

## Transcript: The Genetic Testing ‘Bait-and-Switch’

**Dan:** Hey there. Today's story is about whether it's possible for a health care company to make enough people mad enough that there are actual consequences. And spoiler: The answer may be yes.

One person who got pretty mad was an Arm and a Leg listener named Jessica, who wrote to us. Our producer Emily Pisacreta spoke to Jessica and got the whole story. And we've come to find out, Jessica's not the only one who's noticed something fishy. Hey, Emily!

**Emily:** Hey Dan! This story starts where lots of a health care stories start. At the OBGYN. Jessica had just found out she was pregnant. She and her partner had been trying to have a baby for years, and she'd recently experienced a pregnancy loss. So she was feeling cautiously optimistic when she went for her 8-week scan.

**Jessica:** that's the first kind of big appointment they call it the confirmation appointment, um, where we got our first ultrasound.

That's also where we discovered we were having twins. Um, so I know pretty exciting appointments.

**Emily:** It was at this same super eventful appointment that her doctor said, hey. At your next appointment, the 12-week check-up, we can do this new thing. Non-invasive prenatal testing.

**Jessica:** what they said was, you know, it screens for, um, some trisomy disorders like down syndrome. Um, and it could also tell you the sex of the baby.

**Emily:** He says insurance usually doesn't cover this test. But out of pocket, it's only 99 dollars. Jessica mulled it over. She decided since it was just a simple blood test, it was worth it.

**Jessica:** You know, again, since I'm geriatric or 35. Oh, he decided it's better to know about those chromosomal abnormalities, just because there's a slightly higher risk as you get a little bit older, but we were also, I mean, very eager to know the sex. So we decided the a hundred dollars was that that was worth it to us.

**Dan:** So Jessica gets the test. And if you think she just got a bill for \$99 and it was over, well, welcome to the show.

This is an Arm and Leg. A show about why health care costs so freaking much and what we can maybe do about it. I'm Dan Weissmann, I'm a reporter, and I like a challenge. So our job on this show is to take the most enraging, terrifying, depressing parts of American life and bring you something entertaining, empowering, and useful.

And this weeks story, the story of Jessica and what happened next is definitely energizing. So Emily, Jessica got the blood test, this 99 dollar, non-invasive prenatal test. Then what?

**Emily:** So on a Monday she has her 12-week scan. Everything is good. And she gets her blood taken for the non-invasive pre-natal testing. Afterward, she gets a card from the doctors office to use to register her test with the company that performs them. A company called Natera.

A couple days later, Natera emails her. They say, they got the samples. Cool. And a couple days after that, a cost estimate arrives.

**Jessica:** I said that my estimate was \$250 instead of the 99.

**Dan:** OK we already have some problems. Jessica's doc quoted her 99 bucks for this test. And here's a bill for \$250.

**Jessica:** And at the very bottom of the page in a pretty small print, it said basically, if this estimate is different than what you expected, call this.

So I obviously immediately called that number,

**Emily:** She says it takes her a while to get a hold of anyone at Natera. When she does, they tell her the company has special promotions with certain providers to sell the test for 99 dollars instead of \$250. And they want to know if she's ready to pay that on the spot.

And she's like, hmm. Lemme think about it.

**Jessica:** I was like in the midst of, you know, visiting the family, like we were telling them our good news, et cetera. So I, I didn't want to spend a lot of time haggling with them, which it felt like that was going to happen.

**Emily:** A couple days later, she gets another message from them.

**Jessica:** Pay this \$250 now.

Or basically that offer expires in about a week. Um, and if you don't pay it within that timeframe, then you owe us \$800.

Like that pressure to pay is kind of what made me raise eyebrows

**Dan:** so in the span of a week, the cash price for this test went from 99 bucks to 800 bucks. Jessica had been thinking she'd have to pay out of pocket for this test based on what her doctor told her.

But in the meantime, she heard from one of her coworkers that their insurance had covered it. And even though they didn't have the same kind of insurance, that gave Jessica the idea to at least try it. She calls Natera again. Asks them what her out of pocket cost would be if they ran the test through insurance.

**Jessica:** And that's when they told me. If we do that, you'll get charged \$800.

Like flat out there, like by the time that they would process it, it would cost you \$800 when they deny it.

**Dan:** And then shes asks them, well can I at least get a real, itemized bill? How can I tell whether insurance is going to cover it, without an actual bill with actual billing codes for services provided? Jessica is no fool.

**Emily:** Right? I feel like she could make this show.

**Dan:** Absolutely! But anyway, she says the Natera rep tells her, no. They don't have an itemized bill for her at this time. And it would take a while for them to have it.

**Jessica:** Basically, if you want a bill, it's going to cost you more money to get a bill from us, right. Which I get all of these things are just raising flags in my head of like, this is a shady practice

**Emily:** And as all this is getting sorted out, Jessica's like, let me google these Natera people. And what she finds is a ton of reviews on places like Yelp and the Better Business Bureau. It turns out she's not the only one who has experienced what she now calls the "genetic testing bait-and-switch."

**Jessica:** Women who just say, yes, I just paid the \$350. I just paid the \$250, like, oh, I would've loved it if it was only \$99. So it just overwhelming like responses of women just paying whatever their quote, unquote discount urgent pricing was.

**Emily:** Natera told us that they strive to provide affordable access and to be transparent about costs . They say most patients have a positive experience. But there are ALL those bad reviews out there, and Jessica is certainly not the only one to notice the bad reviews.

At the beginning of this year, Natera's billing practices got the attention of some new people. And not exactly the kind of attention you really want if you're a publicly traded company. That's right after this.

**Dan:** [midroll]

So, for Natera and its shareholders, bad reviews online aren't great, but that is something a lot of businesses deal with. And for whatever it's worth, maybe not much, Natera does have an A+ profile rating on the Better Business Bureau for their responses to those complaints.

But earlier this year, some other folks started crying foul on Natera. The kind of people who can really cause some problems for them.

Short sellers.

The folks who bet against a stock and make money only if the stock price drops.

**Emily:** These short sellers, a firm called Hindenburg Research, were betting against Natera. Betting that their billing practices were so out of line that the company's stock was way overvalued and would eventually tank.

**Dan:** With a little extra nudge from them.

**Emily:** In early March, they published an investigation into Natera, building on interviews with unnamed former employees and industry experts, and analyzing Medicare billing data. And according to their report? What Jessica experienced is the bread and butter of Natera's business.

**Dan:** Listen to this from their conclusion. Quote: The company's approach to revenue growth seems to be reliant on deceiving insurance companies and

terrorizing expectant mothers with sticker-shock bills and aggressive collection practices. Whoa.

**Emily:** Oh, did you catch the words “deceiving insurance companies” in all that?, Yeah: Hindenburg’s report also describes what they call a Natera “scheme” to rook insurance companies into paying for tests.

**Dan:** And here we should say that we haven't independently verified all of the claims in Hindenburg’s report.

And when we asked Natera about it,, the company gave us a statement to the effect of: “Duh, Hindenburg makes money by talking smack about us-- if people believe them and our stock takes a hit. We responded to that crap immediately.”

**Emily:** That response doesn’t address what Jessica called bait-and-switch pricing and what Hindenburg called ‘sticker shock bills and aggressive collection practices.’

And when it comes to sussing out companies that are up to no good, so far Hindenburg has a decent track record.

**Andrew Rice:** A lot of the companies that they have targeted. Have turned out to be exactly what they claim that they are

**Emily:** That's Andrew Rice. He's a contributing editor at New York Magazine. Earlier this year he wrote a profile of Hindenburg and its founder, Nate Anderson, who the magazine dubbed "the Last Sane Man on Wall Street."

Hindenburg caught Andrew's eye when it bet big against a company called Nikola -- an electric vehicle company that was getting buzz for its potential to revolutionize trucking. At one point the company’s stock price was valued more than Ford and Chrysler combined, despite not having produced any actual products. Nate Anderson at Hindenburg found the whole thing really fishy.

**Andrew Rice:** like a lot of investigations, it sounds like. it started with a kind of intuition on Nate. Anderson's part that not everything here was adding up.

**Emily:** Things came to a head when Nikola released a dramatic promo video. Picture this. The American West. A wide open road. And a giant truck called the US Express glides across the landscape.

Dan: I mean, that truck is moving.

Emily: Well, Hindenburg wasn't so sure.

**Andrew Rice:** What Hindenburg acting on a tip was able to, to figure out is that actually this vehicle was not in fact, operating under its own power or battery power or any kind of renewable energy as, as purported. but rather was actually, uh, rolling down the hill under the force of gravity

**Emily:** Eventually, Nikola admitted to faking the video. The government charged the firm with securities fraud and they settled those charges for \$125 million. And Hindenburg Research hasn't publicly stated how much it made on the Nikola short, but it was clearly the right bet. Nikola stock started tumbling right after the report came out.

And it seems the report on Natera had much the same effect on their stock price.

**Dan:** Ooh, not good for Natera.

**Emily:** Yeah, right now their stock price is valued at 50% of where they started the year off.

But to be fair, not all the credit goes to Hindenburg, which announced its bet against Natera in March. The company's stock had already taken a huge beating in January, when Natera and others in the non-invasive prenatal testing business found themselves on the front page of the New York Times. The headline was not rosy -- "Tests Predicting Rare Disorders in Fetuses Usually Wrong."

Yep. And the lead journalist on the story was friend of the show, Sarah Kliff. The story ran the day after New Years.

**Sarah Kliff:** I had a hard deadline of having a baby a few weeks later, so,

**Dan:** But her own pregnancy was not the only reason Sarah had been thinking about non-invasive prenatal testing. If you aren't familiar with Sarah's work, she is best known for stories based on wild medical bills readers send her. (There's a reason we're friends.) And readers had been sending her stories like the one Jessica sent to us, about prenatal testing companies. But in this case, Sarah's reporting took a different turn.

**Sarah Kliff:** I had an very smart editor who suggested what, why don't we look into how these tests perform and, um, you know, What are people actually getting for those bills?

**Emily:** So Sarah got with some researchers, and combined data from multiple studies to get the most accurate read possible on the value of these tests offered by Natera and its competitors. And what they found was that when it comes to certain things, the tests really do seem to work. Like screening for Down Syndrome, which is what the tests were initially designed for.

**Emily:** Same for certain other trisomy disorders. And the American College of Obstetricians and Gynecologists does recommend this type of screening.

**Sarah Kliff:** But there are newer. Often tests for small pieces of missing chromosomes called micro deletions that, in some cases we found most of the positive results are wrong.

**Emily:** For some conditions, these positive results were wrong 85% of the time.

**Dan:** Like, as in 15% right.

**Emily:** Yeah. And Hindenburg says that one of these lesser-reliable tests is one that doctors have to specifically opt out of when they order Natera's panel. Sometimes resulting in a totally separate bill.

**Dan:** Yet obviously, as Sarah's reporting shows, billing headaches are sometimes the least of patients concerns when they get a positive result on a test like this.

**Sarah Kliff:** that's a lot of strife for patients who, you know, are being told that their, future child has a pretty significant developmental disease who have to then, spend a lot of money on follow up testing. You know, some of them. Pretty seriously considering terminating their pregnancy. If it's true,

**Emily:** Natera had a statement for us, throwing heavy shade on the New York Times. For one thing, the company noted that the Times had, quote, 'issued multiple corrections to its story.'

**Dan:** Well, two. And sure, two is a multiple of one. But of those corrections, the first had to do with the location of the headquarters of one of the companies. And the other...

**Emily:** Well, basically, the New York Times wrote that positive test results for the microdeletion that causes one particular syndrome were right about 20% of the time, industry wide. But Natera contends that their test is giving false positives only about \*50%\* of the time.

**Dan:** So, half the time? That's their big claim? Hey New York Times! We're actually right half the time on this one test!

**Emily:** I'm not sure I personally would've led with that. Natera also said to us that the Times story misrepresented what they do, and that, quote, 'rebuttals from the medical and scientific community have been swift and strong.'

**Dan:** ... and I'm not really seeing that. Some well-credentialed folks did have a quibble with the Times saying that false positives were 'wrong.' They said, these are screening tests-- to see if there might be a problem-- not diagnostic tests to see if there is one for sure. They said of course you need good genetic counseling. Which, as some of them admitted, is in short supply.

In April, the FDA issued a public warning about prenatal tests like Natera's, saying patients should not make decisions based on these tests alone. And they reminded the public that these tests are not actually subject to FDA review.

**Emily:** Still, the American College of Obstetricians and Gynecologists now recommends these tests for all pregnancies, and says insurance should pay for them.

**Dan:** Natera says that more and more insurers are covering the tests.

**Emily:** Yeah Natera is definitely trying to reassure investors with that info. Because the Times story and then Hindenburg's report really did a number on their stock valuation. But at this moment, their stock is still in a slump after Hindenburg's report on their business practices.

Dan: Which, in a way, all stemmed from people taking note of patients' outrage over bills. Maybe a little justice.

Emily: Maybe! And as for Jessica, she ended up having to make a ton of phone calls. To her doctor's office, who sent her to a Natera rep who no longer worked there, back to the doctor, to insurance, you know the drill. How many hours is it that Americans spend on the phone with insurance? We did an episode about this.

**Dan:** Yeah that's 12 million hours a week and it does not count all of the time we spend on the phone with people like Natera.

**Emily:** Right. Well ultimately, insurance did cover Jessica's testing from Natera. And because everything is upside down in this health care system, Natera made



more from Jessica's insurance company than the \$250 they were trying to get her to pay.

**Dan:** Wait, really? How much?

**Emily:** Her insurance paid \$651.

**Dan:** Whoa.

**Emily:** And now Jessica's she's out there warning other pregnant people in her life about the whole bait-and-switch it, telling them to check with their insurance before they cave and pay out of pocket for a Natera test.

**Jessica:** don't let that timeline stress you out, uh, that they give you this arbitrary week that you have to pay this bill.

**Emily:** Yeah, it almost sounds like it's just another piece of like folk knowledge that like pregnant people pass between

each other.

**Jessica:** yeah.

**Emily:** It's just like, oh, beware, beware of the troll under this bridge. Right?

**Jessica:** Right. There are a lot of them sadly, in, in healthcare in general, but I'm finding a lot of them during pregnancy that I didn't know existed.

**Dan:** Emily, that is such an apt metaphor for so much of what we cover on this show: Trolls demanding who-knows-what amount of money to let us just live, try to be healthy.

**Emily:** And in this case, thanks to people like Jessica who pipe up, reporters like Sarah Kliff, and some dudes looking to make a buck on Wall Street, this particular [troll?]

**Dan:** Are we gonna call them a troll? I mean, it's a metaphor. This one company, is, at least for right now, licking some wounds.

We'll be back in three weeks with another episode, another health care soapbox. Til then, take of yourself.

This episode of An Arm and a Leg was produced by Emily Pisacreta with help from me, Dan Weissmann, and edited by Marian Wang.

Daisy Rosario is our consulting managing producer. Adam Raymonda is our audio wizard. Our music is by Dave Winer and Blue Dot Sessions.

Gabrielle Healy is our managing editor for audience. She edits the First Aid Kit Newsletter.

Bea Bosco is our consulting director of operations and Sarah Ballema is our operations manager.

This season of an arm and a leg is a co production with Kaiser health news. That's a nonprofit news service about healthcare in America, an editorially-independent program of the Kaiser family foundation.

KHN is not affiliated with Kaiser Permanente, the big healthcare outfit. They share an ancestor. The 20th century industrialist Henry J Kaiser.

When he died, he left half his money to the foundation that later created Kaiser health news. You can learn more about him and Kaiser health news at [arm and a leg show dot com slash Kaiser](http://armandalegshow.com/slash/Kaiser).

Diane Webber is national editor for broadcast at Kaiser health news, and Emmarie Hutteman is a correspondent there. They are editorial liaisons to this show.

Thanks to Public Narrative -- a Chicago-based group that helps journalists and non-profits tell better stories-- for serving as our fiscal sponsor, allowing us to accept tax-exempt donations. You can learn more about Public Narrative at [www dot public narrative dot org](http://www.dotpublicnarrative.org).

And those donations support this show. If you're not a donor yet, we'd love to have you. Come on by to [www dot arm and a leg show dot com slash support](http://www.dotarmandalegshow.com/slash/support).

Thank you!