

## Staying ahead of the double helix: on genetic discrimination

The Delhi High Court [recently ruled against discrimination in health insurance](#) by United India Insurance Company involving a person with a heart condition which was perceived to be a genetic disorder. The court held, “Discrimination in health insurance against individuals based on their genetic disposition or genetic heritage, in the absence of appropriate genetic testing and laying down of intelligible differentia, is unconstitutional.”

While the specific features of this case may depend on clauses in the original policy, this is a critical court decision around the broader question of discrimination on the basis of one's genetic predisposition. As technology for genetic testing and tools to gather family history and compile them in databases become cheaper and more widespread, it becomes imperative that due social and ethical consideration be given to genetic discrimination as the implications are far-reaching and can affect everyone.

### Questionable assumptions

Genetic discrimination (GD) is understood to be differential treatment of those not showing symptoms but who are nevertheless treated differently on the basis of any real or assumed genetic characteristics. We must recognise that GD is nothing new. There were robust policies of eugenics in the U.S. in the 1900s. These led to laws in many States that made sterilisation compulsory for those who expressed a range of conditions believed to be inherited. Such conditions covered those with disability, who were poor, had mental health problems, were promiscuous, were dwarfs, and so on. Eugenics was also practiced in many countries in Europe, not just in Nazi Germany. Nordic countries, for example, passed eugenics laws in the 1930s and some of those stayed in the books until the 1970s.

### No discrimination: on health insurance in India

With newer and cheaper methods to sequence entire genomes, the era of expanded genetic testing is already upon us, although not everyone may associate it with eugenics. Whether specific genetic tests themselves are scientifically valid, whether they add value to those tested, and whether they should be generalised for populations or communities raise a separate but linked set of issues that I will not cover in this article. Rather, I will stay focussed on the issues of insurance and employment when there is family history of disease, the potential complications of genetic tests and their implications.

### American precedent

In the U.S., researchers working with the Council for Responsible Genetics in Cambridge, Massachusetts recorded hundreds of cases of misuse of genetic information obtained through family history, genetic tests, or by employers and insurers accessing personal data.

There are many examples of employers and insurers using genetic information to engage in discriminatory policies. In 2001, the Burlington Northern Santa Fe Railroad Company settled a federal lawsuit in the U.S. The company had violated the Americans with Disabilities Act by threatening to fire a worker who did not give a blood sample to test whether he was predisposed to developing carpal tunnel syndrome. The company conducted genetic tests on its employees without their consent as a means of thwarting compensation claims for job-related stress injuries. A person diagnosed with a condition that causes excessive iron storage, but whose symptoms are otherwise manageable, lost her health insurance despite clear medical evidence that she was healthy.

In the U.S., the Genetic Information Nondiscrimination Act (GINA) was signed into law in 2008. GINA provides strong protection against access to genetic information and genetic discrimination in the context of health insurance and employment. It prohibits insurers from “requesting or requiring” genetic tests from an individual or members of the person’s family, or using genetic information to determine eligibility or establish premiums. It also prohibits employers from “requesting or requiring” genetic information for hiring or promotional decisions, or when determining eligibility for training programmes.

Geneticists are not in agreement on the usefulness of genetic tests or even on their veracity. Most importantly, very few single-gene health problems exist and the vast array of common diseases is related to the functioning of networks of genes in the milieu of other central cellular components and also depend on lifestyle and environment.

### Too much miscommunication

Moreover, the popular notion of deoxyribonucleic acid (otherwise known as DNA) being the central and only player in cellular and genetic information and disease with a mere unfolding of characteristics is deeply flawed. While there is mounting evidence to oppose this perception of DNA as a master molecule, there is a lot of miscommunication among scientists and the media on this topic wherein a gene that codes for a protein associated with the outward expression of a condition is regarded as its cause. Correcting this perception, even when genetic reductionist paradigms have shifted, is an uphill battle when commercial interests such as testing have been unleashed.

The Council of Europe has adopted a set of recommendations on the use of genetic information for the purpose of insurance. Canada’s recent Genetic Non-Discrimination Act makes it illegal for insurers or employers to request DNA testing or results. It is reported that insurers in the U.K. are currently under a voluntary moratorium agreed upon between the Association of British Insurers and the government until 2019. Based on this agreement, results from genetic tests are not to be used for health or life insurance except for Huntington’s disease, which is dominantly inherited with a high penetrance. This simply means that there is a high likelihood that those who have this gene develop the disease, which is inherited as an autosomal-dominant trait. But it must be noted here that even with the rare single-gene conditions the genetic expression varies significantly because of other factors.

India too needs a law that prevents genetic discrimination. In this era of rampant genetic testing, we need to prevent discrimination and uphold “equal treatment under the law”. Would the court have ruled the same way if the insurance company had done a genetic test and included a clause that this particular heart condition would not be covered? Equality under the law cannot have exceptions.

### A complex future

The situation is likely to get worse as people become more accepting of predictive genetic tests and insurance companies insist on them; at the moment, they generally use family medical history as the basis for determining premiums. In the medium term, there are also serious concerns related to the protection and privacy of medical and genetic data. Breaking into databanks, as we are all familiar by now, is not impossible as even America’s Federal Bureau of Investigations and other secure firewalls have been breached.

Looking beyond these immediate issues, everyone has genes for some predisposition or the other, this being the human condition. There should therefore be no discrimination based on genetic information. Insurance is developed from pooling risks. If companies begin to insist on

tests for everyone, then potentially no one will be insurable. Only universal health care can therefore be a viable solution.

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