

## PART IV

# *Genome Time*

Back when the direct-to-consumer genetic testing (DTC-GT) company 23andMe was just getting started, my wife's medical school decided it would offer a free DNA test to every entering student. Since practitioners might soon be confronted with patients who had gotten DNA tests and would then want to know what they meant, the school thought it would be a good idea – maybe even a fun icebreaker – to let first-year medical students see for themselves what consumer genetics had to offer.

As a professor of law, medicine, and bioethics who was also directing their required course in genetics, my wife thought it would be the responsible thing to do to take the test herself. But even before she received the results, she began to have second thoughts. How much did she really want to know about whatever 23andMe's (rather limited) panel of results might reveal? What privacy protections did they have in place? Did she really want to know the company's estimate of her risk for future health complications? She already knew she did not want to learn about Alzheimer's and Parkinson's and so opted out of receiving risk scores for those conditions. It didn't help when she began reading studies that showed wide differences in results obtained from the three best-known DTC-GT companies.

The night she found a call on our answering machine from a stranger in another state claiming kin, she grew affirmatively disturbed. Something about the voice on the machine felt a little creepy. She was bothered to realize that she had voluntarily offered up private information about herself to a third party – in fact, like everyone else who uses these services, she had actually *paid* a corporation to take her personal data. And now she was feeling vulnerable.

Over the years, as news has come out about police departments submitting DNA samples under false names to gain information that would allow them to identify suspects in crimes and about 23andMe's contract with the pharmaceutical company Glaxo Smith Kline to share de-identified health information about subjects in 23andMe's database, enthusiasm for DTC-GT services has begun to wane. To be fair,

23andMe offers its customers the option to opt out of having their data used in for-profit drug development, and it has always had one of the better privacy policies in the business, but like almost all End User License Agreements, it reserves the right to change its privacy policy at any time.

Some of the things that go on in the largely unregulated world of DTC-GT might astonish you. Few people are aware that there are some ninety DTC-GT companies operating in the United States alone. Many of them have appallingly bad privacy policies or no policy at all.<sup>1</sup> Still fewer people are aware of the practice of surreptitious genetic testing in which customers take DNA samples from their spouse or children without their knowledge and submit them for analysis in order to help discover potential infidelities or to aid in a divorce or child custody case. Twenty-seven DTC-GT companies allow or explicitly encourage the submission of surreptitious samples – one advertisement helpfully suggests that you send in discarded cigarette butts, chewing gum, used condoms, dirty underwear, or lipstick stains.

Not all apprehensions about these services concern the protection of personal data. Another troublesome aspect of commercial genetic testing is the problem of what consumers will do with their data once it is returned. Even with the aid of glossy explanatory brochures, many people find themselves needing to pay an additional company to interpret their results, racking up further costs for information that rarely is very useful in a clinical setting. Primary care physicians, in turn, report not having the expertise to know how to interpret detailed genetic data and so often end up referring patients to specialists – an economic burden on society even for those patients who have the means or insurance coverage to afford it.

Most of all, there can be unexpected psychic costs. Long before the phrase “trigger warning” had entered the lexicon, I learned from my students that I needed to be careful about how I approached novels that dealt with breast cancer or Alzheimer’s disease because those books could be disturbing for students with relatives who were afflicted with these conditions. More than once, a student approached me after class to ask whom they should talk to about their own risks or to explain why they did not want to get tested.

Invariably, the anxiety that students were experiencing had a temporal dimension. Here was a test that could reveal their future – or so they (mistakenly) thought – and it was disconcerting to consider that a sequence of letters could open a vista on a danger that lay decades ahead. What would such knowledge do to them in the interim? How would they be changed? After such knowledge, what . . . relief? despair? This, it seems, was the curse of data in the age of genome time.