

Henrietta's Dance

By Rebecca Skloot

Johns Hopkins Magazine

<http://www.jhu.edu/jhumag/0400web/01.html>

Not long before her death, Henrietta Lacks danced. As the film rolled, her long thin face teased the camera, flashing a seductive grin as she moved, her eyes locked on the lens. She tilted her head back and raised her hands, waving them softly in the air before letting them fall to smooth her curlers. Then the film went blank.

Henrietta danced in Turners Station, a small, segregated Baltimore community where she moved in 1943. She had come by train from a plantation town in Virginia, leaving her kin behind, most still picking tobacco long after freedom from slavery. As she sped toward Baltimore, at the age of 23, her husband, David Lacks, waited in their new brick house with a stove that burned gas instead of wood. Henrietta knew she was heading into a more modern world. What she didn't know was that less than a decade later, after giving birth to her fifth child, her womb would give rise to a new age in medicine.

On February 1, 1951, under the cover of a solitary tree, David Lacks stared through the window of his parked car, watching the rain fall. He and his five children, three still in diapers, sat outside Hopkins Hospital, waiting for Henrietta. A few days earlier, she had found blood spotting her underwear. Now, Howard Jones, a Hopkins physician, found a smooth eggplant-hued tumor glistening under the light on Henrietta's cervix. He touched its surface, shocked by its supple texture, and Henrietta bled. Jones carefully cut a section of her quarter-sized tumor, sent it to the lab for a diagnosis, and sent Henrietta home with her family. Then came the news: the tumor was malignant.

Henrietta returned to Hopkins eight days later. While David and the children waited under the tree, physicians covered her cervix with radium in an attempt to kill the cancer. But before applying the first treatment, a young resident took one more sample. This one went to George Gey, head of tissue culture research at Hopkins. He and his wife, Margaret, had been searching for a tool for the study of cancer: a line of human cells that would live indefinitely outside the body. If they succeeded, they could observe and test human cells in ways they could never do in humans. Eventually, they could discover the cure for cancer. They were sure of it. After two decades of failure in their laboratory attempts, the Geys turned their attention to cervical cells, at the request of Richard TeLinde, then Hopkins chairman of Gynecology. TeLinde wanted cervical cells for his own research; the Geys wanted any cancer cells they could get. The day George Gey got his hands on Henrietta Lacks's cells, everything changed. For the Geys, for medicine, and eventually for the Lackses.

Henrietta Lacks's cells multiplied like nothing anyone had seen. They latched to the sides of test tubes, consumed the medium around them, and within days, the thin film of cells grew thicker and thicker. But Henrietta's tumor cells took over her body as quickly as they'd taken over test tubes. Within months, tumors appeared on almost every organ, and Henrietta moaned from her bed for the Lord to help her. The day she died, October 4, 1951, George Gey appeared on

national television with a vial of Henrietta's cells. He called them HeLa cells, held them up to the camera, and said, "It is possible that, from a fundamental study such as this, we will be able to learn a way by which cancer can be completely wiped out." Gey introduced the nation to his hopes for curing cancer while Henrietta's body lay in the Hopkins morgue, her toenails shining with a fresh coat of red polish. And her family knew nothing of any cells.

As a train carrying Henrietta's casket rolled back toward Virginia, her cells shocked Gey with their strength. The local undertaker met Henrietta's body at the station where, less than a decade earlier, she had boarded her train to Baltimore. He buried her in an unmarked grave across the street from her family's tobacco field, behind the house where her mother was born. But in the Lacks family cemetery, where cattle roam freely when the season's right, folks today don't know much about HeLa. They don't know that soon after Henrietta's death in 1951, Gey and his colleagues used her cells to grow the polio virus that was ravaging children throughout the world.

"It was Henrietta Lacks's cells that embraced the polio virus," says Roland Pattillo, a former fellow of Gey's, who is now director of gynecologic oncology at Morehouse School of Medicine. "She made it possible to grow the virus so the vaccine could be developed." That was just the beginning. Gey and his colleagues went on to develop a test, using HeLa cells, to distinguish between the many polio strains, some of which had no effect on the human body. Until researchers knew which strain produced polio's crippling effects, they couldn't know what they were fighting. Through Henrietta's cells, they found their culprit. With this information, Jonas Salk and his colleagues in Pittsburgh created a vaccine, and the National Foundation for Infantile Paralysis established facilities for mass-producing the HeLa cells. They would use them to test the polio vaccine before its use in humans. In the meantime, Gey shared his resources.

Packaged in small tubes tucked in plastic foam containers, with careful instructions for feeding and handling, shipments of Henrietta's cells went out to Gey's colleagues around the world. . . to Minnesota, New York, Chile, Russia. . .the list goes on. Researchers welcomed the gifts, allowing HeLa to grow. They used the cells to search for a leukemia cure and the cause of cancer, to study viral growth, protein synthesis, genetic control mechanisms, and the unknown effects of drugs and radiation. And though Henrietta never traveled farther than from Virginia to Baltimore, her cells sat in nuclear test sites from America to Japan and multiplied in a space shuttle far above the Earth. Still, David Lacks and his children hadn't a clue.

"The [only thing] I heard about it was, she had that cancer," David Lacks says. "They called me, said come up there because she died. They asked me to let them take samples, and I decided not to let them do it." But the researchers told Lacks they could use his wife's cells to study cancer. Something that might strike his family again someday. Their studies might someday help his children and his grandchildren. Lacks was skeptical. *But, he thought, if they want to see how my wife's cancer might affect our children, and get ready to treat them if they get sick, I guess that might be okay.*" My cousins said it wouldn't hurt, so eventually I let them do it. The [doctors said] it was the fastest growing cancer they'd ever known, and they were supposed to tell me about it, to let me know, but I never did hear."

He didn't hear, that is, until a hazy day in 1975, 24 years after Henrietta's death, when his daughter-in-law went to a friend's house for dinner.

In a two-story brown-brick townhouse in Baltimore, five doors down from her home, Barbara Lacks, the wife of Henrietta's eldest son, Lawrence, sat down for dinner at her friend Jasmine's house. The two women had been friends for years, but Barbara had never met Jasmine's sister or brother-in-law, who came all the way from D.C. for dinner. They gathered around the mahogany table, surrounded by plants and soft light, and Jackson, Jasmine's brother-in-law, looked across the table at Barbara. "You know," he said, "your name sounds so familiar." Jackson was a scientist who spent his days in a Washington laboratory. "I think I know what it is. . . I've been working with some cells in my lab; they're from a woman called Henrietta Lacks. Are you related?" "That's my mother-in-law," Barbara whispered, shaking her head. "She's been dead almost 25 years, what do you mean you're working with her cells?"

Jackson explained. The cells, he told her, had been alive since Henrietta's death and were all around the world. Actually, by that time, they were standard reference cells--few molecular scientists *hadn't* worked with them. Barbara excused herself, thanking him, promising she would be in touch, and ran home to tell her husband what she'd heard. *Your mother's cells*, she told him, *they're alive*. Lawrence called his father who called his brothers and his sister. They just couldn't understand. "The question I really had," says Barbara, "the question I kept asking Jackson was, I wonder why they never mentioned anything to the family. They knew how to contact us." But, since no one had called in the two decades after Henrietta's death, instead of continuing to wonder, the Lacks family got on the phone and rang Hopkins themselves. And they did it at an opportune time. Henrietta's cells, it turned out, had grown out of control. Some scientists thought her relatives were the only people who could help.

Henrietta's cells were, and still are, some of the strongest cells known to science--they reproduce an entire generation every 24 hours. "If allowed to grow uninhibited," Howard Jones and his Hopkins colleagues said in 1971, "[HeLa cells] would have taken over the world by this time." This strength provided a research workhorse to irradiate, poison, and manipulate without inflicting harm; but it also meant research labs were only big enough for one culture: HeLa.

Though it took three decades for the Geys to succeed with their efforts to create a human cell line, after their success with HeLa, culturing cells became suspiciously easy. Researchers cultivated tissue samples from their own bodies and the bodies of their families and patients. Most grew successfully. Sure, the samples struggled during the first few weeks, or even months, in culture, but then, suddenly, they flourished. Samples blossomed into full-blown healthy cell lines with the strength of, well, the HeLa cell.

In 1974, a researcher by the name of Walter Nelson-Rees started what everyone called a nasty rumor: HeLa cells, he claimed, had infiltrated the world's stock of cell cultures. No one wanted to believe him. For almost three decades researchers had done complex experiments on what they thought were breast cells, prostate cells, or placental cells, and suddenly, rumor had it they'd been working with HeLa cells all along. To believe this would be to believe that years of work and millions of dollars had, in essence, been wasted.

The truth was, Henrietta's cells had traveled through the air, on hands, or the tips of pipettes, overpowering any cell cultures they encountered. And researchers had no idea. There was no way to know *which* cells were growing in the petri dish. And there was no universally accepted test for a cell culture's identity. To accept or reject the theory that HeLa cells had taken over, researchers wanted more evidence. This required detailed information about the cells' source. But they knew only the barest facts about Henrietta: She was black, she was a woman, and she was dead.

Though it may have been coincidence, soon after the Lacks children called Hopkins asking about their mother's cells, letters appeared in their mailboxes. Several Hopkins researchers wondered, the letters said, if the Lacks family would be willing to donate some blood and tissue samples. Soon, a nurse circled Barbara Lacks's narrow dining room table with needles, blood tubes, and slides, gathering samples from the Lackses. From these donations, researchers would find precious bits of information about Henrietta--like her blood type--that they could use in their attempts to study her cells.

"[It was] an elegant piece of work," Nelson-Rees told a reporter, "by simple Aristotelian class logic and pure applied genetics, you could speculate, to a remarkable extent, as to what Henrietta Lacks's [genetic makeup] was." And this is exactly what the researchers did. But if you ask the family, you'll get a different story.

"The doctors tested us to see what was in my mother's system, was it hereditary," recalls Henrietta's son Sonny Lacks. "But that's all they said. They never got in contact with us again. We contacted them a couple a times, but they said they'd get back at us, then after a while, we just got tired of calling, so everybody just let it go and went back with their lives." But every now and then, they wonder if they have the gene that killed their mother.

This point of confusion between what the researchers intended to do with the samples and what the participants understood their intentions to be is only one of several elements of the Lackses' story that points to important ethical questions. Some have yet to find answers.

"There are at least two issues that cases like Mrs. Lacks's raise," says Ruth Faden, executive director of the Johns Hopkins Bioethics Institute and the Philip Franklin Wagley Professor of Biomedical Ethics. "One is the question of consent, and the other is what, if anything, is morally or legally due to a person if something of commercial value is developed from their cells."

In terms of informed consent, says Faden, "the Lackses' story is a sad commentary on how the biomedical research community thought about research in the 1950s. But it was not at all uncommon for physicians to conduct research on patients without their knowledge or consent. That doesn't make it right. It certainly wasn't right. It was also unfortunately common." Since the era when Henrietta walked through the doors of Hopkins, the field of biomedical ethics was born, and with it came regulations about informed consent. Patients now have something like a legal promise that no physician will take samples without permission. It's the latter issue, the commodification of human body parts, which is still an extremely unsettled area of ethics and law in public policy. And for the Lackses, who don't all have health insurance or the money to afford it, the issue of commercial value in this case is very unsettled. Unsettled, but with little recourse.

Since the development of the HeLa cells, there's been an explosion of both scientific and commercial interest in the use of human tissues for research purposes, yet research subjects generally see none of the returns. "The amazing thing," says Faden, "is that here we are, almost 50 years later, the capacity to develop commercial products from human tissues is dramatically greater now than it was then, and we still haven't figured out how to handle it. . . . In terms of public policy, we're real clear that you can't buy and sell organs, that's illegal. But you can sell blood. You can sell human eggs and sperm. But you can't sell your kidney. And apparently, you can't sell your cells, you give those away. So, nothing is very clear, and there are a lot of deep worries about putting price tags on the human body." This is partially why the United States has recently launched a Presidential Bioethics Advisory Commission to address this and related issues.

To this day, members of the Lacks family feel they've been passed over in the story of the HeLa cells. They know their mother's cells started a medical revolution and are now bought and sold around the world. They're pretty sure that someone, somewhere, has profited from their mother's death. They know that someone wasn't related to Henrietta. And their experience is not well-known. In cases like these, Faden agrees, a good way to begin addressing this problem is through the telling of a story from which everyone can learn. This story starts with Henrietta and the origin of the HeLa cells: They were not from Helen Lane or Helen Larson, as many publications have mistakenly reported, they were from Henrietta Lacks, wife of David, mother of five.

Not long before his death, Walter Nelson-Rees, who devoted his career to containing the spread of HeLa cells, sat in a small chair in front of a television camera. He leaned forward, lifted his arms, and said, "HeLa will live forever, perhaps." And then he paused, staring wistfully ahead. "The dance of HeLa continues," he said, "they're all dancing out there somewhere... the stage is very broad and wide, and the curtain has by no means gone down on them. The music plays on." And somewhere, with freshly painted toenails and curlers in her hair, perhaps Henrietta dances with them.