



Insurance, risk, and genomics

On page 12 of this issue, Dr. Maurie Markman raises concerns about the adverse effects of some possible uses of genetic data.

His article, along with Dr. Nancy Fisher's answer to it (page 8), continues a debate that has been going on for many years concerning the undesirability of knowing too much about individual members of a population over which the cost of insurance is to be spread.

The process of carving up such a population into subsets of relatively well-known risk is called underwriting, and insurance companies do it all the time. Although this is beneficial for people considered to be at low risk of illness, death, disability, or whatever they are being insured against, it works to the detriment of those who, through no fault of their own, are at high risk. It is also beneficial to the insurance companies: the more they know, the less their risk, which is, of course, what we are paying them to assume.

Dr. Alan E. Guttmacher and others involved in the Human Genome Project recognized the potential harm of knowing too much, and it goes far beyond the discriminatory practices of insurance companies. Consider the psychological trauma that would result from knowing you have a genetic marker for a dread disease, like Huntington chorea, that can't be cured.

Dr. Markman also calls attention to the projected ability to intervene in the genetic makeup of individuals. While this power may provide the opportunity to prevent some chronic diseases, it also opens the door to the slippery slope of eugenics.

Genomics is an area, like so many others in science, where knowledge of what we *can* do has preceded a clear understanding of what we *should* do. One legal safeguard is in place, the Health Insurance Portability and Accountability Act (HIPAA), and the Genetic Information Nondiscrimination Act of 2003 is pending in the US House of Representatives after passing the Senate. But we as physicians, who need the best data we can get to give our patients the most effective help for their health problems, must carefully guard our patients' privacy to avoid profiteering at their expense by the unscrupulous.

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