

STANFORD UNIVERSITY MEDICAL CENTER

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Embargoed for release until 8:30 a.m. Pacific Standard Time on Tuesday, Feb. 18, to correspond with presentation at the annual meeting of the American Association for the Advancement of Science (AAAS), held in Seattle at the Washington State Convention and Trade Center at the Sheraton Seattle Hotel.

DNA DATA COULD SPAWN 'GENETIC UNDERCLASS'

STANFORD — Public policy initiatives and increased physician awareness are needed to maintain a healthy balance between the promise of genetic engineering and the potential for genetic discrimination, a Stanford/Veterans Affairs physician maintains.

His assertion is based on new, unpublished findings from his own research, as well as on data he and others published in 1992 and 1996.

Genetic discrimination is already occurring in insurance and employment settings and is reaching into the areas of adoption and military service, said Dr. Paul R. Billings, deputy chief of staff for the San Jose (Calif.) Clinic of the VA Palo Alto Health Care System and a clinical associate professor of medicine at Stanford.

"The storage of genetic information, in DNA banks like the one maintained by the Department of Defense, has already produced important problems. There have been several courts-martial of people who haven't agreed to contribute to the Department of Defense DNA bank," he said.

In addition, his new findings suggest that physicians, many of whom may be unaware of the dangers of genetic discrimination, are being asked to sanction the use of genetic tests as a "medical necessity," Billings said.

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"This important change may increase the incidence of genetic discrimination," he said.

Billings will speak in Seattle on Tuesday, Feb. 18, at the annual meeting of the American Association for the Advancement of Science. His talk is part of the morning session, "The Challenges to Civil Liberties Presented by Human Genetics Research" (8:30 to 11:30 a.m.).

While key issues related to genetic discrimination are being played out in laboratories and in the courts, public policy responses are taking shape in both administrative and legislative spheres, Billings said. For instance, the National Association of Insurance Commissioners has taken steps toward developing a position on the use of genetic tests in insurance matters. Such efforts have had limited effectiveness, however, for a couple of reasons, he said.

"The first reason is that the insurance industry has an enormous amount of power to swing this argument away from public oversight and regulation. Second, through our own survey work and the work of others, we've found not only that consumers are generally unaware that the insurance commissioner's office might be of some help to them, but also that insurance commissioners themselves generally don't think this is an important issue and are not really paying attention to it," he said.

Some 20 states have adopted legislation to protect consumers primarily in the area of health insurance, Billings said. In California, for instance, consumers should direct complaints about infringement of the current law to the office of the insurance commissioner. Civil and criminal penalties can arise if genetic discrimination is shown to have resulted in unfair health insurance practices.

Consumers are often afraid, however, that if they make a public complaint about some genetic issue, they might ultimately be blackballed from getting insurance and might even lose their jobs.

"There's a great deal of fear about losing general access to rights, opportunities or entitlements. These are families that in a greater sense see themselves as vulnerable and stigmatized, and not just genetically. Some of them fear socioeconomic repercussions as well. So they don't want to be further marginalized by having to engage in some sort of quasi-public process for which there is, unfortunately, no guarantee that they are going to get a positive outcome," he said.

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"If policy does not match advances in technology in this field, we will see an increase in those who have no symptoms but are treated as if they are ill — the genetic underclass."

Though the current situation presents difficulties, Billings does not characterize it as hopeless.

"I think that not only in proposed legislation, but also in efforts to enhance the protections provided by the Americans With Disabilities Act, there is at least a potential framework by which the burden of genetic discrimination might be lessened," he said.

For instance, the strong health insurance legislation passed by the State of California makes it illegal to use genetic information for rate setting and policy exclusion. Another California bill, set to be introduced this month, will revive a previously defeated effort to extend these types of protections into employment settings, Billings said.

Federal legislation has also been proposed to deal with problems posed by the Department of Defense DNA bank as well as by insurance discrimination, he said.

These types of efforts are needed to maintain the ethical balance, Billings contends.

"Genetic testing is rapidly increasing. Consumer products [for testing] are available or being developed. There is a great deal of investment by the biotech and academic sectors. This offers promise for both predictive and preventive strategies for reducing disease burdens. But the adverse stigma of genetic discrimination is also significant," he said.

"Public policy efforts can create a framework to lessen the burden of discrimination and thus make the balance between the positive and negative outcomes of genetic information more favorable for those who seek genetic information and self-knowledge."

Billings' research has been supported in part by Stanford's Program in Genomics, Ethics and Society.