologically, personally, and socially.\(^\text{82}\) Especially if the result of the test indicates that he or she has certain defective genes posing a barrier to a happy and healthy life, now and in the future. Thus the concept of genetic testing seriously undermines the adoption process which is meant to promote the best interests of the child by turning the child into a commodity. This not only runs contrary to public policy but is against all basic concept of dignity.

Another harmful effect of permitting genetic testing in the arena of adoption seems to be stigmatization and discrimination.\(^\text{83}\) Based on the results of genetic testing children will be categorized as healthy and non healthy. Basically, every parent longs for a healthy child and prospective adoptive parents being no exception. In today's world of mounting commercialization fiscal concerns, insurance problems of a perfect child with no risk of health problems in the present or future is a better option financially, emotionally, and physically, than a child who will fall prey to illness and suffer.\(^\text{84}\) When the child's genetic predisposition is uncovered, prospective adoptive parents may not choose to adopt the child based on the classification there by substantially reducing the chance of adoption.

Thus it is clear that genetically testing an adoptee child will expose the child to discrimination since a defective child has very less chance of adoption in the present and in future. The child will most likely be classified as "defective" if the genetic test does show a predisposition to an untreatable, adult-onset disorder. The discrimination though, does not end there. Later on in life, the child will most likely be subject to discrimination and stigmatization in the work force and health insurance

\(^{84}\) Supra note 82, See Rothstein at 115.
industry. Employers will see the results of the genetic test, and consider the child, who is now an adult, as a burden on them, costing the employer money. Health insurers will view the tests and see the child, who has grown into an adult, as an added liability and charge higher premiums or deny coverage overall. Therefore, in following the dignity of individual and fundamental human rights an adoptee has the fundamental right to be free from genetic testing by adoptive parents or adoption agencies, which are testing the child for predisposition to untreatable, adult-onset diseases.85

Besides these concerns, requiring the adoptee to undergo genetic testing for future risk of untreatable, life threatening diseases, infringes on his or her fundamental right to privacy and autonomy. Though children can not be said to enjoy the concept of autonomy as they lack the required will.86 "Decisions by adults to test children preclude a child's 'open future." 'Since DNA holds deeply personal information relating to the biological identity of the individual. In balancing the interests of the parties involved in the adoption proceeding--the child, the state, the adoption agency, and the prospective adoptive parents--not only does a fundamental right exist, but also no compelling state interest could justify performance of the genetic test on the child. Whatever all the arguments for a genetic testing are futile because the severe burden placed on the adoptive child overrides all other interests. "children do not come with guarantees."87

Genetic science is not yet fully understood. Immediately following the discovery of the first breast cancer gene, scientists estimated that having this gene conferred an 85% risk of developing breast cancer. Within two years, however, the risk had been downgraded to only 50 percent. Sing genetic information to discriminate at this point in time is so inaccurate as

85 *Supra* note 77, See Jessica at 144.
87 *Supra* note 82, See Rothestein at 112.
to be almost useless--especially in the context of determining who should get a job, or who should be eligible for affordable insurance. Further predictive gene does not necessarily mean you will ever get sick. No one should be passed over for a promotion at work or lose their insurance coverage simply because they might get sick someday. In the face of this uncertainty, the logical course is to ban all genetic discrimination, rather than allowing a "Wild West," anything-goes atmosphere to prevail. The abuse of genetic information has the potential to destroy individuals' careers and do long-term damage to their and their families' health. We must err on the side of caution and ban all genetic discrimination in health insurance and employment.

Genetic discrimination in various contexts discussed above comes together with a host of common issues for international issues to ponder. Although the risk of social discrimination predates the genetics revolution, violations of genetic privacy give rise to a new expression of social discrimination in the form of genetic discrimination. As Murray suggests, genetic information broadens the pool of possible factors that may be used to discriminate against individuals and expands the pool of individuals who may be subjects of discrimination. The net social effect is likely to be the creation of a new social inequality and new social polarization between the genetically advantaged and genetically disadvantaged. Ultimately, genetic discrimination will create an oppressed and marginalized genetic underclass, whose members are denied social rights and opportunities because of a genome they did not choose and

cannot change. Most, if not all, individuals have some mutation in their genetic make-up. Once the researchers expand our knowledge base, we will all be targets for genetic discrimination and invasions of our privacy. When people feel as though they are going to be a target of discrimination, they will be much less likely to get tested. This, in turn, can jeopardize the public's health. When is human variety a disability? Some genetic conditions are distinctly bad news. There is no inherent beauty in prolonged pain and human suffering, genetic or otherwise. There is no glory in the premature termination of sentient human life and sensibility. Relieving pain and suffering and promoting life and sensibility are generally good things. They are worthy objectives of morality and of law. But sometimes disability depends upon the eye or ear or mind or heart of the beholder. Getting agreement on these issues is difficult locally, more difficult nationally and almost impossible internationally. Yet they undoubtedly present an international challenge.

Human Genome and Reproductive Issues
Pre Nata Genertic Testing: Engineering the Unborn

Husband and Wife married for eight years. During Wife's first pregnancy, amniocentesis testing shows that her foetus will develop severe Down syndrome. Husband is employed as a primary school teacher. While wife is not having any job. Due to their financial inability they are worried about caring for a child with Down syndrome. They decide to abort the foetus due to their financial inability to care for such a child.

91 Ibid.
92 Ibid.
93 Ibid.
94 "Down syndrome is usually caused by an error in cell division called non-disjunction." National Down Syndrome Society, What Causes Down Syndrome, available at <www.ndss.org/content.cfm?fuseaction=infoRes.Generalarticle&article=20> (last visited 3-04-2007). All people with Down syndrome have an extra, critical portion of the number [twenty-one] chromosome present in all, or some, of their cells.
The Human Genome Project, and advances in genetic technology is enabling every set of parents that has a little baby to get a map of the genetic structure of their child. So if their child has a predisposition to a certain kind of illness or a certain kind of problem, or even to heart disease or stroke in the early 40's, they will be able to plan that child's life, that child's upbringing, to minimize the possibility of the child developing that illness or that predisposition, to organize the diet plan, the exercise plan, the medical treatment that would enable untold numbers of people to have far more full lives than would have been the case before.\(^5\)

There is a normal inclination to yearn for a healthy and victorious offspring. The vast majority of financially well to do parents-to-be will care for their foetus by routinely visiting the physician, consuming various vitamins, and monitoring pre-natal exposure to injurious materials and substances. Parents persist on with their endeavour all through their children's lives by sending them to fine schools, making them participate in sports and extra curricular activities, preparing them for higher education and professional courses, and so on and so on. But the use and development of technologies aimed at predicting and enhancing the health and success of unborn children creates a new realm of procreative challenges.\(^6\) The questions arise, as genetic technology progresses how will it transform the reproductive experience? Does eliminating particular genetic behaviour construct society in improved condition? What effects will these measures have on children, women, the disabled community, minorities, various racial groups' lower classes and society in full? What are the continuing implications of such know-how?

Various genetic tests exist to predict and diagnose the condition of an

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embryo. This type of testing includes carrier testing, prenatal testing of foetal cells, and pre-implantation testing of embryos formed by in vitro fertilization. Prenatal testing has classically been used to establish the sex of a foetus, but the tests are progressively being used to look for deformities and diseases. Completion of HGP is expected to enhance this capacity and techniques. These diagnoses often become the central deciding factors for many parents-to-be whether to continue or terminate the pregnancy. Advances in genetic testing specially in wake of HGP will only widen the scope of these genetic tests and the traits and distinctiveness which can be determined prenatally. There by leading to more reproductive options. What are the consequences of this there are two views prevailing today.

Professor Robertson one of the leading authorities in this field suggests, most of these choices will lead to negative selection "through methods such as avoiding conception, not implanting an embryo, or aborting a foetus." He also postulates that as the science of genetic therapy catches up with genetic testing, more positive choices, such as genetic enhancement, will be made.

To date, this procedure is only used to test for flaws relating to diseases, but as one HGP scientist concludes, "[b]esides preventing and treating inherited and infectious diseases, gene-transfer technologies probably will make possible the enhancement or replacement of genes that influence other traits such as height, weight, strength, stamina and even intelligence." Although an unperfected science to date, prospective

98 Supra note 96, See Brooke at 58.
100 Ibid.
uses of these therapies to influence non-disease causing traits or in other words engineering the designer babies raise substantial ethical and legal questions.  

There are many supporters of these technologies who argue that genetic enhancement and negative genetic selection are part of the procreative liberty and freedom recognized by current political thinking and jurisprudence. The reason for their concurrence seems to be based on the fact that they believe that the right of a person to genetically change and augment the qualities of their foetus is similar to their right to care for their children. If we analyze the situation closely parents play a vital role in child’s life. Their all effort is aimed at improving their children’s chance of achievement in life. From choosing the school which a child attends to choosing the profession parents all over the world carry out all measures for the welfare of the child. This is what prompts Professor Robertson to state that “[I]f states cannot show that enhancement activities harm the child, then prebirth enhancement through genetic intervention may receive protection as an aspect of this right to rear, even if it were not independently protected as part of procreative liberty.”

Since no right can be absolute, procreative liberty being no exception. Therefore it is essential to put restrictions on negative genetic selection and positive enhancement one of the authorities in this field, Professor Robertson offers a balancing test for determining what protection negative genetic selection should receive. First, he differentiates between the characteristics found in the foetus through genetic testing: to be material and preferential. Robertson considers characteristics that are "central or

102 Supra note 96, See Brooke at 59.
104 Supra note 99 See Robertson at 433
105 Supra note 103, See Robertson at178..
material to a reproductive decision" to be of disease category.\textsuperscript{106} Remaining traits and characteristics fall into the preference category. He asserts that if a woman's decision for negative selection depends on the finding that what is affecting the embryo is central or material to a reproductive decision, the law should not interfere with her decision rather she should be afforded full safeguard under the law.\textsuperscript{107}

But there is more opposition against genetic enhancement than its supporters. They stresses that a prohibition on such augmentation therapy is very intimately connected to maintaining equality, fairness and opportunity. Additionally the expenses related with this know-how only give a stimulus to their case. Economical aspects play a major part in opponent's points in opposition to genetic screening which leads to negative genetic selection.\textsuperscript{108} The costs associated with each gene test or series of tests varies, "ranging from hundreds to thousands of dollars." Obviously, lower classes of society will not be able to afford genetic screening. If negative selection and genetic enhancement are to become part of the normal reproductive experience, lower classes will be excluded, leaving them to bear more children with genetic diseases.\textsuperscript{109}

Genetic improvement or engineering a designer child threatens the idea of equality and fairness in multitudinous ways. In the beginning genetic enhancement may creates a few genetically privileged which will obviously accentuate the inequality in contrast with the genetically undamaged. In addition this new privileged classes will be grabbing all the social and professional opportunities in life in future also. This will not stop with one generations as genetic traits are passed on to future generations in germ cell enhancement. Further the concept of upward mobility so essential for

\textsuperscript{106} Id., at 179.
\textsuperscript{107} Ibid.
\textsuperscript{109} Ibid.
social functioning will suffer as well. For the undamaged traditional methods of social enhancement like marriage, profession and education may not be available. The enhanced would capture all desirable and prominent occupations and fill high status social roles. One scholar noted that "[m]andating prenatal [genetic screening] would reverse this policy consensus by once again coercing vulnerable populations to forego reproduction and to abort when no therapy for an inheritable disease exists or none is affordable." ¹¹⁰

Several types of genetic enhancement and genetic selection regulations have been suggested by the legal and medical communities. One commentator, Professor Mehlman, suggests that self-regulation may be a sufficient means of policing genetic enhancement. Mehlman proposes that by providing society with the option of somatic cell enhancement.¹¹¹ Mehlman also points out that religious and cultural motivations will prevent large numbers of people from altering their children's genetic make-up. Mehlman postulates that humans make rational decisions regarding their children and that these decisions are weighed on a social cost-benefit analysis scale. The potential social costs associated with genetic enhancement like inequality, discrimination toward those with disabilities, etc might outweigh the benefits for many individuals. This is precisely why some commentators encourage professional, state and federal regulation.¹¹²

The American Medical Association's Council on Ethical and Judicial Affairs promulgated a policy statement on genetic enhancement in 1988 and

¹¹⁰ Nathan A. Adams, IV, "Creating Clones, Kids and Chimera: Liberal Democratic Compromise at the Crossroads", 20 Issues, L. & Med. 3, at 17, 2004. He explained that "[g]ene transfer research comprises a variety of approaches including: (1) introducing a gene that supplements the function of a mutated gene, adds a missing function, or regulates the expression of another gene; (2) directly repairing a mutated gene; or (3) suppressing a gene.".
¹¹² Id., at 683
updated it in 1996. The policy statement strongly opposes genetic enhancement with only a few severely restricted exceptions, noting that "genetic manipulation to affect non-disease traits may never be acceptable and perhaps should never be pursued".

It is to be noted that so far no state has enacted legislation completely banning or restricting the use of negative genetic selection or genetic therapy. Like in all cases a balance has to be struck between the interests of parents and societal harms. It is no wonder some sort of restriction are much needed while dealing with technology that has such sweeping effect on the society. State and possibly professional bodies' restrictions will undoubtedly be placed on decisions to genetically enhance a foetus or to selectively abort a foetus for non-medical genetic reasons. Otherwise in the long run this enhancement technology can cause races or classes which are unfavourable to the governing group to fade and vanish seriously impairing states concern in promoting genetic diversity.

Abortion Choices

Though this issue is part of reproductive issues it needs to be discussed separately taking into account the conflicting legal right of females and foetus involved in this process.

Many jurisdictions treat the right to abortion as women's fundamental right. And her private right to be alone other jurisdictions does not go to the extent of treating it as a fundamental right but generally allows

114 Id., at 639.
abortion when it is harmful generally to mother or in some cases child. The issue of abortion will get complicated with the knowledge gathered from HGP will gain prominence. How effectively can the world deal with these new technologies and issues? The improved sciences of genetic testing and enhancement will force society to face the legal, moral and ethical dilemmas of abortion presented by this advanced science. Although these technologies may be born out of a desire to improve human life, their very effects may render them undesirable to much of society. Whatever the result, a balance has to be struck between the interests of concerned parties the pregnant women, the foetus, and the state. It is to be seen whose interest should be paramount. Different viewpoints are prevalent. No body doubts the proposition that abortion should be allowed when the genetic testing shows serious infirmities of the foetus or when the life of the women is in peril.

One of the major problems arises when state tries to force the reproductive decisions for parents. For instance DNA testing of the embryo shows that the child will develop Down syndrome some times in future and the state compels the parents to abort the foetus to improve public health and reduce future financial burden on it. Though the purpose of statutes banning wrongful birth or wrongful life cases is to discourage abortion so as to protect the embryo or foetus. At the same time these statutes also infringe upon a couple’s rights to privacy without advancing a compelling state interest. Libertarians are aghast at the idea that the state could coerce reproductive behaviour. While no one disagreed about the importance of using genetic information to encourage responsible parenting, to many people it seemed wrong for the state to try to compel

117 For Instance In India The Pre Conception and Pre-natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994, was enacted and brought into operation from 1st January, 1996, in order to check female feticide. Rules have also been framed under the Act. The Act prohibits determination and disclosure of the sex of foetus. It also prohibits any advertisements relating to pre-natal determination of sex and prescribes punishment for its contravention.
such behaviour. They also believe that such coercion seriously interferes with the marriage and its privacy. They also put forward a compelling argument that forcing a woman to choose between bearers and raising a child with a disability is an undue burden on her right to procreate.\textsuperscript{118} Mandating the provision of information about who was at risk of procreating a child having a problem and the financial consequences of an unfortunate pregnancy outcome seemed the only way to handle ethically the question of individuals and groups at risk of passing on deleterious genes.\textsuperscript{119}

Another side of the spectrum there may be cases when women may desire abortion just on the basis that the child may develop certain infirmities in the future or just that child is not intelligent enough even against the state interest. In this scenario question arises whose interest has to be supreme whether women’s procreative liberty should be given paramount importance. Any court that takes up a state restriction on negative genetic selection or genetic enhancement must consider the procreative liberty jurisprudence and must error on the side of protecting a woman’s right to choose while balancing the ethical issues presented. Equality is a fundamental cornerstone of our society. Altering the genetic make-up of some of our citizens will undoubtedly characteristically change that equality. The social implications of this control over who will outperform on aptitude tests, which will possess the social ideals of beauty, to even who will be afflicted with disease present possibly the most significant questions today.

Further generally in case of adoptions, decisions are made on behalf of fœtuses and newborn babies who cannot speak for themselves. It is therefore crucial to examine who should make decisions on behalf of a


\textsuperscript{119} http://content.cdlib.org/xtf/view?docld=ft8x0nb630&chunk.id=d0e702&toc.depth=1&docld=d0e702&brand=ucpress> (Last visited on 4-01-2008).
foetus or a baby, and how his or her interests can be identified and protected. Although the circumstances of each case are different and intensely personal, uncertainty of prognosis is common. All decisions, whoever makes them and however they are made, must depend on adequate and accessible information. An important question that those involved in critical care decision making need to address concerns the value they place on the life of a foetus. There are several different views. For example, some believe that a newly formed embryo should have full moral status while others consider that this is not acquired until a baby has a capacity for self-consciousness, which does not appear to develop until some months after birth.

In this scenario the conclusions of the Nuffield Council on pre natal management is significant. They observed that although in moral terms a pregnant woman acts wrongly in harming her future child by acting neglectfully or in a manner that is wilfully harmful, as happens occasionally, it would be wrong to force a woman to behave rightly by submitting to medical or surgical interventions to benefit a foetus against her will. They concluded that the best interests of a baby must be a central consideration in determining whether or to allow abortion. The interests of a baby often concern whether he or she will live or die, and the quality of life that might be enjoyed. In according particular weight to the best interests of a baby, the baby's interests in living or dying, or in avoiding an 'intolerable' life, to be more important than the interests that others may have in any significant decisions made about him or her.

121 Gudrun Schultz, "Top India State Court Rules Unborn Child is "Living Person" Maharashtra state consumer court in India has delivered an unprecedented ruling in favour of a woman seeking an insurance claim on the death of an unborn child--the court determined that the unborn baby was a living human being entitled to personhood and required the insurance company to pay the claim. available at <http://www.lifesitenews.com/ldn/2007/mar/07030702.html> (Last visited on 12--3-2008).
122 Supra note 120, See Nuffield council.
Genes and Patents: To Own or Not to Own DNA

The substantial increase in the rate of patenting of DNA sequences by researchers in both the public and private sectors over the past six years has led to considerable discussion and debate about the acceptability of this practice.123 Because of the exceptionally personal nature of human genetic material, the issue of patenting genes has spawned a controversy that spans legal, philosophical, and social concerns.124

Patent: Meaning and Criteria

Patents are exclusive rights granted over a particular period of time by states to inventors to prevent others from infringing the invention. The overall goals of the patent system are to stimulate innovation for the public good and to reward people for useful new inventions. The patent system aims to achieve this by allowing inventors exclusive rights for a limited period to exploit their inventions, while at the same time promoting competition and innovation by ensuring that such inventions are fully disclosed to the public. The system is intended to balance the interests of the public with those of the inventors.125

Patents can be divided into three categories, though these categories are not formally distinguished in the patent system.

- **Product patent** is a patent on the product itself. The term ‘product’ normally means a chemical or biological entity, substance or composition. An important feature of product patents is that they extend to new uses of the invention that developed subsequently,

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even if these uses were not anticipated or predicted by the owner of the patent.

- **Process patent** is a patent on a method or process. This covers a process, and may also include what is directly produced from the process.

- **Use patent** is a patent on the use of the product for a specific purpose; an important feature of product patents is that they extend to new uses of the invention that developed subsequently, even if these uses were not anticipated or predicted by the owner of the patent.\(^{126}\)

Though there are variation and differences in legal systems certain common features can be discerned for a patent to be granted, those includes

- the claimed invention must be eligible for patenting;
- it must be novel;
- it must be inventive or non-obvious;
- it must be useful or have industrial application;
- It must be fully disclosed in the patent application.

In addition, to be eligible, the invention must not be contrary to morality or *ordre public*.\(^{127}\)

\(^{126}\) Ibid.

\(^{127}\) For instance Indian Patent Act provides for public order Article 27 Patentable Subject Mater. 1. Subject to the provisions of paragraphs 2 and 3, patents shall be available for any inventions, whether products or processes, in all fields of technology, provided that they are new, involve an inventive step and are capable of industrial application. Members may exclude from patentability inventions, the prevention within their territory of the commercial exploitation of which is necessary to protect *ordre public* or morality, including to protect human, animal or plant life or health or avoid serious prejudice to the environment, provided that such exclusion is not made merely because the exploitation is prohibited by their law. 3. Members may also exclude from patentability: (a) diagnostic, therapeutic and surgical methods for the treatment of humans or animals; (b) plants and animals other than microorganisms, and essentially biological processes for the production of plants or animals other than non-biological and microbiological processes. However, Members shall provide for the protection of plant varieties either by patents or by an effective *sui generis* system or by any combination thereof. The provisions of this subparagraph shall be reviewed four years after the date of entry into force of the WTO agreement.

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Genes as Subject Matter of Patents

The original discovery that gave rise to the gene-patenting controversy occurred in 1953 when scientists James Watson and Francis Crick discovered the double-helical structure of DNA. Building upon that discovery, modern bio geneticists have developed a means of separating the two strands of natural DNA to obtain gene sequences. Later the writings of Lord Edward Coke also dealt with this issue briefly. He wrote "the burial sic of the cadaver is nullius in bonis, J and belongs to ecclesiastical cognizance." meaning human body parts cannot be property. 129

The case credited with giving birth to the now burgeoning biotechnology industry was the 1980 landmark decision, Diamond v. Chakrabarty. In Diamond, the U.S. Supreme Court held that live, human-created bacterial micro-organisms are patentable under the US rule. The reason cited by the court was that the patentee had "produced a new bacterium with markedly different characteristics from any thing found in nature and one having the potential for significant utility". Due to this, it was held that, "His discovery is not nature's handiwork, but his own; accordingly it is patentable subject matter," 131

The patent controversy is expected to get a boost with the completion of HGP. The potential subject matter of gene patents can be grouped into the following four broad categories:-

(I) Genetic technologies – The methods and items used in genetic research and genetics – based healthcare, including those used in

131 Ibid.
sequencing DNA, medical genetic testing, other diagnostic uses and gene therapy;

(ii) Natural genetic materials – Forms of genetic material in their natural state, including DNA, RNA, genes and chromosomes;

(iii) Isolated genetic materials – Forms of genetic material isolated from nature, including genetic materials of whole genomes, single genes and gene fragments;

(iv) Genetic products – Item produced by the use of genetic materials, including proteins, nucleic acid probes, nucleic acid constructs such as vectors and plasmids, and anti-sense DNA.¹³²

Different perspectives exist regarding different types of gene patents. The least controversial is relating to genetic technologies and genetic products. Both these seems to fulfil the patent criteria’s laid down under the legislations and ethically agreeable too. Regarding patents to genes in its natural state there seems to be a consensus as most of the experts are against the idea of patenting it. In their support they generally put forward the proposition that Genes in natural state can not fulfil the legal requirement of invention and novelty besides failing in ethical arguments also. The major controversy of gene patent thus relates to patentability of isolated genetic materials. Apart from these specific legal criteria’s and reasoning several other reasoning’s are involved in this controversy The entire patentability of human genetic material revolves around two conflicting ethical aspects First, is it ethically permissible to patent segments of the human genome when these segments represent part of our individual and collective "natural" heritage? Second, is it ethical to deny patenting parts of the human genome given the vast economic resources and human effort expended in identifying it?¹³³

¹³³ Supra note 125, See Nuffield Council.
Potential Arguments for Gene Patenting
Genes as Property

The proponents of gene patenting vociferously support the view that genes are patentable. In their support they point out various organ donation act and transplantation of organs act. For instance The Uniform Anatomical Gift Act (UAGA), enacted in various forms throughout the USA, enables donors to designate body parts to be used for medical research or transplant. 134 This illustrates society’s current treatment of body parts as property, since patents are a form of property, the rationale for their justification lies within the justification of property rights in general.

There are essentially two approaches to justifying property rights. The first argues that there are no ‘natural’ property rights, but that such rights are basically a matter of public convention. This leads to a utilitarian justification of property rights as a system of public rules which provide security and incentives for investment by individual owners of property, but which can and should be adapted wherever the public interest is thereby served. The second approach, famously propounded by Locke, holds that there is ‘natural’ right to that with which one has ‘mixed one’s labour’. This view can be said to be acceptable in the context of intellectual property and genes, 135

Promoting Scientific Research

Two key features of patents are that they stimulate invention and promote the disclosure of inventions, which enables other inventors to learn about

134 Uniform Anatomical Gift Act Section 4.provides Subject to Section 8, an anatomical gift of a donor’s body or part may be made during the life of the donor for the purpose of transplantation, therapy, research, or education in the manner provided in Section 5 by:(1) the donor, if the donor is an adult or if the donor is a minor and is:(A) emancipated; or B) authorized under state law to apply for a driver’s license because the donor is at least [insert the youngest age at which an individual may apply for any type of driver’s license] years of age;(2) an agent of the donor, unless the power of attorney for health care or other record prohibits the agent from making an anatomical gift; (3) a parent of the donor, if the donor is an unemancipated minor; or (4) the donor’s guardian
135 Supra note 125 See Nuffield Council.
them and to develop improvements and alternatives. Patents represent one of the most important incentives for commercial enterprises to undertake research and development, by allowing them to enjoy returns on the generation and application of knowledge. The patent system provides an incentive to invest in the production and application of knowledge by allocating benefits directly to those companies making the investments, and because it grants property rights which recognise an inventor’s exclusive right to prevent others, for a fixed term, from making, using or selling an invention based on that knowledge without licence.  

It seems fundamentally unfair to require researchers and investors to expend enormous resources, publicize results, and provide benefit to the public without the guarantee of potential return on the investment. The injustice is magnified by the fact that patents are granted in all similar scientific fields of research and development. Further even if you go by the adage of giving to each his due." It inevitably leads to support of genetic patenting. In addition without an adequate patent protection may gravely effect the development of medicine jeopardizing public health, as one of the major aims of Human Genome Project was to develop therapeutic cure for various diseases.

Potential Arguments Against Gene Patenting

Genes as Common Heritage of Humanity

One argument about the special status of DNA focuses specifically on the proposition that human DNA has a special nature compared to the DNA of other organisms and argue that it should be treated separately This view has been expressed and endorsed by various declarations and committees who declared genome to be the common heritage of

136 Ibid.
137 Ibid.
While the genes of a particular individual are responsible for his or her uniqueness, genes are simultaneously an omnipresent component of every human.

From the perspective that genes are our common, universal possession symbolizing humankind's collective heritage, genes seem an inappropriate substance in which to grant individual intellectual property rights. In support they point out that if genes are to be the subject of property rights, it should be publicly rather than privately owned. The concept of public property or common heritage has applied, in legal and political terms, to such things as the navigable waterways. As regards these; the public interest is protected through vesting rights of ownership in the state or some international body, or by declaring that they are not amenable to ownership. This viewpoint was succinctly stated by the French Minister for Research and Technology, Hubert Curien, in a 1991 letter to the journal, 'Science: "It would be prejudicial for scientists to adopt a generalized system of patenting knowledge about the human genome. . . . Such a development would be ethically unacceptable. A patent should not be granted for something that is part of our universal heritage."

It is also argued that genes the common heritage of humanity should not be patented on the basis of the ethical principle of distributive justice. Distributive justice principles establish a connection between a person's characteristics and the morally correct distribution of burdens and benefits in society. This viewpoint was clearly evident from the Bilbao Declaration," an international statement on the legal implications of the Human Genome Project, where the scientists and jurists observed that

138 "Protection of the Human Genome" by the Council of Europe opinion of Council of Europe's Committee on Legal Affairs and Human Rights (2002).
139 Art 1, Universal Declaration of Human Genome and Human Rights declare Genome to be the common heritage of the Humanity.
140 Supra note 125 Se Nuffield Council.
“National and international rules should be developed, having as their objectives . . . the just distribution to people everywhere of the benefits of the Human Genome Project whose product belongs ultimately not to individual scientists, nor to sponsoring nations but to human beings in every land: of this generation and of all generations to come.” 141

In support of the argument that genes are the common heritage of mankind, experts also point out the inalienable stature of genes. They point out that as human beings we owe respect to others and others things implying there by people may not be owned by others as slaves. It is argued that this inalienable right to self ownership brings with it an inalienable right to ownership of ones body including genes. This view has been widely accepted. European commissions directive which reads “The human body, at the various stages of its formation and development, and the simple discovery of one of its elements, including the sequence or partial sequence of a gene, cannot constitute patentable inventions.” 142

Genes as Discoveries

Patent law addresses the universal heritage question by distinguishing between mere discovery of something existing independently in nature, which is unpatentable, and a true invention, where there is a significant element of human intervention making the product patentable. In Reynolds v. Smith the court held that the difference between discoveries and invention is that “discoveries increase the knowledge; inventions increase the technical skill”.143 Another leading decision on the distinction between inventions and discoveries was made in the case of Antamanid.144 The court held that naturally occurring substances are patentable. For DNA

141 Bilbao Declaration Art 1.
143 20,RPC 123, P 126
sequences, this means that an Isolated gene, which is identical to the
gene found in nature, may be patentable if the gene sequence has never
been isolated before. It is currently difficult to obtain a consensus of
opinion whether gene sequences are a discovery or an invention. There is
a deep rooted belief that genes are naturally occurring entities that are to
be discovered and not invented. Under this interpretation identification of
genes is a discovery, since genes exist in the world in our bodies.\textsuperscript{145} This
is the reason Europe and most of the countries patent laws explicitly
exclude discoveries from qualifying as patentable.\textsuperscript{146}

**Privacy**

Patenting human genes and gene sequences may ultimately meddle with
privacy rights as it interferes with an integral bodily and personal part.
Genes are the building blocks of human life and an integral part of every
cell in the human body. Genes are intimately and inextricably related not
only to the physical body, but also to our emotional and intellectual
composition. Consequently, they are in a zone of privacy that may be
violated by assigning patents on human genes to others.

**Unjust Enrichment**

Though the concept of unjust enrichment is not against genetic patenting
per se but against granting patent which enrich a person at the cost of

\textsuperscript{145} Supra note 125 See Nuffield Council.

\textsuperscript{146} Supra note 127, See Indian Patent Act A patent can be granted for an invention
which may be related to any process or product. The word "Invention" has been defined
under the Patents Act 1970 as amended from time to time. India amended its Patents Act
again in 2002, The Third Amendment of the Patents Act 1970, by way of the Patents
(Amendment) Ordinance 2004 came into force on 1st January, 2005 incorporating the
provisions for granting product patent in all fields of Technology including chemicals,
food, drugs & agrochemicals and this Ordinance is replaced by the Patents (Amendment)
Act 2005 which is in force now having effect from 1-1-2005. Under The Patent Act A
patent can be granted for an invention which may be related to any process or product.
The word "Invention" has been defined under the Patents Act 1970 as amended from
time to time. "An invention means a new product or process involving an inventive step
and capable of industrial application" (S. 2(1) (j)) meaning discoveries are beyond the
scope of patents.
someone else. The case of *Greenberg v. Miami children’s hospital* 147 provides a classical example for such a situation. In this case the research subjects who instigated research to isolate the gene for Canavan disease and who for numerous years supplied vital and critical materials and resources for the investigation. They were kept out of the information regarding commercialization. Their claim for unjust enrichment has been upheld by the court and hospital authorities were asked to pay compensation.148 But there has been case which held otherwise also In *Moore v. Regents of the University of California* the court held that a patient has no ownership right over tissues removed from his body during normal medical procedure.149 This case situation raises serious dignitary concerns of individuals or groups in society regarding genetic patent.

These problems can get accentuated in the cases of races and various indigenous groups who view genetic identity as intrinsic to all peoples. They believe that genetic material is owned not just by the individual who supplies the genetic material but also belongs to generations, past and future, which are present in the germ line."150 If we go by the global trend there is a lot of emphasis on group, racial and minority research. An example being the International Hap Map Project undertaken by the NIH.151 This endeavour, a pilot program to explore scientific methodology, has raised a cluster of issues, including the scientific soundness of race-based research152 A balance has to be struck between scientific research


152Homepage: <http://www.hapmap.org/> The goal of HMP is to take the concept of familial-pedigree studies up to the population level--to compare the genetic sequences of
and unjust enrichment. Perhaps nobody will question the essentiality of granting compensation to research subjects. But the problem will be to calculate the value of sample supplied by the subject. Many times it may not be possible to measure because they were indispensable for the research and not readily available from any other source. In this regard the provisions of Convention of Bio Diversity regarding benefit sharing relating to biotic and genetic resources can provide a significant guideline in this area also.¹⁵³

In summary genome research provides insight into the genetic structure and function of life, permitting technological advancements in the curing of disease, the understanding of history, and predictions for future life. It is indisputable that genomic research deserves international attention in the form of adequate funding and support. The concerns raised by researchers and critics of gene patentability addressing the ethical, legal, and moral implications of gene patenting are real. As such, genes need to be removed from the category of patentable subject matter. Genes can and should be removed because they are naturally occurring. The argument that genes are patentable because they are purified and isolated, and thus altered to the point that they are manmade, is without merit. The alteration and purification technique does not change the underlying biochemical and functional definition of a gene. Genes are

different individuals to identify chromosomal regions where genetic variants are shared. HMP was commenced in October 2002.

¹⁵³ The Convention on Biological Diversity, known informally as the Biodiversity Convention, is an international treaty that was adopted in Rio de Janeiro in June 1992. The Convention has three main goals: conservation of biological diversity, sustainable use of its components; and fair and equitable sharing of benefits arising from genetic resources. Art19 of the Convention provides that 1. Each Contracting Party shall take legislative, administrative or policy measures, as appropriate, to provide for the effective participation in biotechnological research activities by those Contracting Parties, especially developing countries, which provide the genetic resources for such research, and where feasible in such Contracting Parties. 2. Each Contracting Party shall take all practicable measures to promote and advance priority access on a fair and equitable basis by Contracting Parties, especially developing countries, to the results and benefits arising from biotechnologies based upon genetic resources provided by those Contracting Parties. Such access shall be on mutually agreed terms.
naturally occurring, regardless of whether they are in a purified and isolated state, and thus genes should not be patented. Overall, the exclusion of genes from patentable subject matter under the Patent Act and the establishment of genes as naturally occurring manifestations of nature will have a beneficial impact on society and will ensure that the Patent legislations serves its original purpose -- to reward invention.\textsuperscript{154} We must formulate a more comprehensive solution that addresses the ethical and policy concerns specific to the gene-patenting controversy to fully address the complexity of the controversy in the international community... Ultimately, the greatest ethical, legal, and social goals relative to the genome are reached when human beings everywhere benefit from the practical therapeutic, diagnostic, pharmaceutical, and scientific products that result from human genome research.

**Integrating Knowledge of Human Genome into Criminal Justice System**

You, your joys and your sorrows, your memories and your ambitions, your sense of personal identity and free will, are in fact no more than the genetically determined behaviour of a vast assembly of nerve cells and their associated molecules.—Francis Crick.\textsuperscript{155}

As medical and biological scientists struggle with the developing genetic studies and conclusions, the law has also begun to wrestle with their scientific confusion.\textsuperscript{156} The study of genetics and its resulting theories has long been the subject of scientific debate. With the advances in genetic science especially the completion of Human Genome Project the tendency to attribute everything to genes is gaining prominence, Criminal justice system being no exception. This rising amalgamation of scientific genetic

\textsuperscript{154} Supra note 124, See Stephani at 748..  
\textsuperscript{155} Teresa K. Baumann, “Proxy Consent and a National DNA Databank: An Unethical and Discriminatory Combination, 86 Iowa L. Rev. at 667,( 2004).  
\textsuperscript{156} Jonathan Herring, Medical Law and ethics, at 93, (2006).
Genetic research has played considerable roles in criminal investigations. For example, "DNA fingerprints" have become an accepted way of identifying, and in many cases, eliminating criminal suspects. Genetic proofs routinely are offered in paternity actions; in future many more area of criminal justice system will come up under the influence of genetical advances. Genetic tests will soon flood the courtroom with evidence purporting to support medical and non medical cases alike. But the most significant challenge the knowledge of human genome will present to the criminal justice system relates to the possible relation between criminal behaviour and genetic make up. This thesis addresses only one issue, one which our judicial system ultimately must address: the criminal responsibility one will bear for committing a crime when the actions are determined by the actor's genetic make-up. Is predisposition to an aggression a defence in criminal cases? Will genetic predisposition be over determined in both concept and evidence?

**Behavioural Genetics and Criminal Justice System**

Before analyzing how the legal system may respond to this challenge by the revelation which may be brought by the HGP regarding possible correlation between genes and behavioural traits, it is essential to have a look at the close relation between genetics and behavioural traits. In the early times debates about genes, environment, and behaviour were in the form of Nature versus Nurture discussions. Toward the middle of the century, behavioural scientists came to appreciate that the "either/or" needed to be changed to a "both/and." In a prescient presidential address to the American Psychological Association in 1953, Anne Anastasi went even further by suggesting that research needed to focus on "how genes

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157 Ibid.
interact with environments” to influence behaviour. \textsuperscript{158} It was believed that almost all human behaviours have some genetic influences on the panorama of individual differences seen amongst us. They viewed genes as somewhat "static" in their effects.

Thereafter, two lines of thinking emerged that seriously challenged the statue model. Initially some strange behaviours appeared to be genetic like the amount of TV watching, divorce, etc.\textsuperscript{159} Second, advances in molecular biology and neuroscience demonstrated that genes actually respond to environmental events like adaptation to stress, the formation of memory, and the very task of learning all involve genetic responses to environmental contingencies. Indeed, today one of the ways in which neuroscientists document that a certain brain region is involved in learning, memory, etc., is to measure the change in genetic activity in that region.\textsuperscript{160} A new model later emerged out of the synthesis of these models. The new model views genes and the environment as engaging in a life-long association.

It is to be noted that much time and effort has been devoted to finding the empirical causes of behaviour and its connection with genetics. The major studies relating to behaviouralism cantered around three doctrines: free will, biological determinism, and genetic essentialism. The doctrine of biological determinism is based upon the notion that conduct is always the product of some matrix of causal factors that necessarily determines choice.\textsuperscript{161} Genetic essentialism adopts the idea that personal traits are predictable and permanent, determined at conception and "hard-wired" into the human constitution. The doctrine of free will is based upon the

\textsuperscript{160} Id., at 26.
\textsuperscript{161} Glannon, \textit{Genes and Future People}, at 128, (2001).
premise that all human behaviour is produced through the deliberate intent and agency of the individual. 162

Interest in biological explanations of behaviour continued and got an impetus when scientists shifted its emphasis to find explanation of criminal behaviour which is of great interest to legal system. The approach was started in the nineteenth century by the Italian criminologist, Cesare Lombroso, who wrote extensively on the association between crime and physiognomy. Lombroso believed that criminals had distinguishable physical characteristics and that the likelihood for criminal behaviour could be determined by comparison of a person's physical characteristics to those of known criminals. 163 Furthermore, Lombroso believed that the propensity to commit a given crime would be manifested in physical characteristics different from the physical characteristics of both non-criminals and persons who committed other types of crime. 164 For example, a rapist would have different physical characteristics than a murderer. Based upon his studies, Lombroso concluded that crime was caused by physical characteristics and not due to a person's ability or inability to exercise free will choices to engage in criminal behaviour. 165 Interest in Lombrosan criminology waned, but this movement expressed a widespread and persistent enthusiasm for identifying a physical explanation of crime. 166

Sociological characteristics as family background, education, and friends were emphasized in criminal behaviour by E.A. Hooton, an American physical anthropologist; He believed "that physical inferiority is of principally hereditary origin, that these hereditary inferiors naturally

162 Ibid.
164 Id., at 445
gravitate into unfavourable environmental conditions, and that the worst or weakest of them yield to social stresses which force them into criminal behaviour." 167

Apart from these empirical studies, some substantial and wide scale studies were undertaken to understand the relation between crime and genetics. The major studies undertaken in this field are that of twin and adoption studies.

The largest study of twins conducted in world is "The Minnesota Study of Twins Reared Apart" which was conducted by behavioural researchers at the University of Minnesota. 168 More than 100 sets of identical twins and triplets participated in the study, which concentrated on measurable similarities and differences between identical twins that were separated early in their lives and reared apart. The Minnesota study led some researchers to the general conclusion that genetics, rather than environment, has a much greater effect upon psychological traits. 169 Specifically, University of Minnesota researchers found that differences in psychological traits, which could be caused by environmental factors, showed no significant variations between identical twins reared apart and identical twins reared together. 170

The Twin Studies findings support, to some extent, the theories of biological determinism and genetic essentialism, and tend to discredit the doctrine of free will. Proponents of biological determinism believe that many traits are directly inherited. Among those traits are dangerousness, aggressive personality, and the tendency to commit arson. Biological determinists consider findings such as those resulting from twin studies as

167 Ibid.
169 Id., at 225
170 Ibid.
indications that social problems -- including crime -- are due to genetic makeup rather than environmental factors. 171

More or less same findings were evident in adoption studies One major assumption behind adoption studies was that if genetics is determinative of criminal behaviour, children born to criminal biological parents would show a greater predisposition to criminal behaviour than would adoptee born to noncriminal biological parents. This would be expected to be true whether or not the adoptive parents were criminals.

The most comprehensive adoption study completed to date was one conducted in Denmark. 172 The results of the study were based upon no fewer than 10,000 parents broken down into four categories, and 13,000 adoptees. If either parent had a criminal conviction, the parents were counted as criminals. Of the adoptees that had neither biological nor adoptive criminal parents, 13.5% had at least one conviction. This percentage rose to 14.7 for adoptees who had criminal adoptive but non-criminal biological parents.

The jump in percentages of adoptees that had at least one criminal conviction was observed for adoptee that had criminal biological parents but not criminal adoptive parents (20%). The highest percentage of adoptee that had a criminal conviction (24.5%) was observed from those who had criminal adoptive parents as well as criminal biological parents. The results also showed that biological parents who had three or more convictions were three times more likely to produce chronically criminal sons than were biological parents who had no convictions. 173

171 Ibid.
172 Supra note 163, see Marcia Johnson at 447. She points out that Mednick, Gabrielli, and Hutchins carried out a study of the genetic influence on criminal behavior using an extensive data set consisting of 14,427 Danish adoptees (ranging in age from twenty-nine to fifty-two years) and both sets of biological and adoptive parents
173 Ibid.
The results of modern twin and adoption studies have led many behaviouralists to conclude that there is a significant correlation between genetic factors and behaviour. Such findings favour the doctrines of genetic essentialism and biological determinism and disfavour the doctrine of free will as related to the causation of criminal behaviour.

Another study which supported the proposition that genetical make up does influence criminal or anti social behaviour relates to XXY chromosome studies. In 1965 a paper was published based on research involving almost 200 males who had been committed to the State Hospital at Carstairs in Scotland.\(^{174}\) Seven of the men were found to have an extra Y chromosome, a much higher rate than was thought to be the case in the general population. The research raised the possibility that this genetic abnormality could be related to the aggressive behaviour of the inmates.

Further research showed that XYY males were more likely to be taller than average and of low intelligence, but failed to provide conclusive evidence about a link to aggressive or violent behaviour. In 1976 a paper was published which concluded that XYY males were more likely to be imprisoned, but that this was due to their low intelligence and low socioeconomic status which placed them at higher risk of being caught. The current state of opinion on the XYY issue is that there is insufficient evidence to establish any firm link between the particular genotype and an increased risk of aggressive behaviour, although there does appear to be an increased risk of offending.\(^{175}\)

The preoccupation with the relationship between crime and genetics continued even in 1990’s when Han Brunner and colleagues were asked by members of a Dutch family to investigate why a significant number of

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175 Supra note 166, see Nuffield.
males in the extended family engaged in peculiar behaviour, including aggression and inappropriate sexual behaviour. At the end of their investigation they found that affected members all carried a mutant blueprint (gene) for the enzyme monoamine oxidase A (MAO-A). These results were portrayed in the media as the "aggression gene" and the "violence gene." Many scientists protested that there was no relation between this gene and aggression. Nevertheless, many geneticists at that time were called upon by legal counsellors to request testing on the MAO-A gene for their accused or convicted clients.177

This scientific evidence was evoked in the celebrated case of Stephen Mobley who had killed a store manager. Relying on the discovered violent gene the lawyers for Mobley argued that Mobley be tested for MAO)-gene, the request was turned down because "the theory of genetic connection and violent behaviour ... is not at a level of scientific acceptance that would justify its admission."178

These studies some where favour genetic determinism and reject the concept of individual as having freewill. These findings are expected to get an impetus with the successful completion of HGP, It is speculated and expected that scientists will be able to discover genes for criminal behaviour. But these conclusions have its flipside also. Although such interest and conclusion are understandable, it is important that a desire for a simple, intelligible cause of a serious social problem should not deviate our attention from the real scientific aspects. That is the exact reason some commentators have suggested that the search for genes that influence crime or antisocial behaviour is fundamentally misconceived; since crime is a socially constructed phenomenon.

177 Ibid.
Nikolas Rose has noted that biological criminologists are: 'quick to acknowledge that crime as such does not exist; that lawbreaking acts are heterogeneous; that crime is culturally and historically variable; that infraction of law is common; that those arrested, charged and convicted are not representative of those who break the law but a skewed sample produced through all sorts of social processes. Crime is a complex phenomenon, and interpretations of crime that focus on one set of factor are likely to be misleading.  

Could genes directly influence antisocial or criminal behaviour? We do not know. Furthermore, current technologies are not enough to provide an unequivocal answer to this question. What we can say without any qualification is that there can not be only genetic aspects behind criminal behaviour that some aspects of the social environment must be involved in this difference. But the question is that how would such a finding impact medical and legal practice and social ethics? Should individuals with the high-risk genotype be viewed as less culpable than those with the low-risk genotype? Should such differences be considered in the penalty phase? These are the major question that our criminal justice system where justice, guilt, and punishment are based upon the doctrine of free will. Will have to address in the future.

Challenging the Concept of Mens Rea

There are possibly two areas of criminal justice which may be affected by the finding that Genes control or determine behaviour and advances in research in behavioural genetics:

180 Supra note 166, See Nuffield.
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- **Exculpation**: Whether genetic information about a behavioural trait should affect our attributions of legal responsibility, that is, as an exculpatory factor.
- Whether genetic information about a behavioural trait should affect the way in which we sentence and treat convicted offenders. 182

If we take the first aspect, traditionally, the criminal law bases its notions of responsibility on the assumption that every adult is answerable for his or her acts, and has never shown much consideration to the idea of genetic determinism which is against existence of free will and individual responsibility. At the core of criminal responsibility is the notion that human action consists of an act and an accompanying guilty mental state, usually an intention on the part of the individual. With the exception of offences of strict liability the mental element or menses- behind action is of great importance in the law. 183 Our criminal justice system is rooted on the principle that a person who commits a crime must be punished. Further free will or mens rea clearly justifies concepts of retribution and punishment as reinforcement of the fundamental theory that people are to be held accountable for their own actions. When a person is without such ability because her mental faculties are so impaired that she cannot exercise free will, then that person is not subject to criminal culpability. The defence of insanity generally found in legal system provides an example.

The advances in genetic research bring forth the possibility of an addition to the category of defence where mental element is lacking for the commission of an offence. If the criminal justice system adopted the genetics determinism theory, it would necessarily create a new class of criminal defendants who would be excused from culpability because they

182 Supra note 166, See Nuffield Council.
183 Ibid.
could not have exercised free will. Technological advances in genetics are creating the probability of finding and identifying genes linked to violence. Once genes for behaviour are identified, many geneticists believe a person's genetic predisposition to violent behaviour can be shown. When scientific evidence can be shown that genetic predisposition is so compelling that a person cannot overcome the compulsion to act in accordance with non-criminal behaviour, the question arises how can we attribute free will to his or her actions. The presumption favouring free will might initially, at least, survive the scientific isolation of genetic characteristics for violent behaviour. However, a direct linkage between an identifiable gene and criminal activity could effectively rebut that presumption. A criminal defendant suffering such a genetic predisposition could be found not guilty by reason of genetic determinism. The burden would be then on the defendant to prove, that his behaviour was genetically predetermined. He would also have to prove that this predisposition impaired his ability to act alternatively.

Thus, whether genetic inclination to commit crimes should be a full defence like cases of insanity or minority where mens rea is deemed to be absent or a mitigating factor, all these will be ardently debated by the jurists in the near future. Two views are prevalent. One of the problem of accommodating genetic predisposition to criminality as a full defence is that, one of "the fundamental principles of criminal law is to prevent the parson from committing that crime again. The theory of retribution is based on this principle. There are various methods to do that which includes, releasing back a person to the mainstream of society once found not guilty. If the defendant is found guilty but genetically impaired he can

185 Supra note 163, See Marcia Johnson, at 444.
be confined in a penal institution. These methods are possible and valid in the normal cases of medical defects.

If we take the case of insanity, medical science advances can possibly treat and perhaps even cure the disorder. Where the issue is one of genetical defect, the question is whether institutionalization would be any different from imprisonment since there is currently no treatment available for a criminally influential genetic defect. Thus the legal system will have to look to other methods. Perhaps the criminal justice system can take the benefit of genetic engineering as a means of eradicating the criminal gene present in the defendant as a substitute to the conventional method of punishment. All these methods have their own drawbacks

Thus whether scientific genetics ever be used in the guilt phase of a trial is questionable. Given today's knowledge of genetics, the closest that one might come is when a defendant suffers from a rare genetic disorder that has severe mental retardation which makes it impossible for him to act otherwise. But it can not be the case in the stage of penalty phase.

There are various in which genetic evidence may be helpful in sentencing. Firstly when a defendant has a known genetic syndrome which makes a harsher punishment beyond any comprehension. Imagine a conviction where convicted murderer has an IQ almost on the verge of mental retardation. We lack technical and scientific expertise to comment about the legal ramifications of this situation, but it certainly deserves careful consideration. Further none of the purposes of the criminal law-rehabilitation, deterrence, and retribution-is satisfied when a person who lacks the capacity to either control or understand his actions are punished.186

Genetic explanations of behaviour may not in near future change the fundamental assumptions on which criminal justice system but coming years may not be the same. In the past, also new scientific knowledge has taken its own time to be accepted by the courts and legal fraternity. Example being DNA fingerprinting test. The disinclination of the courts to accept particular medical or scientific explanations should not be assumed. Equally, nor should their capacity for assessing the validity of novel scientific claims be over estimated.

Of course, there are significant problems which the genetics poses for our society and criminal justice system the costs of genetic testing may make the "gene defence" available only to the wealthy. Gene engineering and splicing could eliminate gene pool diversity. Determining which gene is good and which is bad is couched in social, economic, racial, and other biases. Genetic determination itself has social implications, including creating in a person the belief that they are limited by their genealogical map. These are all issues that a responsible society must address as the technology develops, "In the long run, the issue is not the genetic knowledge itself, but what kind of soil that knowledge grows in. It was not bad genetic knowledge that led the Nazis astray; it was their culture of racism and anti-semitism that allowed that knowledge to flourish and take root."

**DNA and Racial Profiling**

DNA profiling and data basing have become routine in criminal investigation and prosecution. This is expected to get a boost with the sequencing of Human Genome. Lot of state laws permit DNA profile data basing of offenders convicted of particular crimes, of lost and missing persons and their relatives, and of DNA profiles from criminal-case

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187 Ibid.
evidence where the depositor is unknown.\textsuperscript{188} The past decade has witnessed a striking increase of criminal databases world wide in both in dimension and purpose. For example in USA the initial state statutes of the 1990s clearly restricted the databases to retaining profiles from sexual offenders based on the belief and conviction that they are likely to be repeaters and often leave biological proof. Most states have extended their databases in the last few years to include DNA samples from additional categories of individuals like arrestees, Juvenile offenders.\textsuperscript{189}

Recent trends indicate that people who aren’t even suspected in any way of a crime may end up in databases. In USA Louisiana passed a law requiring DNA samples from new police applicants.\textsuperscript{190} In 1999, then-New York City Mayor Rudolph Giuliani proposed collection of DNA samples from all newborns for both medical and law enforcement purposes. It is not farfetched to imagine that states may decide to routinely collect DNA from public school teachers, immigrants, truck drivers, or any other category of people whose catalogued DNA profile might be justified on the basis of safety precautions or merely identification purposes.\textsuperscript{191} According to the Global Survey by Interpol 77 of its 179 member countries perform DNA analysis and 41 member countries have forensic DNA databanks which include both physical samples and databases of DNA profiles.\textsuperscript{192}


\textsuperscript{189} Tania Simoncelli, Barry Steinhardt, "California’s Proposition 69: A Dangerous Precedent for Criminal DNA Databases", 34 J.L. Med. & Ethics at 199, (2001).


\textsuperscript{191} D. McCullough, "What to Do with DNA Data?" Wired News (February 6, 1999), available at <http://www.wired.com/news/print/0, 1294, 32617, 00.html> (last visited on 26-02-2007).

\textsuperscript{192} Global DNA Inquiry Results 2002, The Interpol DNA Unit conducted an inquiry into the use of DNA analysis in criminal investigations among the 179 Member States present in 2002. a brief overview shows that: 77 Member States (43%) perform DNA analysis, 41 Member States (23%) house an operative DNA database, the number of DNA databases has increased by 14% between the years 1999 and 2002, 38% of the Member States are predicted to house a DNA database in the next few years, available at
In sum, in a very short time, we have witnessed the ever-widening scope of the target groups from whom law enforcement collects DNA and rapid-fire proposals to expand the populations to new and ever greater numbers of persons, policy makers, criminal investigators, and legal professionals have been able to depict a series of benefits already derived or potentially derivable from the increasingly routine use of this technology and its expanding applications. These benefits include: the potential to make speedy and robust suspected offender identifications through automated profile comparisons in centralized criminal justice databases; the ability to confidently eliminate innocent suspects from investigations; the increased likelihood of generating reliable and persuasive evidence for use in court; a reduction in the cost of many investigations; the likely deterrent effect of DNA data basing on potential criminal offenders; and a possible increase in public confidence in policing and in the wider judicial process.\(^\text{193}\)

Proponents of expansion argue that reducing the social cost of crime justifies the creation of a population-wide database, and that a universal database is necessary to maximize the utility of DNA profiling.\(^\text{194}\)

Although a few countries, such as Iceland and Estonia, are establishing national DNA databases for research purposes, no country has implemented a population-wide database for forensic purposes. Yet such an endeavour may not be far off. In 2005, the Portuguese government announced its intention to create a DNA database including the DNA profiles of all its approximately ten million inhabitants.\(^\text{195}\)

This trend of rapid expansion in size and function heightens existing

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human right concerns which include the threat to the bodily integrity of citizens who are subject to the forced and non-consensual sampling of their genetic material; the intrusion and denigration of privacy rights caused by the storage and use of tissue samples; the potential for the future misuse of such samples held in state and privately owned laboratories; the prospect of long term bio-surveillance occasioned by the storage of genetic information in police databases and biological samples in forensic laboratories; and the possibility for the deceptive use of DNA forensic evidence in police investigations and criminal prosecutions. 196

Among the various shortcomings of DNA profiling, in spite of what is portrayed in both the media and the courtroom, DNA testing is not infallible. Like all technological tools, the accuracy of DNA testing whether performed on a simple sample taken from a crime scene or one taken directly from an individual is subject to human error. The fallibility of DNA testing was made painfully clear when, in January, 2003, in USA the Houston Police Department's crime lab was shut down following an investigation that revealed widespread problems, including gross mishandling and misinterpretation of DNA evidence by laboratory personnel. 197

Further errors in the collection, handling and storage of DNA samples can result in incrimination of an innocent person. This type of error is known to have occurred in several cases. Celebrated case being that of Lazaro Soto Lusson in Las Vegas.198 Errors associated with the DNA analysis itself are perhaps the least recognized. Many people assume that DNA testing is "objective," but significant ambiguity can arise in interpreting the

computer-generated graph displays that are produced in DNA testing. A disadvantage associated with the measure is that it will gradually promote over reliance on DNA technology as a crime-solving method. Not denying that DNA technology can play a major role in crime detention we must understand that DNA testing is not foolproof, and thus should not be treated as a substitute for detailed investigative work. For instance a match between crime scene DNA and an individual's database profile does not necessarily mean that the individual is guilty. For example, a murder suspect might have acted in self-defence or there may be some other reason to account for the presence of DNA found at the crime scene. DNA testing should remain only one tool of many that are used in criminal investigations, and the level of funding that is poured into this technology in relation to other crime-solving tools should reflect these inherent limitations.

Besides this among the human right concerns, the threat to privacy gains prominence. Which was clearly highlighted by Justice Douglas in Osborn v. United States?

"The privacy and dignity of our citizens is being whittled away by sometimes imperceptible steps. Taken individually, each step may be of little consequence. But when viewed as a whole, there begins to emerge a society quite unlike any we have seen -- a society in which government may intrude into the secret regions of man's life at will."

The leading privacy concerns about more inclusive DNA forensic databases are that this powerful information and the biological samples

200 Ibid.
from which it is obtained would be collected on a routine basis without any individualized suspicion of wrongdoing, that individuals would be coerced to provide samples, the refusal to provide samples would cause stigmatization and bias against him, that relatives of potential suspects would be tested, and that the original specimens would be retained indefinitely. Thus, main privacy concerns stem not so much from the DNA test per se, but rather from the permanent retention of the biological sample. The DNA samples, which are being held by state and local governments, can provide insights into the most personal family relationships and the most intimate workings of the human body, including the likelihood of the occurrence of over 4,000 types of genetic conditions. Thus, potential threats to genetic privacy posed by their collection extend well beyond the millions of people whose samples are currently on file. The most important would have been to require destruction of the DNA samples and profiles in the event that there is no conviction. Instead, the law allows for including those profiles in the database for many years, and then only removing them upon written request and approval. For instance, the Californian law regarding DNA Profiling does not provide for destruction of the biological samples, once they have been profiled. Retention of the biological samples leaves open the possibility that the samples will be misused. All privacy concerns are also exacerbated under the Californian law because it specifically allows for offender profiling to be outsourced to private laboratories. Private laboratories looking out for their own profits are even more likely to misuse stored DNA samples.

If we examine the legislations which requires the collection of DNA samples from all arrestees exacerbates the problem. Storing DNA taken from individuals who have not been convicted of a crime in a criminal database undermines the principle of presumptive innocence. Arrest does not equal guilt and a person shouldn’t suffer the consequences of guilt.

202 Supra Note 189 See Tania at 215
203 Supra note 163, See Marcia Johnson, at 446.
unless and until he or she has been convicted. To find otherwise is to empower police officers, rather than judges and juries, with the power to force persons to provide the state with evidence that harbours many of their most intimate secrets and those of their blood relatives. Taking DNA samples from arrestees is one problem -- retaining them indefinitely is yet another. For instance Proposition 69 does not provide a way to ensure that DNA samples and associated records from persons who are arrested and then proven innocent are expunged. Proposition 69 places the onus on the innocent person to get their DNA back.

If we analyze the criminal justice system in various countries unfortunately, there is a disturbing element of racial and other disparity that runs along the systems. That can get compounded by the expansion of DNA profiling. For instance in the wake of terrorism countries like USA and Australia may demand DNA testing and profiling of immigrants of particular country, race or religion. Such problems have been uncovered in various places. For instance the State of New Jersey has conceded that its state police engage in racial profiling over a period of ten years in incidents that were documented by nearly one hundred thousand pages of state police memoranda, reports, and other papers. The problem was determined to be so serious that the state entered into a consent decree with the Department of Justice.

The recent history of unbridled DNA database development and expansion has occurred absent a much-needed national and international debate. Such a debate would address fundamental questions as to who should be included in this database and why, what protections should be

204 Proposition 69, DNA Samples, Collection, Database, Funding State of California requires DNA samples even from arrestees. Section 296(2) provides (2) Any adult person who is arrested for or charged with any of the following felony offenses:


afforded to the stored data, and who should have access to it. It should also consider the value of such databases to society relative to other steps that might be taken to reduce crime, assist victims of crime, or otherwise improve the criminal justice system.

DNA testing is undoubtedly one of the most revolutionary tools available for aiding criminal investigations and exonerating the innocent. However, neither of these uses requires the creation, let alone the expansion, of permanent DNA collections. Any DNA collection poses extraordinary concerns about individual privacy, cost, and potential for error, and racial bias. Each time we expand a criminal DNA database to include more categories of people and more DNA samples, human right concerns also increase. This trend in future may bring us to a day when the entire population finds itself in a government database and it is not inconceivable to imagine that DNA testing could become part of a procedure to apply for or renew a state driver's license or school admission.

Concluding Remarks

This chapter has described the legal questions that are raised by HGP. We have seen that genetic technology from HGP will raise a host of new property, constitutional and Human Right questions. Questions like, to what extent will we permit intellectual property rights in genetic tests and materials or the actual ownership of human embryos? Should we permit genetic testing in employment and insurance? What are the protections which can be guaranteed for protecting genetic privacy?

Beyond the risks of discrimination and loss of privacy, however, society's fascination with HGP and genetic testing has other social and political consequences. An overemphasis on the role of genes in human health neglects environmental and social factors, thus contributing to the image of people with "defective" genes as "damaged goods." This in effect,
encourages a "blame the victim" mindset, directly contrary to the public policy embodied in the various human right conventions. Economic and social resources end up being diverted into finding biomedical "solutions" while societal measures get short-changed. 207

Law may approach new genetic technologies using traditional laws family laws, intellectual property, public health and informed consent laws or by embracing existing definitions of discrimination. Whether significant scientific concepts, will play a strong role in shaping the social response, as articulated by legislatures and conventions is to be seen. Although the legislature is vested with powers that science lacks, there has been a grafting of science onto the actual laws and texts of the statutes. It can be expected that courts will admit into evidence a vast variety of genetic information that never would have previously been acceptable in a court of law. There is no need for a proposal for science courts, as was offered in the early 1960's during the Cold War and the "Space Race" to bring the latest technology to every school child. 208 Our courts of law are de facto science courts already. Science and medicine have a place and should be appropriately integrated into the various parts of our legal system. Instead, what is needed is not a science court or a new set of science-evidence rules for the application of genetic technologies to daily life; a system that will meaningfully bring genetics to the science of governance: jurisprudence, by enabling scientists to bring their full participation and knowledge to existing judicial decision making structures, that will prohibit certain types of bad uses of information, such as the resurrection of genetic discrimination and invasions of privacy.

207 Supra note 6, See Bereano.