**The Spitterati and Trickle-Down Genomics**

by Marcy Darnovsky, [*Mother Jones* blog](http://www.motherjones.com/blue_marble_blog/archives/2008/11/10616_the-spitterati-part-two.html)  
November 3rd, 2008

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| [[http://www.geneticsandsociety.org/img/pic/spittoon.jpg](http://www.geneticsandsociety.org/img/original/spittoon.jpg)](http://www.geneticsandsociety.org/img/original/spittoon.jpg) |
| A gold-inlay spittoon |

Just before the world's financial system hit the skids, the [*New Yorker's*](http://www.newyorker.com/talk/2008/09/22/080922ta_talk_schulman) Talk of the Town and the [*New York Times'*](http://www.nytimes.com/2008/09/14/fashion/14spit.html) Sunday Styles section both featured lengthy accounts of a celebrity "spit party," at which notables in cocktail attire ejected their saliva into test tubes. The chic gala, hosted by media moguls Barry Diller, Rupert Murdoch, and Harvey Weinstein, was the latest episode of a remarkable publicity push by [23andMe](https://www.23andme.com/), the start-up biotech firm whose mission is "to be the world's trusted source of personal genetic information."

The Google-backed company launched its celebrity strategy this past January, when it distributed a thousand free spit kits at the elite World Economic Forum in Davos, Switzerland. But the genomes of the rich and famous were just the first step. Early this fall, 23andMe announced that it's slashing its prices to Christmas-stocking levels, in a bid to make DNA tests this year's high-tech must-have.

This is shrewd promotion. Though the spreading economic gloom may put a ding in sales of $399 spit kits, 23andMe remains on a media roll. The company has been attracting gobs (so to speak) of fawning attention for months, and *Time* just put it at the top of a list of the ["50 best innovations"](http://www.time.com/time/specials/packages/0,28757,1852747,00.html) of 2008. Its habit of inviting key reporters to its fancy parties, and throwing in free kits along with the glamour and glitz, hasn't hurt a bit.

The celebrity coverage and top-of-the-list triumph constitute a fanfare introduction to the new direct-to-consumer personal genomics industry. They also serve to deflect attention from the array of criticisms and concerns about the new gene tests that have been voiced by medical experts, public interest groups, and policy makers.

23andMe is just one-though by far the most publicized-of the couple dozen companies that now offer to analyze your DNA if you'll just send them some spit and a wad of cash. Some of the companies promise information about your risk of specific serious conditions such as multiple sclerosis. Others offer tests for "hair loss" or "addiction," or claim to reveal the optimum foods for your genetic profile. Several, including 23andMe, scan your entire genome for variants that supposedly predispose you to a range of conditions, from Alzheimer's to arthritis to athletic performance.

Even observers who typically greet DNA claims with unquestioning enthusiasm have raised serious concerns about whether direct-to-consumer gene tests are ready for prime time. First of all, they point out, we know little about the accuracy of these tests because they're so inadequately regulated.

Secondly, when the tests are technically accurate-that is, when they identify the genetic sequences they say they do-it's often unclear what they mean. Especially for non-disease traits such as athleticism, the evidence for genetic links is sketchy at best.

And even when a correlation between a genetic variation and a condition is well characterized, having it doesn't mean you'll necessarily get the disease in question. It may increase your odds, but that doesn't tell you when, how seriously, or what to do about it.

So if your family history suggests that a gene test might be meaningful, you're far better off taking it in the context of a doctor's care and a genetic counselor's advice. Otherwise, you may find yourself facing weighty medical or life decisions on the basis of preliminary and possibly spurious consumer gene test results.

These realities, along with the practices and marketing claims of the personal [genomics companies](http://www.motherjones.com/news/special_reports/1998/05/genes.html), prompted the health departments of California and New York to intervene. In June, they sent "cease and desist" letters to several companies, basically telling them to stop practicing medicine without a license. But the California regulators have since backed down.

Efforts by California and Massachusetts to assert regulatory oversight of direct-to-consumer gene testing companies elicited predictable howls in the libertarian-leaning regions of the blogosphere. The gist of the don't-tread-on-me argument: Those are my DNA sequences; keep your hands off.

23andMe understands this impulse, and appeals to it. On the "values" page of its [website](https://www.23andme.com/), for example, it says, "We believe that your genetic information should be controlled by you….Though we store and help you interpret it, your genetic information is yours to have and explore."

Well, sort of. What the company doesn't quite come out and say is that its real business plan isn't selling spit kits or interpreting DNA tests, but compiling vast databases of genetic and phenotypic information that it can sell to researchers at drug companies. In other words, there's gold in them thar genes, and Google, other investors, and the [consumer genetics](http://www.motherjones.com/news/special_reports/1998/05/lauerman.html) sector are laying their stakes to it. But though this entire enterprise depends on the results of the government-funded Human Genome Project and is likely to have significant social consequences, regulators are supposed to back off.

And the people who pay hundreds or thousands of dollars for the freedom to contribute their DNA samples? They'll have no claim or control. Buried in the [*New York Times*](http://www.nytimes.com/2008/09/14/fashion/14spit.html) account is the detail that while purchasers can choose not to participate in the company's survey about their phenotypic traits, they "cannot opt out of having their information anonymously shared" with researchers.

The direct-to-consumer genomics industry isn't the first to make its customers part of its product. Media companies, for example, earn most of their money by delivering audiences to advertisers. But while you can turn the page or close the pop-up window to avoid ads and commercials, 23andMe won't let you take your genetic information out of the massive DNA databases it plans to build.

There may be even more to worry about. The [consumer genomics](http://www.motherjones.com/news/feature/2001/11/gene.html) enterprise raises additional concerns that are more subtle, and perhaps more troubling. Will 23andMe-type gene tests reinforce exaggerated ideas about the role of DNA in who we are as individuals and how we see each other? Will they change the way we arrange our communities and our society?

The answers to these questions, like the results of today's gene tests, are blurry. Unsurprisingly, 23andMe co-founder Anne Wojcicki (who is married to Google's Sergey Brin) sees a rosy future: "We envision a new type of community where people will come together around specific genotypes, and these artificial barriers of country and race will start to break down." Along similar lines, the company's press release announcing its recent price cut described the move as a way to "democratize personal genetics."

But where boosters see barriers of country and race tumbling down, others see new-or revived-hurdles to social justice. Without careful handling, the new genetic tests could easily stoke tendencies to explain our health-and our social and health disparities-in terms of inherited biology, rather than access to education, housing, and health care.

As the director of the National Human Genome Research Institute from 1993 until earlier this year, Francis Collins is in a good position to assess these matters. "I very much worry that all this emphasis on a 'gene for this' and 'gene for that' raises the risk that people will conclude that that's the whole story," he told the [*Washington Post*](http://www.washingtonpost.com/wp-dyn/content/article/2008/03/24/AR2008032402750_pf.html) in March. The front-page article described Collins' concern that gene tests will encourage "the kind of DNA-deterministic thinking that fed the early 20th-century eugenics movement, in which people with `undesirable' traits underwent forced sterilizations."

Personalized medicine may well hold promise for future benefits in health care. But its positive potentials-and the good intentions of many trying to develop it-aren't the whole story. The direct-to-consumer genetic testing industry is harnessing its plans to high-tech glitter and Google's clout, and hurtling ahead with little consideration of the social policies and oversight we need.

So for now, we'd best be careful where we spit.

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