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1973-1974

"It's Alive"

On a hazy day in 1973, in a brown brick row house five doors down from her own, Bobbette Lacks sat at her friend Gardenia's dining room table. Gardenia's brother-in-law was in town from Washington, D.C., and they'd all just finished having lunch. As Gardenia clanked dishes in the kitchen, her brother-in-law asked Bobbette what she did for a living. When she told him she was a patient aide at Baltimore City Hospital, he said, "Really? I work at the National Cancer Institute."

They talked about medicine and Gardenia's plants, which covered the windows and counters. "Those things would die in my house," Bobbette said, and they laughed.

"Where you from anyway?" he asked.

"North Baltimore."

"No kidding, me too. What's your last name?"

"Well, it was Cooper, but my married name is Lacks."

"Your last name is Lacks?"

"Yeah, why?"

"It's funny," he said, "I've been working with these cells in my lab

for years, and I just read this article that said they came from a woman named Henrietta Lacks. I've never heard that name anywhere else."

Bobbette laughed. "My mother-in-law's Henrietta Lacks but I know you're not talking about her—she's been dead almost twenty-five years."

"Henrietta Lacks is your mother-in-law?" he asked, suddenly excited. "Did she die of cervical cancer?"

Bobbette stopped smiling and snapped, "How'd you know that?"

"Those cells in my lab have to be hers," he said. "They're from a black woman named Henrietta Lacks who died of cervical cancer at Hopkins in the fifties."

"What?!" Bobbette yelled, jumping up from her chair. "What you mean you got her cells in your lab?"

He held his hands up, like *Whoa, wait a minute*. "I ordered them from a supplier just like everybody else."

"What do you mean, 'everybody else'?" Bobbette snapped. "What supplier? Who's got cells from my mother-in-law?"

It was like a nightmare. She'd read in the paper about the syphilis study at Tuskegee, which had just been stopped by the government after forty years, and now here was Gardenia's brother-in-law, saying Hopkins had part of Henrietta alive and scientists everywhere were doing research on her and the family had no idea. It was like all those terrifying stories she'd heard about Hopkins her whole life were suddenly true, and happening to her. *If they're doing research on Henrietta*, she thought, *it's only a matter of time before they come for Henrietta's children, and maybe her grandchildren.*

Gardenia's brother-in-law told Bobbette that Henrietta's cells had been all over the news lately because they'd been causing problems by contaminating other cultures. But Bobbette just kept shaking her head and saying, "How come nobody told her family part of her was still alive?"

"I wish I knew," he said. Like most researchers, he'd never thought about whether the woman behind HeLa cells had given them voluntarily.

Bobbette excused herself and ran home, bursting through the screen door into the kitchen, yelling for Lawrence, "Part of your mother, it's alive!"

Lawrence called his father to tell him what Bobbette had heard, and Day didn't know what to think. *Henrietta's alive?* he thought. It didn't make any sense. He'd seen her body at the funeral in Clover himself. Did they go dig it up? Or maybe they did something to her during that autopsy?

Lawrence called the main switchboard at Hopkins, saying, "I'm calling about my mother, Henrietta Lacks—you got some of her alive in there." When the operator couldn't find a record of a patient named Henrietta Lacks in the hospital, Lawrence hung up and didn't know who else to call.

Soon after Lawrence called Hopkins, in June 1973, a group of researchers gathered around a table at Yale University at the First International Workshop on Human Gene Mapping, a first step toward the Human Genome Project. They were talking about how to stop the HeLa contamination problem, when someone pointed out that the whole mess could be sorted out if they found genetic markers specific to Henrietta and used them to identify which cells were hers and which weren't. But doing that would require DNA samples from her immediate family—preferably her husband as well as her children—to compare their DNA to HeLa's and create a map of Henrietta's genes.

Victor McKusick, one of the scientists who'd first published Henrietta's name, happened to be at that table. He told them he could help. Henrietta's husband and children were still patients at Hopkins, he said, so finding them wouldn't be difficult. As a physician on staff, McKusick had access to their medical records and contact information.

The geneticists at the conference were thrilled. If they had access to DNA from Henrietta's children, they could not only solve the contamination problem but also study Henrietta's cells in entirely new

ways. McKusick agreed, so he turned to one of his postdoctoral fellows, Susan Hsu, and said, "As soon as you get back to Baltimore, get this done."

McKusick didn't give Hsu instructions for explaining the research to the Lackses. All she knew was that Victor McKusick had told her to call the family.

"He was like a god," Hsu told me years later. "He was a famous, famous man, he trained most of the other famous medical geneticists in the world. When Dr. McKusick said, 'You go back to Baltimore, get this blood drawn,' I did it."

When Hsu got home from the conference, she called Day to ask if she could draw blood from his family. "They said they got my wife and she part alive," he told me years later. "They said they been doin' experiments on her and they wanted to come test my children see if they got that cancer killed their mother."

But Hsu hadn't said anything about testing the children for cancer. There was no such thing as a "cancer test," and even if there had been, McKusick's lab wouldn't have been doing one, because he wasn't a cancer researcher. McKusick was a renowned geneticist who'd founded the world's first human genetics department at Hopkins, where he maintained a catalog of hundreds of genes, including several he'd discovered himself in Amish populations. He compiled information about known genes and the research done on them into a database called *Mendelian Inheritance in Man*, the bible of the field, which now has nearly twenty thousand entries and is still growing.

McKusick and Hsu were hoping to use somatic-cell hybridization to test the Lacks family for several different genetic markers, including specific proteins called *HLA markers*. By testing Henrietta's children, they hoped to find out what Henrietta's HLA markers might have been, so they could use those to identify her cells.

Hsu had come to America from China, and English wasn't her native language. According to Hsu, when she called Day in 1973, she told him this: "We come to draw blood to get HLA antigen, we do ge-

netic marker profile because we can deduce a lot of Henrietta Lacks genotype from the children and the husband."

When I asked her if Day seemed to understand, Hsu said, "They are very receptive to us when I made phone call. They are pretty intelligent. I think Mr. Lacks pretty much already knew that his wife made a contribution and are very aware of the value of HeLa cells. They probably heard people talking that the cell line is such important thing. Everybody talking about HeLa back then. They are a very nice family, so they very nicely let us draw blood."

Hsu's accent was strong, and so was Day's—he spoke with a Southern country drawl so thick his own children often had a hard time understanding him. But language wasn't their only barrier. Day wouldn't have understood the concept of immortal cells or HLA markers coming from anyone, accent or not—he'd only gone to school for four years of his life, and he'd never studied science. The only kind of cell he'd heard of was the kind Zakariyya was living in out at Hagerstown. So he did what he'd always done when he didn't understand something a doctor said: he nodded and said yes.

Years later, when I asked McKusick if anyone had tried to get informed consent from the Lacks family, he said, "I suspect there was no effort to explain anything in great detail. But I don't believe anyone would have told them we were testing for cancer because that wasn't the case. They would have just said, 'Your mother had cancer, the cells from that cancer have been growing all over the place and studied in great detail, in order to understand that better, we would like to have that blood from you people.'"

When I asked Susan Hsu the same question she said, "No. We never gave consent form because you just go to draw blood. We are not doing some kind of medical research, you know, not long term. All we wanted is a few tubes of blood and to do genetic marker test. It's not involved in a human research committee or things like that."

Although this attitude wasn't uncommon at the time, NIH guidelines stipulated that all human subject research funded by NIH—as

McKusick's was—required both informed consent and approval from a Hopkins review board. Those guidelines had been implemented in 1966, in the aftermath of the Southam trial, and then expanded to include a detailed definition of informed consent in 1971. They were in the process of being codified into law when Hsu called Day.

McKusick began his research on the Lacks family at a time of great flux in research oversight. Just one year earlier, in response to Tuskegee and several other unethical studies, the Department of Health, Education, and Welfare (HEW) had launched an investigation into federal oversight of human-subject research and found it to be inadequate. As one government report said, it was a time filled with "widespread confusion about how to assess risk," as well as "refusal by some researchers to cooperate" with oversight, and "indifference by those charged with administering research and its rules at local institutions." After halting the Tuskegee study, HEW proposed new Protection of Human Subjects regulations that would require, among other things, informed consent. A notice inviting public comment on that proposed new law would be published in the *Federal Register* in October 1973, just a few months after Hsu called Day.

After Day got off the phone with Hsu, he called Lawrence, Sonny, and Deborah, saying, "You got to come over to the house tomorrow, doctors from Hopkins coming to test everybody's blood to see if you all got that cancer your mother had."

When Henrietta died, Day had agreed to let her doctors do an autopsy because they'd told him it might help his children someday. *They must have been telling the truth*, Day thought. Zakariyya was in Henrietta's womb when she first got the cancer, and he'd had all those anger problems ever since. Now Deborah was almost twenty-four, not much younger than Henrietta had been when she died. It made sense they were calling saying it was time for her to get tested.

Deborah panicked. She knew her mother had gotten sick at thirty, so she'd long feared her own thirtieth birthday, figuring that whatever

happened to her mother at that age would happen to her too. And Deborah couldn't stand the idea of her own children growing up motherless like she had. At that point, LaTonya was two, Alfred was six, and Cheeta had never paid child support. Deborah had tried welfare for three months but hated it, so now she was working days at a suburban Toys "R" Us that took more than an hour and three buses to get to, then nights at a hamburger place called Gino's behind her apartment.

Since Deborah couldn't afford a babysitter, her boss at Gino's let Tonya and Alfred sit in the corner of the restaurant at night while Deborah worked. On her eight-thirty dinner break, Deborah would run behind the building to her apartment and put the children to bed. They knew not to open the door unless they heard her secret knock, and they never put the kerosene lamps near a curtain or blanket. Deborah practiced fire drills with them in case something went wrong while she was at work, teaching them to crawl to the window, throw out a sheet-rope she kept tied to the bed leg, and climb to safety.

Those children were all Deborah had, and she wasn't going to let anything happen to them. So when her father called saying Hopkins wanted to test to see if she had her mother's cancer, Deborah sobbed, saying, "Lord don't take me away from my babies, not now, not after everything we been through."

A few days after Susan Hsu's phone call, Day, Sonny, Lawrence, and Deborah all sat around Lawrence's dining room table, as Hsu and a doctor from McKusick's lab collected tubes of blood from each of them.

For the next several days, Deborah called Hopkins again and again, telling the switchboard operators, "I'm calling for my cancer results." But none of the operators knew what tests she was talking about, or where to send her for help.

Soon, Hsu wrote a letter to Lawrence asking if she could send a nurse out to Hagerstown to collect samples from Zakariyya in prison. She included a copy of the George Gey tribute written by McKusick and Jones, saying she thought Lawrence would like to see

an article about his mother's cells. No one in the family remembers reading that article—they figure Lawrence just put it in a drawer and forgot about it.

The Lacks men didn't think much about their mother's cells or the cancer tests. Lawrence was working full-time on the railroad and living in a house filled with children, Zakariyya was still in jail, and times had gotten tough for Sonny, who was now busy selling drugs.

But Deborah couldn't stop worrying. She was terrified that she might have cancer, and consumed with the idea that researchers had done—and were perhaps still doing—horrible things to her mother. She'd heard the stories about Hopkins snatching black people for research, and she'd read an article in *Jet* about the Tuskegee study that suggested doctors might have actually injected those men with syphilis in order to study them. "The injection of disease-causing organisms into unaware human subjects has occurred before in American medical science," the article explained. "It was done eight years ago in New York City by Dr. Chester Southam, a cancer specialist who injected live cancer cells into chronically ill elderly patients."

Deborah started wondering if instead of testing the Lacks children for cancer, McKusick and Hsu were actually injecting them with the same bad blood that had killed their mother. She started asking Day a lot of questions about Henrietta: How'd she get sick? What happened when she died? What did those doctors do to her? The answers seemed to confirm her fears: Day told her that Henrietta hadn't seemed sick at all. He said he took her into Hopkins, they started doing treatments, then her stomach turned black as coal and she died. Sadie said the same thing, and so did all the other cousins. But when she asked what kind of cancer her mother had, what treatments the doctors gave her, and what part of her was still alive, the family had no answers.

So when one of McKusick's assistants called Deborah and asked her to come into Hopkins to give more blood, she went, thinking that if her family couldn't answer questions about her mother, maybe the scientists could. She didn't know the blood was for a researcher in

California who wanted some samples for his own HeLa research, and she didn't know why McKusick's assistant was calling her and not her brothers—she figured it was because the problem her mother had didn't affect boys. She still thought she was being tested for cancer.

Deborah went into McKusick's office to give more blood on June 26, 1974, four days before the new federal law went into effect requiring Institutional Review Board (IRB) approval and informed consent for all federally funded research. The new law—published in the *Federal Register* one month earlier—applied to all "subjects at risk," meaning "any individual who may be exposed to the possibility of injury, including physical, psychological, or social injury, as a consequence of participation as a subject." But what constituted "injury" and "risk" was heavily debated. Numerous researchers had appealed to HEW, asking that collection of blood and tissues be exempt from the new law. After all, doctors had been drawing blood for centuries for diagnostic testing, and aside from the pain of a needle stick, there seemed to be no risk. But HEW did not exempt those procedures; in fact, it later clarified the law to specifically include them.

McKusick's research on the Lacks family coincided with the beginning of a new era of genetic research, in which the concept of risk to patients would change completely. With the ability to identify genes from a blood sample or even a single cell, the risk of a blood draw was no longer just a minor infection or the pain of a needle stick—it was that someone could uncover your genetic information. It was about violation of privacy.

Deborah met McKusick only once, when she went into Hopkins to give blood. He shook her hand and said that Henrietta had made an important contribution to science. Then Deborah bombarded him with questions: What made her mother sick? How was part of her still living? What did that mean? What did Henrietta do for science? And did all those blood tests he was doing mean Deborah was going to die young like her mother?

McKusick did not explain why he was having someone draw blood from Deborah. Instead he told her about Henrietta's cells being used for the polio vaccine and genetic research; he said they'd gone up in early space missions and been used in atomic bomb testing. Deborah heard those things and imagined her mother on the moon and being blown up by bombs. She was terrified and couldn't stop wondering if the parts of her mother they were using in research could actually feel the things scientists were doing to them.

When she asked McKusick to explain more about the cells, he gave her a book he'd edited called *Medical Genetics*, which would become one of the most important textbooks in the field. He said it would tell her everything she needed to know, then autographed the inside front cover. Beneath his signature he wrote a phone number and told her to use it for making appointments to give more blood.

McKusick flipped to the second page of the introduction. There, between graphs of "Disease Specific Infant Mortality" and a description of "the homozygous state of Garrodian inborn errors," was the photograph of Henrietta with her hands on her hips. He pointed to the paragraph that mentioned her:

Parenthetically, medical geneticists making use of the study of cells in place of the whole patient have "cashed in" on a reservoir of morphologic, biochemical, and other information in cell biology derived in no small part from study of the famous cell line cultured from the patient pictured on this page, Henrietta Lacks.

The book was filled with complicated sentences explaining Henrietta's cells by saying, "its atypical histology may correlate with the unusually malignant behavior of the carcinoma," and something about the "correlate of the tumor's singularity."

Reading magazines took Deborah a long time because she had to stop often to look words up in her dictionary. Now she sat in the clinic gripping McKusick's book, not even trying to read the words.

All she could think was that she'd never seen that photograph of her mother before. *What happened to her to make her end up in there?* she wondered. *And how did he get that picture?* Day swore he'd never given it to McKusick or any of Henrietta's doctors; Deborah's brothers swore they hadn't either. The only thing Day could figure was that maybe Howard Jones had asked Henrietta for a picture, then stuck it in her medical record. But as far as Day knew, no one had ever asked permission to publish it.

When I talked to McKusick several years before his death in 2008, he was seventy-nine and still conducting research and training young scientists. He didn't recall where he'd gotten the photo, but he imagined Henrietta's family must have given it to Howard Jones or another doctor at Hopkins. Though McKusick remembered the research he conducted on the Lacks family, he didn't remember meeting Deborah or giving her his book, and said he'd never had firsthand contact with the family. He'd left that up to Hsu.

When I talked to Susan Hsu, now a director of medical genetics at the American Red Cross, she told me that working with McKusick on HeLa cells was a highlight of her career. "I'm very proud," she told me. "I probably will Xerox these paper and tell my kids this is important." But when I explained to her that the Lackses thought she was testing them for cancer, and that they were upset about scientists using the cells without their knowledge, she was shocked.

"I feel very bad," she said. "People should have told them. You know, we never thought at that time they did not understand."

She also told me she had a message she hoped I'd give to the Lacks family when I talked with them next: "Just tell them I'm really grateful," she said. "They should be very proud of the mother or the wife—I think that if they are angry probably they didn't realize how famous the cells are now in the world. It's unfortunate thing what happened, they still should be very proud, their mother will never die as long as the medical science is around, she will always be such a famous thing."

Toward the end of our conversation, Hsu mentioned that she could learn much more from testing the family's blood today, since DNA technology had advanced so much since the seventies. Then she asked if I'd tell the Lacks family one more thing for her: "If they are willing," she said, "I wouldn't mind to go back and get some more blood."