

OMG - Guess what my genes say?

Researcher discusses ethics of posting genetic info online

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(PhysOrg.com) -- Spit in a tube, mail away the sample and learn what's in your genome. A decade ago, this was science fiction; now, thanks to personal genomics companies such as Silicon Valley's 23andMe, it's straightforward science fact.

But who owns your genetic information? Who can use it and why? And is it really a good idea to put your gene data on Facebook? Uta Francke, MD, a professor of genetics and of pediatrics at the Stanford University School of Medicine, explored some of the ethical questions that arise from our new ability to peer into our own genes at the annual American Association for the Advancement of Science meeting.

“Right now, we understand very little of the meaning of those 3 billion nucleotides,” Francke said, adding that although private companies aren't yet reading all 3 billion genetic “letters,” inexpensive, widely available whole-genome sequencing is just around the corner.

Though our insight is limited, learning about your genes already has benefits: About 20 potentially preventable health problems can now be detected with gene testing, allowing those at high risk to take measures to ward off disease. A woman with a dangerous [breast cancer](#) gene might opt for frequent mammograms or a preventive mastectomy, for example.

And yet, because so much is still unknown, sharing personal genetic data

in a public forum is “like publishing a book where you can’t read most of it yet,” Francke said. “But it will be readable in five to 10 years, and if the book is out there, anybody can read it.”

This becomes particularly troubling when you consider that your genome isn’t yours alone, she added. “You share your genome with your family. Shouldn’t they be asked before you put your [genome](#) on the Web?” First-degree relatives, such as parents, children and siblings, share 50 percent of their gene sequences.

In addition to exploring the issues above, Francke’s presentation explained the journey science has taken from the [Human Genome Project](#) to direct-to-consumer gene sequencing. She discussed the Genetic Information Nondiscrimination Act of 2008, which restricts how employers and health insurers can use an individual’s [genetic data](#). And she talked about whether there is a fundamental right for individuals to choose not to know what’s in their genomes, and asked how such a right could be protected in the Information Age.

Provided by Stanford University Medical Center

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