

DNA self-tests: More hype than help?

March 20 2009, By Maria M. Perotin

With a little spit and a few keyboard strokes, you can unlock the secrets of your DNA. At least, it seems that simple at an array of Internet sites that are pitching genetic tests directly to consumers.

The businesses claim to examine customers' genes for conditions grave or mundane - from their risk of cancer to their likelihood of baldness.

They offer a tantalizing peek at the most personal facets of health. But the tests have raised eyebrows among genetic counselors and government regulators, who are skittish about consumers tapping into their DNA without a doctor's involvement.

"Genetic counselors are very concerned about people ordering some of this predisposition testing on their own on the Internet," said Becky Althaus, a genetic counselor at Texas Health Dallas hospital. "A lot of times, this stuff is very complicated. And the results are not that easy to interpret."

Alex Wong, director of products at a California-based company named 23 and Me, said consumers have a right to access their own genetic details.

"We try to make it understandable to the average person," Wong said.
"We don't just say that your risk has been increased by X-number percent and that's that."

Wong's business markets do-it-yourself kits that are supposed to reveal



details about buyers' genealogy and health traits. The company, which includes Google among its investors, invites customers to "get the latest on your DNA with \$399 and a tube of saliva."

The 23andMe test addresses dozens of conditions, from life-threatening diseases to genetic curiosities. Among them: whether you have a genetic predisposition for <u>breast cancer</u>, your risk of <u>celiac disease</u>, what type of earwax you have, whether you can taste bitter flavors and whether you're resistant to malaria.

Some of the tests are well-established among scientists, while the significance of others is far less certain.

"We're actually very careful to educate our users about the relative reliability of that information," Wong said.

Among the other tests available to consumers:

Colorado-based Sciona sells "personalized genetics assessments" that purport to reveal how your genetic makeup affects metabolism, diet, nutritional processing and lifestyle.

California-based Psynomics offers a test for two genetic mutations supposedly associated with bipolar disorder.

California-based HairDX says its test, only available from certain doctors, can predict the risk of baldness.

ScientificMatch.com pitches help finding a mate with "physical chemistry" based on your immune system genes. The Florida company says this boosts your chances of having a satisfying sex life, making healthy babies and avoiding infidelity. A lifetime membership is on sale for \$995.



GOVERNMENT WARNINGS

Skepticism abounds about the tests.

The Federal Trade Commission - together with the Food and Drug Administration and the Centers for Disease Control and Prevention _ issued a warning in 2006 against at-home genetic tests.

The federal Government Accountability Office also sounded caution in 2006 after the agency investigated four DNA-testing Web sites _ including one that sold "personalized" dietary supplements and another that said its pills could repair damaged DNA.

Its findings: The businesses made misleading, medically unproven predictions. And they offered ambiguous recommendations based on consumers' lifestyles - not any unique genetic profile.

Last year, regulators in California and New York stepped up their scrutiny of the industry. And in April, a federal advisory committee concluded that there's insufficient oversight of the labs that market genetic tests to consumers and raised concern about potentially "adverse patient outcomes."

Jame Restau, a clinical nurse specialist at Baylor Medical Center at Irving, Texas, said patients are often curious about new research and which genetic tests may become available.

She tells them that many potentially meaningful tests are in the pipeline but warns that some businesses are promoting unproven tests.

"If it sounds too good to be true, it probably is."

Restau said.



Althaus, of Texas Health Dallas, said genetic testing gets a lot of hype but holds a lot of promise. "Right now, we're just starting with tests for some pretty specific cancer genes. And now, there's a test for Alzheimer's, and there's a test for a predisposition for heart disease. So we really are getting some new information that can help people," she said. "Every day, they're discovering new things that can be valuable in helping us in treatment and in prevention."

BEFORE YOU BUY A GENETIC TEST

Know that at-home tests aren't a substitute for a traditional health evaluation with conventional lab tests.

Realize that genetic tests provide only one piece of information about your susceptibility to a disease. Other factors, such as family background, medical history and environment, are also important.

Keep in mind that finding a particular gene doesn't necessarily mean a disease will develop.

Be wary of claims that you can protect against serious disease with nutritional supplements. The same goes for predictions about your ability to withstand environmental exposures, such as cigarette smoke.

Talk to your doctor beforehand about whether a genetic test might provide useful information and which test would be best for you.

Ask your doctor or a genetic counselor to help you understand your test results. Do that before making any dietary or other health-related decisions.



Check the testing company's privacy policy to see how it may use your personal information, including sharing it with marketers, and whether it posts results online.

Source: Federal Trade Commission

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