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Inside 23andMe founder Anne Wojcicki's $99 DNA Revolution

The $126 million genetic-testing company can tell you how to live smarter, better, and longer. It can also tell you what might kill you.

23andMe CEO **Anne Wojcicki**'s radical idea has a simple motivation: "There are choices you can make in life that will make you as healthy as possible."
[PHOTOS BY JEFF BROWN]

BY ELIZABETH MURPHY

LONG READ

There's a lot you can do for your child with 99 dollars.

You can purchase 14 gallons of organic milk or 396 lollipops. You can give her 33 rides on the Ferris wheel at the state fair, or you can get him a couple of violin lessons. You could put the money in a savings account, you could buy her her very own LeapFrog LeapPad Explorer digital learning tablet, or you could buy enough pizzas to feed all of her friends on the block. So many options, so many choices.

I took that money and got my daughter's genes tested, ordering up an analysis of the composition of her very small self and its odds of living a long and healthy life. And in so doing, I in some small way tied her fate to the success of the company doing the analysis, a genetic-testing startup called 23andMe in Mountain View, California.

Last May, Angelina Jolie revealed in a New York Times op-ed that she had chosen to have a double mastectomy after testing positive for a likely lethal BRCA1 mutation. Her generous manifesto spoke to the value of knowledge and the ability to act upon it. That morning, emails, texts, and calls came pouring in for Anne Wojcicki, founder and CEO of 23andMe. "Did you see this? Did you see this? Do you test for that?" Yes, she had seen it. Yes, her company might test for it (Jolie's exact mutation was not disclosed)–it tests hundreds of possible risk associations, including the three most common BRCA1 and 2 mutations. "Angelina Jolie talking about a technical subject and saying, 'I did this, you can do this' is a great thing for us," says Wojcicki. "She did something to *prevent* disease, and that's exactly what we want people thinking about."

Wojcicki has been thinking deeply about this for years. A former Wall Streeter with a degree in biology, she has parlayed a personal interest in wellness into a thriving, potentially groundbreaking business. Since founding 23andMe in 2006–with the backing of an impressive list of investors including her husband, Sergey Brin, and the company he then ran, Google–she has been working toward two goals: bringing the power of genetic testing to everyday consumers so they can better manage their own health care, and using the aggregated data from those tests to help doctors, scientists, hospitals, and researchers discover new cures for diseases that emanate from troublesome genetic mutations. (Wojcicki and Brin announced their separation in August. A 23andMe spokesperson says, "He remains committed to the company.") It has not been a business for the faint of heart–the three other similarly positioned startups in the field have changed course–but Wojcicki has deep pockets, having raised more than $126 million since 23andMe's inception, with Yuri Milner, the Russian billionaire who's invested in Facebook, Twitter, and Airbnb, joining as a backer last December.

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Wojcicki is connected to the fabric of Silicon Valley, which has served her well. But her goals are global. "We're not just looking to get a venture-capital return," Wojcicki says. "We set out with this company to revolutionize health care." On the same December day when she closed a $59 million round of financing, she dropped the price of 23andMe's genetic testing from $299 to $99. While prices like that may not make taking control of one's health a universal, democratic reality, they accelerate our society's move in that direction. The end result could be a wholesale shift in the way we treat illness, a move away from our current diagnostic model to one based on prevention. That's why, if Wojcicki gets it right, 23andMe could help change the health care industry as we know it. "At $99, we are opening the doors of access," she says. "Genetics is part of an entire path for how you're going to live a healthier life."

As 23andMe scales, its business model will shift. Right now it gets most of its revenue from the $99 that people like me pay in return for test-tube kits and the results we get back after we send off our spit-filled tubes. "The long game here is not to make money selling kits, although the kits are essential to get the base level data," says Patrick Chung, a 23andMe board member and partner at the venture-capital firm NEA. "Once you have the data, [the company] does actually become the Google of personalized health care." Genetic data on a massive scale is likely to be an extremely valuable commodity to pharmaceutical companies, hospitals, and even governments. This is where the real growth potential is.

But first Wojcicki needs spit. Her goal is to sign up a million customers by the end of 2013. Eventually, she says, "I want 25 million people. Once you get 25 million people, there's just a huge power of what types of discoveries you can make. Big data is going to make us all healthier. What kind of diet should certain people be on? Are there things people are doing that make them really high-risk for cancer? There's a whole group of people who are 100-plus and have no disease. Why?" As of September, 23andMe had 400,000 genotyped customers. It's betting on quite an impressive fourth quarter.

I had never really considered getting genetic testing before taking on this story assignment. (And getting the testing was not a mandate–my editors just wanted me to write about the process of considering it.) But my 5-year-old daughter, whom my husband and I adopted as a baby from Ethiopia, had started asking questions about her birth family that we couldn't answer. Did we think they looked like her? Were her siblings fast like her? Where had her grandparents come from? With kindergarten fast approaching and with emotionally loaded projects such as constructing a family tree looming on the horizon, I thought maybe I could erase at least a few of the question marks. The same saliva that allows 23andMe to find genetic mutations that increase or decrease your odds of getting a disease also reveals a lot of data about your genealogical roots.

There's something scary about asking for cold, hard, computer-driven data about someone you love. did i really want to know?

I went back and forth for a few days before deciding to get her tested. There's something scary about asking for cold, hard, computer-driven data about someone you love. Did I really want to know? What would I do with the information? Would I change as a parent if I found out she was at risk for something scary, and would that change be helpful or harmful to her?

ILLUSTRATION BY KARLSSONWILKER

Wojcicki believes it's a parent's duty to arm herself with her children's genetic blueprint, that the power of knowledge outweighs its burden. She's already put that pragmatism to work for her family. In 2008, her husband took a 23andMe test that revealed he possesses a genetic mutation called LRRK2, which gives him a sharply increased risk–30% to 75%, compared to 1% for the general population–of contracting Parkinson's. His mother possessed the same gene and was diagnosed at the age of 47. It also meant there was a 50% chance their two young children would inherit his mutation. "I'd rather have Sergey be proactive," says Wojcicki, when I meet with her in August. "He's drinking coffee and exercising all the time [two behaviors thought to reduce a person's risk for Parkinson's]. I'd rather we give a lot of money to Michael J. Fox than be surprised at 50 when [Sergey] is diagnosed and say, 'Well, shit, I wish I could've done things.' And as for my kids, they're going to die of something." My eyes widen at her frankness, and she

starts laughing. "It's just the reality. Everyone's going to die and everyone's going to get sick at some point. But I do believe that there are choices you can make in life that will make you as healthy as possible."

Ultimately, I found her logic persuasive. And if I was willing to do it for my daughter, I was certainly brave enough to do it for myself. My husband felt differently. "I go with fate," he said. He felt that what seemed like a forbidden glimpse at elevated risk factors or rare carrier states wouldn't improve the quality of his life, but would instead saddle him with a sense of helpless anxiety. Still, he agreed that we owed our daughter as much information about herself as we could find. In June, a package with our test tubes arrived in the mailbox. "Remember," my husband warned kindly as I opened the envelope, as user-friendly as the Netflix DVD variety. "There's such a thing as having too much information."

Finding people who want their genes tested was never going to be easy for 23andMe. There's always something intimidating about a new technology that's difficult to understand.

In 2003, an international scientific research team successfully completed the Human Genome Project, the first full sequencing of the human genome. (Think of the human genome as the house for every person's hereditary belongings, furnished with the DNA sequences within our 23 chromosome pairs: half passed down from our mother, half from our father.) It was a Herculean effort that took 13 years, the combined brainpower of thousands of scientists, and $2.7 billion. It was science and health care's equivalent of landing on the moon. Soon the technology was made available to people through physicians, albeit at sky-high prices–Steve Jobs reportedly had his genome mapped for $100,000. Eventually, through doctors, patients able to pay upwards of $5,000 were able to sequence specific genes, which means they could learn the precise order of nucleotides in a DNA molecule. Jolie's test, which sequenced two genes, cost about $3,000. What 23andMe offers is called SNP genotyping, named for single nucleotide polymorphisms (aka snips). The process covers less than 0.1% of the entire genome, but even that contains so much data that 23andMe can offer customers information on more than 254 factors, from disease-carrier status to drug-response likelihoods to ancestral information.

Geneticist Ricki Lewis remembers the pandemonium that arose when 23andMe and three other companies revealed at a 2007 American Society of Human Genetics meeting that they planned to start offering personal genetic testing directly to consumers, without the traditional middlemen of doctors and insurance companies. "People were so up in arms they didn't even eat the cookies," she says. "That's the first time I've been to a conference where the food just piled up." There were many currents of outrage. Scientists argued that the public wasn't prepared emotionally or intellectually to process this kind of data.

Others felt that the data were largely meaningless, anyway. "If people want to engage in a genetic parlor game, that's fine," says Dr. Jim Evans, a general practitioner and professor of medicine and genetics at the University of North Carolina, Chapel Hill. "We're all a bit narcissistic. But the truth is that finding anything worthwhile about your health from one of their tests is *really*rare. Finding out something really scary is rare too."

Genetic testing also suffers from its portrayal in our cultural landscape. For many of us, the bulk of our genetic knowledge comes from guilty viewings of the *Maury Povich Show*, in which some sleazeball learns he's the daddy because of a hair sample, or from gnarly episodes of *House*. Or perhaps we remember the 1997 dystopian science-fiction film *Gattaca*, in which Ethan Hawke's genetically inferior hero resists his second-class status. It's a portrait of a society that uses genetic data as the basis for a chilling program of eugenics.

Wojcicki was always unfazed by what she was up against. Her company first began offering testing services to consumers in November 2007, for the lofty cost of $999. Those original tests offered 14 reports, from the silly (Is your earwax more likely wet or dry?) to the serious (Do you have markers that put you at risk for type 2 diabetes or venous thromboembolism?). And its direct-to-consumer approach attracted a wave of media coverage. In 2008, *Time* magazine named 23andMe the "invention of the year." But consumers were slow to sign up, and Wojcicki and the other early employees spent the first few years developing their technology, establishing scientific credibility, and zeroing in on three specific disease populations–including Parkinson's–for research. By 2010, the company had signed up only 35,000 paying customers.

Consumer leeriness, however, might be easing. The idea of getting more data about your very self seems a lot less weird in an era when people are walking around wearing Nike FuelBands to monitor their daily activity. And as with any technology, genetic testing has become more familiar as its value becomes more apparent. Jolie's *New York Times* article, for example, provoked a rush of orders for 23andMe. In 2013 alone, the company has signed up 220,000 folks.

Still, Wojcicki wants that 1 million, or better yet 25 million. And she wants them as soon as possible. So in June, she hired Andy Page, the former president of a well-established Internet consumer brand, Gilt Groupe, as her company's president. He and marketing chief Neil Rothstein, who'd come from Netflix, set about boosting 23andMe's customer outreach.

Rothstein's team charged right in, conducting a series of focus groups to evaluate the potential consumer base. Rothstein accepted some stark results: 23andMe might have serious trouble winning over the segments of the population who reflexively reject the idea of genetic testing on the basis of privacy concerns or fear of the unknown. So he decided to concentrate the company's resources on attracting those consumers who want to be proactive about their health. In August, 23andMe launched a multimillion-dollar advertising campaign aimed squarely at that crowd. "We're not really focused on a specific age group or gender or fitness level," says Rothstein. "It's people who have this control mind-set."

People more like Wojcicki, in other words, whose ambitious nature is balanced with a committed rationality. Every day, Wojcicki rides her elliptical bike to the 23andMe headquarters, in Mountain View. She has no office there of her own. Instead, she totes her laptop over either to a red sofa near the research department or a table in the cafeteria, which is across from the gym where her employees gather every afternoon for yoga, Pilates, or Crossfit. One morning, she and I meet in an empty conference room. She glances at the bottle of coconut water I helped myself to from the company refrigerator. "I'm at a slightly higher risk for type 2 diabetes and my grandmother had diabetes," she tells me. "My hemoglobin a1c, which is one of the measures, started being a little high when I was drinking a ton of that coconut water." Is coconut water bad for you? I ask. "All I know," she says with a laugh, "is I was drinking four a day and my hemoglobin a1c was high, and when I stopped, it went down. I took that more seriously because I have a genetic risk."

She's dressed in her usual work uniform–Lululemon shorts, a tank top, and flip-flops. "When I was on Wall Street, I had to wear a skirt suit every day, so this is a little bit of my rebellion," she explains. Wojcicki grew up nearby, on the Stanford University campus, where her father is a renowned professor of physics. Her mother is a high school journalism teacher. Both were incredibly frugal. Her mother used to take her and her two sisters to Sizzler and order two all-you-can-eat salad-bar plates, having the girls rotate in the bathroom to avoid detection. To this day, her mother stands in line at 4 a.m. on Black Friday to "fight for laptops," she says. "My parents were passionate about what they did, very cheap, and very focused on doing good in society."

Wojcicki was always headstrong. When she was 2 years old, she started figure skating. But after several years, "it started to be a little bit like Honey Boo Boo on ice," she says. "And you weren't going to dress me up and make me look pretty in a pageant." So she quit and started playing ice hockey instead. When she graduated from Yale with a degree in biology, she went to work for a biotech-related hedge fund, despite the fact that her folks were outright offended. "It was always embarrassing to come home," she says. "People were like, 'Oh, Anne, you Wall Street girl.'" She says she spent 10 years on Wall Street–mostly at Investor AB and Passport Capital–watching how companies made money on sickness and listening to CEOs insist it wasn't their responsibility to understand how their companies' drugs worked. "I went to this one event in D.C.," she says, "and there was just this football-field-size room with people in dark suits who were all there to learn about maximizing billing codes."

She left Wall Street in 2000, with the intention of taking her MCATs and going to medical school. "But I couldn't find a doctor who would tell me to go," she says. "Think of it: You graduate, it's a ton of debt, it beats you down." One night she was at a dinner with Markus Stoffel, then a scientist at Rockefeller University. He described plans for a genetics project that would explore the variations associated with high blood pressure, obesity, and diabetes in the population of the Micronesian island of Kosrae. "He said they had so much data it was overwhelming," says Wojcicki, "but also not enough data to make sense of things. We talked about what would happen if you could get the world's DNA. And he said it would change the world."

"We talked about what would happen if you could get the world's DNA," recalls Wojcicki. "And he said it would change the world."

Now she has a company that is, she hopes, finally poised to deliver on that idea. Wojcicki has a simple way of summing up its mission. "Healthy at 100," she says. I joke that some mornings I feel used up at 39. Wojcicki, 40, looks at me in disbelief. "I think life is pretty awesome," she says. "I mean, there's going to be space travel at some point."

I first met my daughter in an Ethiopian guesthouse in 2009. The social worker put her in my arms, gave my husband a half-used bottle of lukewarm prescription medicine with directions on it printed in Amharic, and wished us all a happy life together.

The next day, we sat down in the Addis Ababa adoption agency office with the uncle who had relinquished her after her parents had died of complications from undiagnosed lung disease. A shy and elegant man, he told us that this little 11-month-old who slept tucked under the lapel of his frayed blazer was already funny like his brother and beautiful like her mother. We were too stunned by the intensity of the meeting to even think of asking about medical histories, not that he would have likely been able to provide much in the way of concrete information. We said a painful goodbye and returned home to America with a baby who was a beautiful, perfect mystery.

There was some relief in her being an unknown. My mother suffered for decades from bipolar disorder until she finally committed suicide at the age of 44. My brother is also bipolar and the disease has in many ways robbed him of an emotionally rich and productive adulthood. I feel like I dodged a genetic bullet, though I have always feared the menace that roils in my people's blood. My adopted daughter, however, could grow up without me searching in her eyes for shadows of my ruined family members. She could emerge before us without the burden of premonition.

But one Saturday morning, after we hadn't had anything to eat or drink for 30 minutes, she and I turned on some cartoons, and after years of hollering at her to cool it with the spitting, I instructed her to do just the opposite. Together we sat in front of an episode of Doc McStuffins and sputtered into our tubes. Turns out this is an enterprise a young child will undertake without question. Then I sealed them both back into our respective stamped and addressed boxes and dropped them in the mail.

I was told to expect the results back from the lab within the month.

23andMe has yet to turn a profit. But Page is planning on massive customer growth ahead. And with that growth will come increasingly massive data, resulting in more "research partnerships where we get paid well for it," as he says. In other words, sometime next year 23andMe could turn the corner and start making its data really pay off.

When a 23andMe customer receives her results, she is directed to log on to the company's enormously user-friendly interface to pore over the findings. There she'll encounter a nonthreatening, be-a-good-citizen invitation to "opt in" to 23andMe's research program. The company only works with data that is anonymous and aggregated, but it tries to engage those who do opt in as much as possible. Each one is asked to participate in a seemingly infinite number of surveys, thousands of questions looking to gather further information. To date, more than 200 million questions have been answered by 23andMe members. That's more than have been answered on Yahoo Answers or Quora.

23andMe president **Andy Page** dismisses privacy critics: "I view this as a tidal wave of inevitable data."

Not surprisingly, given Brin's results, the company has a special focus on Parkinson's. 23andMe offers anyone who's been diagnosed with the disease a free test kit. The company has since amassed data from more than 10,000 people with Parkinson's, forming the world's single largest Parkinson's community for genetic research. In one study that would've taken the medical establishment tens of millions of dollars and up to a decade of research, 23andMe was able to analyze all that data and identify two novel genes that are highly correlative to people who have Parkinson's. But the study also identified this odd group of people who were predisposed to Parkinson's but were not symptomatic. So the research team created another community of customers and identified a gene that might possibly be protective. "That not only cost us nothing to do," says VC investor Patrick Chung, "but it was something, frankly, you could never have done before 23andMe."

"Suddenly that data becomes incredibly valuable to pharmaceuticals, hospitals, and other large organizations that really want to understand a data set they currently do not have access to," says Sara Holoubek, CEO and founder of consultancy firm Luminary Labs. Holoubek says she is in conversations every day with big pharma companies looking to partner with 23andMe. But it's tricky. "In the case of dollar amounts," says one pharma exec, "no one has figured out the right dollar amount and the right revenue model to pay for that online community's rich source of data. Because online data is messy. Say you have 200,000 patients online and some give you their blood pressure information, but 40% don't. We're still trying to figure it out, to be honest."
23andMe recently has received more than half a million dollars in funding from the National Institutes of Health to crowdsource studies on allergies, asthma, and other conditions. The company also has numerous pending research exchanges with everyone from the NIH to biopharma companies looking to recruit 23andMe populations for studies on specific diseases, such as cancer and arthritis.

Another source of revenue points to the way genetic testing can get controversial very quickly. Chung says that 23andMe will make

money by partnering with countries that rely on a single-payer health system. "Let's say you genotype everyone in Canada or the United Kingdom or Abu Dhabi," he says, "and the government is able to identify those segments of the population that are most at risk for heart disease or breast cancer or Parkinson's. You can target them with preventative messages, make sure they're examined more frequently, and in the end live healthier lives, and the government will save massive expenses because they halted someone who's prediabetic from getting diabetes. 23andMe has been in discussion with a bunch of such societies."

Chung believes that 23andMe can have a role in making the citizens of those countries less anxious. "Say a country like China could just pass a law one day that says every baby that's been born is going to have a blood sample taken at birth, and we're going to genotype that blood sample," he explains. "The data is meaningless unless you get those people to report other biological and lifestyle information. And what are the chances that the Chinese government is trusted or competent enough to produce a website where people can feel like they can tell the government everything about their health? 23andMe has proven this is something we've done very, very well."

"We want to be that last mile of communication and interpretation of genetic data," says Page. "As more and more people do that, and we establish more partnerships where we become that interface between institutions that are offering the tests [and individuals], we can build communities around certain disease states." In other words, if 23andMe amasses 75,000 Crohn's disease patients, or diabetes patients, or heart disease patients, there are giant ways to monetize that data as new treatment options emerge.

Luminary Labs' Holoubek agrees that the potential is enormous. "Let's say an innovator says, 'I have used their data and discovered this unique correlation where I'm going to add a data set and be able to, within 99% degree of confidence, identify people who are going to have a heart attack within a year,'" she says. "That would be incredibly valuable, and lots and lots of people would pay money for that service, not just consumers. Hospitals or pharmaceuticals would pay large sums of money."

"Your 23andMe Results Are Ready!" trumpets the email. It's 7:30 on a Saturday morning, and the coffee is brewing. My results have arrived before my daughter's, and I approach them like a wild animal to a carcass. They show that I have only a few elevated risk associations for diseases, which fluffs me up with a grandiose sense of wellness.

When I speak with genetic counselor Laura Hercher, she brings me back down to earth. "I think on science, 23andMe is very strong," she says. "It's accurate. But my exception is, okay . . . take an example like diabetes. They say you have this and this genetic variant, and therefore your risk of diabetes is increased 10% over the general population. Side note! Increasing your risk 10% is a completely useless thing to find out, because the amount that variants contribute relative to lifestyle, diet, exercise, and weight is tiny. It's like if you had a hundred stocks, and you looked at three of them and said these three went up 10%, so you're up 10% for the year. Well, yeah, except for the other 97 stocks."

I had assumed that these risk associations and drug-response sensitivities would be potentially useful data for my physician to have on file. Hercher warns me not to expect my doctor to respond so positively. "Anyone who works in medicine will tell you that doctors have a very limited genetics background," she says. A recent survey said that 74% of internists from academic medical centers deemed their knowledge of genetics as "very/somewhat poor." Nevertheless, I print out my many pages of percentages and variant-absent-or-present columns and make an appointment with my 68-year-old primary-care physician. "I'm doing a story on personal genetics testing," I say to him when we meet. He takes the papers and gives them a quick, dismissive glance. "The story is, it's bullshit." He looks at them again with an expression of disdain, not unlike the one Carson the butler on Downton Abbey bestows on the house's new telephone. Perhaps my doctor is just unfamiliar with how he might incorporate a patient's genotypic results into his practice. "That assumption is so arrogant," he says, annoyed not at me, he promises, but at what he believes are fads periodically pushed on his practice from the tech world. "It assumes that we doctors don't know our asses from our elbows." When I leave, I ask him if we wants to at least keep my 23andMe results on file. He demurs.

Later that week, I get an email addressed to my daughter, whom I had just tucked in for the night. Her results are ready, and I approach them with an even greater ravenousness. At first glance, everything looks great. She is a carrier for hemochromatosis, a condition that causes the body to absorb too much iron, which she could pass on to biological children if their father is also a carrier. But that doesn't seem like such a big deal. Then I unlock the area with results for more gene-predictive conditions such as Parkinson's, BRCA1 and 2 mutations, and Alzheimer's. I blunder past the notes of caution, hungry to maintain the pseudo promise of my daughter's invulnerability.

And there it is, screaming out at me from my computer screen. My daughter, who is learning to read and tie her shoes, has two copies of the APOE-4 variant, the strongest genetic risk factor for Alzheimer's. According to her 23andMe results, she has a 55% chance of contracting the disease between the ages of 65 and 79. My husband, who is out of town on business, texts that he will call

me at 8:30. "Everything okay?" he adds. "All good," I write back, "except our daughter is going to get Alzheimer's."

There are three main variants of the APOE gene: e2, e3, and e4. Each of us has two copies of the gene, one handed down from our mother, the other from our father. E2 is the rarest version, and is believed to protect a person against Alzheimer's. E3 is the most common. E4 is trouble; not only does it seem to dramatically increase the likelihood of a person developing Alzheimer's, but it also increases her chances of doing so at an earlier age. Roughly 22% of the population has one copy of e4; about 3% have two copies. My daughter's genes place her in that dreaded narrow sliver. "A vanishingly small number of [23andMe's] results fall into that category where you can say, 'Oh, all right, I'm going to get this disease or I'm not,'" says UNC's Evans. "The APOE-4 approaches that." Meanwhile, my results show that I have a copy of the protective e2 gene, locked impotently within each of my cells, where it can do my daughter zero good. My family has found out, as Evans would say, something really scary.

Three days after receiving these results, I return to the offices of 23andMe. Wojcicki is dressed once more in Lululemon and flip-flops, and there are streaks of turquoise, pink, and purple in her hair. "My son and I were getting these hair colors in," she says, picking at some glue at the front of her scalp around one of the extensions. "We thought it'd be fun." When I tell Wojicki about my daughter's e4/e4 status, her expression, alert and unemotional, doesn't flicker. She tells her assistant to cancel a networking meeting with a Yale graduate. "The way to think about it is, half of the people don't get it," she says. "So if half the people aren't getting it, why? What are they doing with their behavior?"

"People like your daughter are invisible to pharma," Emily Drabant, a former Stanford neuroscientist who's now 23andMe's manager of business development and alliances, explains later. "The way these research studies are typically done is they bring in people with Alzheimer's, give them a drug, and see what happens. Do they get better? Like a number of other brain diseases, the Alzheimer's process starts before you start having symptoms, so the changes in your brain are happening before you are actually manifesting dementia. Most of pharma's trials have failed, and the key takeaway is a) they may have been targeting the wrong molecule and b) they were intervening too late. So now what pharma wants to do is new trials in people who are at high risk, who are like 60 and e4 carriers. But what's hard for pharma is this: How do you find people who don't yet have Alzheimer's and aren't sick? They're not going to a doctor. Well, we have 65,000 people in 23andMe who are e4 carriers, and we have 6,000 people in 23andMe who have the same genotype as your daughter's." Back home, I tell my husband about the conversation. A week later he spits in a tube. He says part of his change of heart is morbid curiosity. The other is a desire to contribute to the vague greater good of 23andMe's database.

On September 4, the NIH announced that it had issued a $6 million grant to fund the first-ever randomized trial to "explore the risks and benefits" of whole genome sequencing. The volunteer group? Four hundred eighty Boston newborns. The five-year study, known as the BabySeq Project, "will accelerate the use of genomics in clinical pediatric medicine by creating and safely testing novel methods for integrating sequence into the care of newborns," says Dr. Robert Green, a medical geneticist and genomics researcher at Harvard Medical School who heads up the study. Many of the parents will learn whether their babies have genes that put them at risk for untreatable adult-onset conditions, such as my daughter's APOE-4 markers.

What will happen with this information? Genetic data may lead to cures, but what if it also leads to discrimination? I am concerned enough myself that, out of uncertainty and respect for my child, I am writing this article under a pseudonym.

"Your genetic results should be guarded as closely as possible," says attorney jeffrey taren, whose law firm successfully litigated one of the first genetic discrimination cases.

In 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA), which makes it illegal for health insurers and employers to hold a person's genetic information against her. The basic concept is that an individual can't pick her genes; therefore, it's against the law to penalize her for them. Still, there's an incredible gray area. "Your genetic test results should still be guarded as closely as possible," cautions attorney Jeffrey Taren, whose Chicago law firm Kinoy, Taren, and Geraghty litigated one of the first GINA cases. "It cannot be used in any way by an employer, but believe me it's not going to be ignored if it comes across their desks."

Here's another gray area: The confines of GINA don't yet extend to long-term-care insurance. Several states have banned the discriminatory use of genetic information in all areas, but there is not yet any sweeping federal protection. "A company can use your genetic information as part of their decision in your coverage," says Jennifer Wagner, a lawyer who works out of the University of Pennsylvania's Center for the Integration of Genetic Healthcare Technologies (and is nonetheless a 23andMe customer). For instance, a long-term-care insurance company might in the future ask a potential customer if she had genetic testing, and if the results linked

her to a higher risk for Alzheimer's disease. "If you get this genetic information, what do you need to disclose?" she asks. "If you don't disclose everything, is that withholding information and you're somehow fraudulent?" In a statement, Genworth, the largest supplier of long-term care insurance in the U.S., says that it "does not require or request applicants to disclose that they've had genetic tests done or require genetic testing in the application process."

For the past 12 years, BabySeq Project's Green has been overseeing a groundbreaking study in which his team examined how people react after they learn they carry the APOE-4 marker, like my daughter. They don't crumble into states of depression and anxiety. What they do instead is take practical steps to prepare for a now uncertain future. Upon learning of their APOE-4 status, people are six times more likely to alter their long-term-care insurance. Periodically, Green is invited to speak to leaders in the long-term-care insurance industry. He says they are driven mad by his findings. "What these executives make clear is they are a business, and if consumers of their business have information that they [themselves] do not have in order to practice their underwriting, they cannot function," he says.

"They're losing their shirts," says public policy professor don Taylor, of long-term-care insuranceproviders.

Don Taylor, an associate professor of public policy at Duke who has published research on the implications of genetic testing and insurance in Health Affairs, predicts that our current long-term-care insurance system is about to break. "They're losing their shirts," he says, pointing to the fact that Genworth temporarily stopped selling new policies completely in its biggest market, California. "Whatever we have now is not going to come close to existing when your daughter is old enough to buy it." But nobody yet knows what might replace it.

What I–and all the parents in the BabySeq Project and all of 23andMe's customers–also have to wrestle with is whether offering up DNA has compromised our children's and our own rights to privacy. 23andMe's privacy statement clearly states that it collects a person's genetic, registration, web browsing, and self-reported information. The company can share its data with third parties "[after] it has been stripped of Registration Information and combined with data from a number of other users sufficient to minimize the possibility of exposing individual-level information while still providing scientific evidence." Minimize the possibility does not equal a legal-bound guarantee.

"Why should 23andMe have my health information so they can sell it?" asks genetic counselor Hercher.

"Nothing's private. It's your genetic sequence. It's literally the best identifier that we have!" I ask her if she finds the fact that I gave my daughter's genetic information to 23andMe unethical. "Does it bother me that you, a loving mother of a 5-year-old kid whom you have no history on did this? No," she says. "It doesn't trouble me at all. Does it bother me globally that when we do direct-to-consumer testing via these Internet things, we have privacy issues and confidentiality issues that can't be controlled? That is a problem."

Page disagrees. "I view this as a tidal wave of inevitable data and a trend in the marketplace," he says. "The technology is available; the price point is decreasing. There are so many organizations and engineers and companies that are focused on this. So if it's a foregone conclusion that the tidal wave is coming, what is the best way of delivering the data, and what is the most integrous way of presenting it and partnering? We're the best-case example of a company that is not focused on short-term profits."

Ten years from now, my daughter's freshman-year science teacher may well be passing out 23andMe tubes to the students for a class project. Penn State professor of anthropology Nina Jablonksi is working alongside Harvard's Henry Louis Gates Jr. and 30 geneticists, lawyers, bioethics experts, and social scientists on grant proposal initiatives to develop a personal genetics curriculum for middle, high school, and undergraduate students.

"We are convinced that this is a really good hook to get kids interested in scientific investigation," she says. "Through looking at their DNA, through investigating their genealogy, they become detectives of their own lives." The curriculum wouldn't touch upon individual health issues or risk factors, just the lighter stuff, like earwax consistency.

In our own home, my husband and I must decide for ourselves when and if to share the more unsettling pieces of our daughter's DNA

with her. The reality is that her double e4 status mutation may never affect her. But if she chooses to have biological children, they too will each inherit a copy of the mutation. Now that I'm a member of its online community, 23andMe will keep me abreast of the latest research surrounding Alzheimer's and how that raises or lowers my daughter's risk. Even 23andMe's critics agree that the company does an expert job of presenting clients with information and links to relevant studies.

So many of the well-meaning people I spoke with while reporting this article had advice for me going forward. "You have this potential now to engage her in all kinds of activities," said Wojcicki. "Do you get her focused on her exercise and what she's eating, and doing brain games and more math?" The geneticist Ricki Lewis echoed the importance of proactive measures. "Send her to a great school. Send her to music lessons. Reading is so important. She needs to read her whole life; it'll give her more synapses. The hippocampus is the part of the brain that Alzheimer's affects, so if you just do a lot of early learning she'll have more brain connections."

But I appreciate the advice from Duke's Don Taylor most. "It's possible the best thing you can do is burn that damn report and never think of it again," he said. "I'm just talking now as a parent. Do not wreck yourself about your 5-year-old getting Alzheimer's. Worry more about the fact that when she's a teenager she might be driving around in cars with drunk boys."

A week after my last trip to Mountain View, I get an email addressed to my daughter in our anonymous 23andMe account (the sender doesn't know to whom it's being sent). "A relative would like to make contact with you," reads the subject line. It is from an adoptive mother in Chicago whose 3-year-old son is from the same region of southern Ethiopia as my daughter. The 23andMe Relative Finder has matched our children's shared DNA and revealed them to be fifth cousins. The woman is part of a private 152-member Facebook group for 23andMe users who want to discover biological connections within the Ethiopian adoptive community. Her email on behalf of her son to my daughter is short and to the point: "Would you like to share genomes?" I accept.

Since then, my daughter has been matched with handfuls of young Ethiopian adopted children whom 23andMe has identified as her third to fifth cousins. With every match, her web of connection grows another strand stronger. I choose to think of this as a potentially beautiful new world opening up for her–but one that requires an extraordinarily thoughtful bravery from all of us.

Note: To protect the privacy of her daughter, the author's name has been changed.