

The Impact of the "Genetic Revolution" on the Insurance Industry

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On June 27, 2000, newspapers across the country heralded a long-awaited milestone - the deciphering of the human genome, the elusive double helix of DNA molecules that predetermines a large part of an individual's physical and mental destiny. The unlocking of the human genetic code, almost five years in advance of the original goal of 2005, has left employers and insurance providers unprepared for the potential legal and ethical problems associated with access to an employee's genetic information. Although genetic tests are still not used by the insurance industry, it would be naive to assume this trend will continue once genetic testing becomes both cost-effective and widely available. Considering the fact that insurers already base policy-making decisions on genetic information such as family history and diagnostic tests performed in past occurrences of medical care to the applicant, the use of actual genetic data to make insurance decisions is only to be expected.

The Potential for Discrimination

The Health Management Act of 1973 forever changed the landscape of insurance by marking the beginning of the era of managed care. The new for-profit, market driven Managed Care Organization's ("MCO") goal is to control costs through improved efficiency and coordination. Significantly, the MCO structure has effectively shifted the locus of control of medical practice from physicians to financial managers, with a resulting emphasis on cost rather than care. It is well documented that MCOs use discriminatory practices to insure only the healthiest individuals in order to control costs and maintain their market position. Based on the profitability mandate of the MCO, access to genetic information would provide a scientifically justifiable way with which to identify and exclude individuals who seemingly have a higher probability of contracting illness.

In addition to the transformation of the medical insurance industry, the rapid progress in the sharing of patient information among physicians, hospitals, payors, employers and other related health care agencies, will significantly contribute to the stigmatization of individuals who possess detrimental genetic traits.

Legislative Initiatives and Delays

Confronted with the potential legal and ethical dilemmas of the use of genetic information, employers and insurers have, justifiably, looked to the legislature for guidance in using the newfound knowledge of genetic discoveries. States legislatures currently offer varying and often conflicting guidance to insurers. This poses a particular dilemma for larger multi-state insurers, who will be forced to juggle diverse and often conflicting mandates from differing state legislatures. The lack of uniformity in the states that have enacted legislation, and the total absence of legislation in approximately half the states, point to a need for federal action to provide guidance to insurers. The federal government, however, has been less than responsive to the challenges posed by access to genetic data.

On the federal front, the main protection against the misuse of genetic information in the health insurance industry is the Health Insurance Portability and Accountability Act of 1996 ("HIPPA"). HIPPA's protection, however, does not extend to uninsured individuals who apply for individual coverage or who fail to continue coverage through COBRA provisions. Moreover, the Act also does not prevent insurance companies from charging higher premiums to an entire group on the basis of the genetic information of individual members, thereby encouraging employers to discriminate against

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individuals to gain lower insurance rates. These limitations in HIPPA's protections have spurred Congress to introduce a large number of bills addressing genetic discrimination in employment and insurance, none of which has, as yet, been enacted into law.

Court Decisions

In contrast with the inertia of the legislature, the courts have begun to address the privacy rights of individuals to their genetic information, with potentially serious consequences for insurers and health care providers.

In a 1998 action, *Norman-Bloodsaw v. Lawrence Berkeley Laboratories*, employees alleged that, in the course of their mandatory employment entrance examinations and without their knowledge or consent, Lawrence tested their blood and urine for "intimate medical conditions" -specifically, syphilis, sickle cell trait, and pregnancy. In a decision that may have a significant impact on genetic testing in the workplace, the court held that the fact that employees signed medical releases authorizing the collection of blood and urine did not imply their consent to allow the Company to "investigate the most intimate aspects [of their lives]." The court concluded there are "few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up," and remanded the case to the district court for adjudication.

More recently, Burlington Northern Santa Fe Railroad announced that it would stop genetic testing of workers with carpal tunnel syndrome following a widely publicized suit by the Equal Employment Opportunity Commission ("EEOC"). The EEOC charged that the railroad's practice of requiring employees who submitted work-related carpal tunnel syndrome claims to provide blood samples to determine if they might have a genetic propensity for the condition violated the Americans with Disabilities Act.

Time for Proactive Measures by Insurers

Faced with legislative inaction and the potential for judicial activism in the area of medical privacy rights, insurers should be focusing their efforts on lobbying for clear and effective guidance from Congress regarding the use of genetic information. While awaiting the resolve of the legislative impasse, insurers and health care providers should be using industry organizations and committees to forge operating principles to face the advent of the "genetic era."

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