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**Position statement**

**Equal rights to health insurance and employment: Prevention of discrimination based on genetic information: Position statement of the Society for Indian Academy of Medical Genetics (SIAMG)**

**Background:**

Recent advances in genetics and genomic technologies have enabled prevention, diagnosis and improvements in health of general public. However currently all the health insurance providers exclude genetic conditions, birth defects, congenital disorders and congenital anomalies from the purview of coverage. The Society for Indian Academy of Medical Genetics strongly believes that an individual's genetic information should not be used for discrimination from health insurance coverage or discrimination in employment.

**Present status:**

The Insurance Act, 1938, envisaged the establishment of the Insurance Regulatory Development Authority (IRDA) for regulating the insurance sector in India. The guidelines issued by IRDA on February 20, 2013, excluded conditions like pregnancy, infertility, congenital and genetic conditions, but did not define 'genetic' conditions (1). Following this, the insurance companies in India amended the terms of their policies and excluded 'genetic conditions' from insurance coverage. On July 29, 2016, IRDA issued a new guideline for standardization of insurance in health care in India, in which, 'genetic condition' was not mentioned and only 'congenital anomalies' were mentioned (2). On February 26, 2018, Delhi High court held that 'genetic disorder' was a vague term and should not be used to exclude insurance claims and directed the IRDA to re-look at their exclusionary clauses to prevent rejection of claims by insurance companies on the basis of genetic status of individuals (3). On March 19, 2018, IRDA issued a notification directing all insurance companies not to include 'genetic diseases' as one of their exclusion criteria in all health insurance policies (4). The Honorable Supreme Court of India has stayed the operation judgment of the Delhi High Court on August 27, 2018 (5).

The Universal Declaration of Human Rights (6), 1948 states, "Everyone has a right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care, and necessary social services, and the right to security in the vent of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control". The European Convention on Human Rights & Biomedicine does not allow discrimination of any kind on the basis of genetic heritage and permits genetic testing for the purposes of health or for scientific research only and not for insurance purposes. Predictive genetic testing should not be done for insurance purposes (7).

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Many European countries like Austria, Belgium, Switzerland, Denmark and Portugal have made legislations for use and regulation of genetic data (3). Several countries across the world have enacted laws in respect of genetic discrimination by insurance corporations. The Genetic Non-discrimination Act, 2008, in United States of America, bars the use of genetic information in health, education and employment and prohibits charging of higher premium based on the genetic predisposition of an individual for developing a disease in future (8).

Article 14 of the Constitution of India prohibits discrimination of any kind, which includes discrimination based on genetic heritage of an individual (9). The Right to Health is a Fundamental Right, as an integral part of Article 21 (10) and Right to Healthcare is also a Fundamental Right and the right to avail an insurance is an integral part of Right to Healthcare. Hence it is unconstitutional to discriminate individuals based on their genetic status.

### **Society for Indian Academy of Medical Genetics position on discrimination against individuals with genetic conditions:**

Genetic and genomic information of an individual should not be used for discrimination against health insurance and employment. Any such discrimination would amount to misuse of such information.

Explanation:

1. Genetic and genomic information: This means history, clinical evaluation, imaging or medical tests that provide genetic information or reveal the genetic constitution of an individual. Genetic constitution of an individual is determined at the time of conception and well before birth of an individual. They can be revealed by several means: clinical evaluation, family history, analysis of pedigree, blood/urine or any other laboratory tests, imaging (CT scan, MRI, and ultrasonography), genetic/genomic tests (Sanger sequencing, next generation sequencing or any other traditional or specialized genetic tests) and participation in genetic research. Genetic information of an individual aids healthcare of an individual.

2. Discrimination in health insurance: This includes levying additional premiums, asking for genetic/genomic information of an individual, refusing health insurance, refusing claims based on genetic and genomic information and refusing renewals.

3. Discrimination in employment: Employers cannot discriminate in appointment, remuneration, promotion and provision of medical facilities based on genetic and genomic information.

### **References:**

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4. [https://www.livelaw.in/irdai-directs-insurance-companies-stop-excluding-genetic-disorders-new-health-insurance-policies-cites-delhi-hc-judgment-read-notification/\(Ref:IRDAI/HLT/REG/CIR/046/03/2018\)](https://www.livelaw.in/irdai-directs-insurance-companies-stop-excluding-genetic-disorders-new-health-insurance-policies-cites-delhi-hc-judgment-read-notification/(Ref:IRDAI/HLT/REG/CIR/046/03/2018))
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6. Universal Declaration of Human Rights, UN (December 10, 1948)
7. European Convention on Human Rights & Biomedicine, Oviedo (1997)
8. Genetic Non-discrimination Act of USA (2008)
9. Article 14 in The Constitution Of India 1949
10. Article 21 in The Constitution Of India 1949

The executive committee members of the Society for Indian Academy of Medical Genetics (SIAMG) approved this document on 21 November 2018. Correspondence to [info@iamg.in](mailto:info@iamg.in). The statement is available online at the society's website [www.iamg.in](http://www.iamg.in)

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