

Survey Dispels Worries of Genetic Bias by Insurers

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SAN ANTONIO — The specter of discrimination based on genetic test results has turned out to be greatly overblown, Dr. Kenneth Offit said at a breast cancer symposium sponsored by the Cancer Therapy and Research Center.

"It's a topic we've heard a lot about. Maybe too much," added Dr. Offit, chief of the clinical genetics service at the Memorial Sloan-Kettering Cancer Center, New York. "Forty percent of our patients come in saying that this is their major concern, not medical issues. They're worried they'll lose their insurance and that employers will discriminate against them.



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DR. OFFIT

This is a profound concern," he noted.

Yet this concern has not been borne out in the more than 4,000 patients at Sloan-Kettering who have undergone genetic testing, nor has it been confirmed in the 600 known cancer mutation carriers who are being followed there on a regular basis.

"We've asked them, and not one of them has had an episode of genetic discrimination in the workplace or their insurance," the oncologist continued.

Similarly, a careful seven-state survey conducted a few years ago found no cases of genetic discrimination (*Am. J. Hum. Genet.* 2000;66:293-307). "Yet the press and the media still harp on the issue of genetic discrimination," he said.

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there is going to be a supply."

If addicts don't buy the meth directly from a cartel, there are ways to cook it without using cold medicines, although it is more complicated without the ephedrine or pseudoephedrine, Dr. Mohammad said. "Now they will have to turn to people who are more educated and have more knowledge in chemistry."

The Combat Methamphetamine Epidemic Act also included other provisions related to helping meth addicts and their families. Mr. Piper pointed to one provision sponsored by Rep. Sheila Jackson Lee (D-Tex.) that creates grant programs to establish treatment centers for parenting and pregnant women.

"Generally speaking, most drug users tend to be men, but when it comes to meth, about 50% are women," he said. "There is a huge lack of resources for drug treatment for women, especially women with children. If you are [being treated] in-house, you can't bring your child with you, and if you are an outpatient and you don't have child care, it's much more difficult." ■

"Insurance companies in North America are paying for genetic testing, they're paying for counseling, and they're paying for preventive surgery. And in one of the least-told stories around, companies like Blue Cross/Blue Shield and Aetna in New York don't require that genetic test results even go back to them," Dr. Offit said.

Two federal statutes—the Americans with Disabilities Act and HIPAA—protect patients from genetic discrimination. There is also a federal precedent in the

form of a Burlington Northern and Santa Fe Railway Company settlement with the Equal Employment Opportunity Commission that helps protect the medical confidentiality of genetic test results. Moreover, in 2003 the U.S. Senate unanimously passed a bill banning discrimination in employment or health insurance based on genetic testing. The bill hasn't passed in the House of Representatives simply because genetic discrimination is no longer seen as a priority concern there, he said.

Yet genetic discrimination continues to be a high-visibility worry for the public—and this can have destructive consequences. For instance, in a 384-patient study, 14% of women at risk for hereditary breast cancer declined BRCA mutation testing because of concern about insurance discrimination, and based on testing of other women in the study, one-half of those who declined testing would have been expected to be BRCA positive (*Cancer Epidemiol. Biomarkers Prev.* 2002;11:79-87). ■

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