DNA Dilemma: Should I Take a Genetic Test? One writer's quest to determine if she should take an at-

home gene test. First in a weeklong series.

by Mary Carmichael | August 2, 2010 The Daily Beast/Newsweek

On July 22, Congress held a hearing on direct-to-consumer (DTC) genetic tests, services that analyze your DNA and interpret the results in exchange for a few hundred bucks—no doctor necessary. The hearing could have been a thoughtful national conversation about science, business, and ethics. Alas, it devolved instead into a series of gotcha moments, starring a General Accounting Office sting operation that came off like a cross between the ACORN videos and the world's worst ad for snake oil.

Time and again, on tape, an undercover agent called up an unidentified testing company and asked an ill-informed question. ("Is it OK if I stop taking my cholesterol meds and instead take the nutritional supplements you sell? If I can manage to get hold of my fiancé's saliva without him knowing, will you run it through your machines so I can surprise him with the 'gift' of his own data?") And time and again, the phone rep sank to the occasion and made the company look awful. (Sure, lay off the pills and take our supplements! Of course we'll analyze your fiancé's spit without his permission even though that's illegal, unethical, and weird!)

I listened to the tape several times the day it was released, despairing at the way people were taking advantage of gullible, albeit fictional consumers, which was clearly how the congressmen who held the hearing wanted me to react. Then I started to worry about something else. How much time did I even have left to decide whether I was going to take a test myself? Even before the hearing, the FDA had announced its plans to regulate all DTC genetic tests, possibly so heavily as to keep them off the market; the hearing was just the sort of thing that could push it to move faster. What if, by the time I finally decided if I wanted one of these tests, I couldn't buy one anymore? My credit card was sitting next to my laptop. I did something that in retrospect seems a bit rash. There's a DNA-collection kit on my desk now, taunting me—because although I bought the thing, I still can't decide whether I actually want to use it.

I'm not the only one who's ambivalent: while most Americans are curious to learn what's in their genes, fewer than 100,000 have actually bought the scans available to them. A few weeks ago a friend asked me if I'd had my DNA scanned, and I told him I hadn't, but that I'd "love to find out what's in there." If that was true, why hadn't I bought the test already? Are there legitimate reasons to hesitate? To find out, I decide to embark on a weeklong project, asking the questions I had hoped the congressional hearing would tackle, and seeking answers from some of the most trusted voices on the Net—as well as from readers and commenters offering feedback.

I've been following DTC genetics since 2007, when wide scanning first became available to the public. Since then, a number of writers have gotten wide-scale genetic tests and expounded on the results. Indeed, I sometimes wonder if I'm the last science reporter on earth with virgin genes. (Technical virgin: My doctor gave me a cystic fibrosis carrier test when I was pregnant.) Initially, I put off getting a full-genome scan because I wasn't sure how useful such a test would be. I had no particular reason to take one, save curiosity. I wouldn't expect to find anything

serious and potentially life-altering like the Huntington's disease gene in my results, because my family medical history is thankfully rather boring. The data most likely to be medically relevant to me would concern the genetics of common diseases, and at the time, many comprehensive and well-designed studies of those were still getting underway. I decided to wait a few years and see how research progressed. But here I am, three years later, still unsure.

Plenty has changed since 2007, but those changes have in some ways made the decision harder. Scientists have learned many interesting things about the genetics of common disease in the last three years. One of the things they've learned is that they have a long way to go in refining their understanding. Meanwhile, the DTC genetics industry has gone completely unregulated, and in a lot of senses the market has become more difficult to navigate. The hearing—which rehashed many of the same points made in a similar hearing four years ago, before wide-scale DTC scanning was even available to the public—may have confused things even further. The GAO tape, for instance, doesn't name the companies its fake callers are consulting. The result is a flattening effect that conflates all the companies with each other. It's a little like taking the nutrition information for the Outback Steakhouse Aussie Cheese Fries with Ranch Dressing, breathlessly broadcasting it—2,900 calories! 240 carbs! 182 grams of fat! —and using it as evidence that food, period, is bad for you.

Still, there are legitimate questions to ask about these tests—how do they work, exactly? How do the companies ensure that their genotyping is accurate and their risk predictions are based on solid genetic and epidemiological statistics? Is there any point in getting a risk estimate if it's by necessity an incomplete one—especially if you're from a non-European ethnic group with understudied DNA—or if the results aren't something you can act on, medically speaking? How well do people really understand what they're getting with these tests? Where does ancestry testing, often offered as part of the package, fit in? Is DTC genetics medicine, recreation, or some strange hybrid of the two? Is it a "trivialization of genetics" or an attempt to make science relevant and interesting to broad swaths of people? Is it both?

These are the kinds of questions I've been trying to answer to my own satisfaction over the last three years, and they're the questions I'll pose to the experts assembled on this Web site in the coming days. All of our official contributors were given a few basic instructions: (1) Keep it short and sweet. The issues surrounding DTC genetics are already potentially confusing; don't make them more so. (2) At the same time, don't insult my intelligence. The GAO's fictional callers may be painfully gullible, but I'm not and neither are my readers. (3) Admit your biases. If you have a financial stake in the personal genomics industry's success or its failure, tell us; otherwise someone else will probably point it out for you. I'd extend those directions to anyone who comments on the project, because I hope to take many of those opinions as seriously as I take those of the people we specifically asked to weigh in.

Of course, even if our reader poll ends up being 99 percent pro-test, I may decide to abstain. What I'm doing here is simply gathering a wide variety of opinions and information that may or may not help me choose. I'll make my decision on Friday, Aug. 6, after reading all the feedback.