

The BBC interviewed Deborah in front of the home-house in Clover; they shot Day and Sonny leaning on Henrietta's mother's tombstone, talking about what a good cook Henrietta was, and how they never heard anything about the cells until researchers called wanting blood. And they followed the Lacks family to Atlanta for a conference organized in Henrietta's honor by Roland Pattillo, the scientist who would soon steer me to Deborah.

Pattillo grew up in the thirties, the son of a blacksmith turned railroad worker in a small segregated Louisiana town. He was the first in his family to go to school, and when he learned about Henrietta as a postdoctoral fellow in Gey's lab, he felt immediately connected to her. He'd wanted to honor her contributions to science ever since. So on October 11, 1996, at Morehouse School of Medicine, he organized the first annual HeLa Cancer Control Symposium. He invited researchers from around the world to present scientific papers on cancer in minorities, and he petitioned the city of Atlanta to name October 11, the date of the conference, Henrietta Lacks Day. The city agreed and gave him an official proclamation from the mayor's office. He asked Howard Jones to contribute an article recording his memories of diagnosing Henrietta's tumor. Jones wrote:

From a clinical point of view, Mrs. Lacks never did well. . . . As

Charles Dickens said at the beginning of [*A Tale of Two Cities*,

'It was the best of times, it was the worst of times.' But it was the best of times for science in that this very peculiar tumor gave rise to the HeLa cell line. . . . For Mrs. Lacks and the family she left behind, it was the worst of times. Scientific progress and indeed progress of all kinds is often made at great cost, such as the sacrifice made by Henrietta Lacks.

Pattillo got Deborah's phone number through a physician friend at Hopkins and called her. When she heard about his plans for the conference and the official naming of Henrietta Lacks Day, she was ecstatic: finally, a scientist was honoring her mother. Soon the Lacks

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## After London

The story of Henrietta Lacks eventually caught the attention of a BBC producer in London named Adam Curtis, and in 1996, he began making the documentary about Henrietta that I would later watch in Courtney Speed's beauty parlor. When Curtis arrived in Baltimore with his assistants and cameras and microphones, Deborah thought everything would change, that she and the rest of the world would learn the true story of Henrietta Lacks and the HeLa cells, and she would finally be able to move on. She started referring to periods in her life as "before London" and "after London."

Curtis and his crew covered the Lacks family story in more depth than anyone ever had, filling dozens of hours of video interviewing Deborah, prompting her from off camera to speak in complete sentences, and not wander off topic. Deborah said things like "I used to go into a corner after I was married. My husband didn't even know anything about me, you know, just being sad and crying to myself. . . . I just ask these questions in my head. . . . *Why, Lord, did you take my mother when I needed her so much?*"

The interviewer asked, "What is cancer?"

family—Day, Sonny, Lawrence, Deborah, Bobbette, Zakariyya, and Deborah's grandson Davon—piled into an RV that Pattillo rented for them and drove to Atlanta, with the BBC film crew following behind. At a gas station along the way, Deborah smiled into the camera and explained why they were headed to Morehouse.

"They gonna have a lot of doctors there talking on different subjects and different areas of the science field," she said. "And they're gonna hand out plaques to my brother and my father and me in honor of our mother name. So I know it's gonna be a great occasion."

And it was. For the first time, the Lackses were treated like celebrities: they stayed in a hotel, people asked for their autographs. But there were a few glitches. In all the excitement leading up to the ceremony, Sonny's blood pressure shot up dangerously high and he ended up in the hospital, nearly missing the whole event. Zakariyya emptied the minibar in his room, then emptied his father's and Deborah's. He yelled and threw programs when he saw that they listed him as "Joseph Lacks" and Henrietta as the woman who'd "donated" the HeLa cells.

Deborah did her best to ignore all that. When she walked onto the stage, she was so nervous the podium shook when she touched it. She'd worried for weeks that there might be a sniper in the audience—a scientist who'd want to take her out to do research on her body, or to keep the family from causing problems. But Pattillo assured her she was safe.

"Excuse me if I mispronouncing a word," she told everyone at the conference, "but I have problems and I didn't get the right teaching when I was coming up in school. I was not even allowed to have hearing aid until after I was grown. But I'm not ashamed of it."

Then, with Pattillo cheering nearby, Deborah cleared her throat and began her speech:

When Dr. Pattillo called me, it all became real. For years, it seem to be a dream. Not knowing what was going on all these years. Didn't know how to even talk about it. Can this about our

mother be true? Not knowing who to go to for understanding. No one from the medical field took the time.

Then, without so much as a pause, she began talking directly to her mother:

We miss you, Mama. . . . I think of you all the time and wish I could see and hold you in my arms, like I know you held me. My father said that you told him on your dying bed to take care of Deborah. Thank you, Ma, we will see you again someday. We read what we can and try to understand. My mind often wonder how things might would be if God had you stay here with me. . . . I keep with me all I know about you deep in my soul, because I am part of you, and you are me. We love you, Mama.

It seemed like things were going better for the Lackses, like Henrietta would finally begin getting the recognition Deborah hoped for. Soon the BBC showed up in Turner Station, asking locals about life there in the forties and fifties. News of their visit, like news of everything else that happens in Turner Station, quickly found its way to Speed's Grocery, where Courtney Speed learned the story of Henrietta Lacks for the first time. It felt like serendipity—she and several other women had recently founded the Turner Station Heritage Committee, and they were organizing events to bring attention to black people from Turner Station who'd contributed good things to the world: a former congressman who became president of the NAACP, an astronaut, and the man who'd won several Emmy awards as the voice of Sesame Street's Elmo.

When they learned about Henrietta and HeLa, Speed and a sociologist at Morgan State University named Barbara Wyche went into overdrive. They wrote letters to Congress and the mayor's office demanding recognition of Henrietta's contribution to science. They also got in touch with Terry Sharrer, a curator at the Smithsonian National Museum of American History, who invited the Lacks family to a small

event at the museum. There Day admired old farm equipment and insisted that he wanted to see his wife's cells. (The museum had a flask of HeLa in storage somewhere, the medium as dark as a murky pond, but it wasn't on display.) People came up to Deborah with tears in their eyes and told her that her mother's cells had helped them overcome cancer. Deborah was thrilled. After hearing a researcher talk about cloning, Deborah asked Sharrer whether it was possible to take DNA from HeLa cells and put it into one of Deborah's eggs to bring her mother back to life. Sharrer said no.

After the event, Sharrer wrote a letter to Wyche suggesting that, to commemorate Henrietta, she and Speed consider starting an African-American health museum in Turner Station. The women soon founded the Henrietta Lacks Health History Museum Foundation, Inc., with Speed as president. They planned events featuring Henrietta Lacks look-alikes—a few Turner Station women who'd style their hair like Henrietta's and wear suits identical to the one she wore in her iconic photo. To raise awareness of Henrietta's contribution, Speed used her own money to make and give away Henrietta Lacks T-shirts, and someone else made Henrietta Lacks pens. The local papers wrote about their plan for a \$7 million museum, and Speed and Wyche opened a Henrietta Lacks Foundation bank account, filed for a tax ID number, and began trying to collect as much money and information as they could for the museum. One of their first goals was getting a life-sized wax Henrietta statue.

Deborah wasn't appointed as an officer or foundation board member, but Speed and Wyche called occasionally to ask if she'd speak at various celebrations honoring her mother—once under a small tent near Speed's Grocery, other times at a nearby church. Eventually someone suggested that Deborah donate Henrietta's Bible and the locks of hair from Henrietta and Elsie that she kept tucked inside. It was for safekeeping, people said, in case Deborah's house ever caught fire. When Deborah heard that, she ran home and hid her mother's Bible, telling her husband, "That's the only things I have from my mother, now they want to take it!"

When she found out that Speed and Wyche had started a foundation and bank account in her mother's name, Deborah was furious. "The family don't need no museum, and they definitely don't need no wax Henrietta," she said. "If anybody collecting money for anything, it should be Henrietta children collecting money for going to the doctor."

Deborah only agreed to help with the museum project when it looked like Speed and Wyche might turn up information about her mother. The three of them hung handwritten flyers in Speed's grocery store and around Turner Station, asking, "Who knew her favorite hymn? Who knew her favorite scripture? Who knew her favorite color? Who knew her favorite game?" The first two questions were Speed's; the second two came from Deborah.

At one point Speed and Wyche invited Gey's former assistant, Mary Kubicek, to an event in the basement of the New Shiloh Baptist Church in Turner Station, to talk about how she grew HeLa cells. Mary stood wrapped in scarves on a small platform stage, nervous and going blind, as distant Lacks cousins and locals not related to Henrietta yelled questions from the audience, demanding to know who made money off the cells, and whether Gey had patented them.

"Oh no," Mary said, shifting from foot to foot. "No, no, no . . . there was no way to patent cells then." She told them that in the fifties, no one imagined such a thing might someday be possible. Gey just gave the cells away for free, she said, for the good of science.

People in the room grumbled, and tension grew. One woman stood up and said, "Them cells cured me of my cancer, if I got cells that can help somebody like her cells help me, I say take em!" Another woman said she still believed Gey had patented the cells, then yelled, "I hope in the future this could be rectified!" Deborah just fluttered around the room saying that her mother had cured cancer and everyone should just calm down. Then she asked Mary to tell the story about seeing her mother's red toenails during the autopsy—the one Deborah had read in Gold's book. Mary did, and the audience fell silent.

While Speed worked with other Turner Station residents to gather memories of Henrietta, Wyche wrote letter after letter, trying to get recognition for Henrietta and attract donors to pay for the museum. And she got results: the Maryland State Senate sent a resolution on fancy paper, saying, "Be it hereby known to all that The Senate of Maryland offers its sincerest congratulations to Henrietta Lacks." On June 4, 1997, Representative Robert Ehrlich Jr. spoke before the U.S. House of Representatives, saying, "Mr. Speaker, I rise today to pay tribute to Henrietta Lacks." He told Congress her story, saying, "Ms. Lacks was not acknowledged as the donor of the cells." He said it was time for that to change. This, everyone seemed to believe, was where Hopkins should come in.

Wyche had been working on that: she'd written a meticulously detailed three-page, single-spaced letter to William Brody, then president of Johns Hopkins. She called Henrietta an "unsung local heroine," explaining the importance of the HeLa cells, and quoting a historian saying the HeLa story was "one of the most dramatic and important in the history of research at the Johns Hopkins Medical Institution." She also wrote this:

The [Lacks] family has suffered greatly. . . . This family is, like so many others today, attempting to grapple with the many questions and the moral and ethical issues that surround the "birth" of HeLa, and the "death" of Mrs. Lacks. . . . The questions of (1) whether or not permission was received from the "donor" or her family for either the "use" of HeLa worldwide or the "mass," and commercial, production, distribution, and marketing of Mrs. Lacks' cells . . . (2) whether or not scientists, university and government personnel and others have acted ethically in these two areas or in their interactions with the family . . . Other social issues also arise because Mrs. Lacks was an African American Woman.

One month later, Ross Jones, assistant to the president of Hopkins, replied. He said he was "uncertain what role Hopkins might

play in any plan to celebrate Mrs. Lacks' life," but that he wanted to share this information with Wyche:

Please let me emphasize that Hopkins never used the HeLa cells in a commercial venture. Hopkins never sought, nor realized, any money from the development, distribution or use of the HeLa cell cultures. In keeping with almost universally accepted practice at the time, physicians and other scientists at Hopkins and elsewhere did not seek permission to use tissue removed as part of diagnostic and treatment procedures. Also, in keeping with traditions of academic research at the time, the cultures were shared freely, without compensation and in good faith with scientists around the world who requested them. Indeed, willingness of Hopkins scientists to provide access to the cultures is perhaps the principal reason for the great benefits that have derived from their use.

As I'm sure we both know, many standards of practice in academic medicine have changed dramatically in recent years, and I hope and trust that there is increased sensitivity to, and awareness of, the wishes and interests of patients when they seek medical care or participate in research. That is all to the good, for academic medicine and those we serve.

He also told Wyche that he had circulated her letter to "others at Hopkins for comment and consideration." Soon a small group of people at Hopkins began meeting unofficially, without telling Wyche or Speed, to discuss what the university might do to honor Henrietta and the Lacks family.

Then they heard about Cofield.

Sir Lord Keenan Kester Cofield was the cousin of Deborah's husband's former stepdaughter, or something like that. No one in the family remembers for sure. They also don't know how or when he learned about Henrietta's cells. What they do remember is that one day Cofield called Deborah, saying he was a lawyer and that

she needed to protect herself and her mother by copyrighting the name Henrietta Lacks. He also said he believed Hopkins was guilty of medical malpractice, and that it was time to sue for the family's cut of all the money Henrietta's cells had earned since the fifties, a percentage of which he would take as his fee. He would charge nothing up front, and the Lackses wouldn't have to pay if he didn't win.

Deborah had never heard about needing to copyright anything, but the family had always thought they should talk to a lawyer about the cells, and Cofield sounded like one they could afford. Deborah's brothers were thrilled, and she soon introduced Cofield to Speed and Wyche as the family's lawyer.

Cofield began spending his days at Hopkins, digging through the medical school's archives, taking notes. Of all the people who'd come to the Lackses over the years talking about the cells, he was the first to tell the family anything specific about what happened to Henrietta at Hopkins. The way the Lackses remember it, his findings confirmed their worst fears. He told them that one of the doctors who treated Henrietta didn't have a medical license, and that another had been expelled from the American Medical Association. On top of that, Cofield said, Henrietta's doctors had misdiagnosed her cancer and might have killed her with an overdose of radiation.

He told Deborah he needed to read her mother's medical records to investigate how the doctors had treated her, and to document any possible malpractice. Since only Henrietta's family members were authorized to request her records, Deborah agreed to go with him to Hopkins, where she filled out a request form. But the photocopy machine was broken, so the woman behind the desk told Deborah and Cofield they'd have to come back later, once the machine was fixed.

When Cofield returned alone, the staff refused to give him the records because he wasn't a doctor or a relative of the patient. When Cofield said he was Dr. Sir Lord Keenan Kester Cofield, the Hopkins medical records staff contacted Richard Kidwell, one of Hopkins's attorneys. Kidwell got suspicious the moment he heard that someone

was poking around Hopkins using the title "Dr. Sir Lord," so he did some quick background research.

Keenan Kester Cofield wasn't a doctor or lawyer at all. In fact, Cofield had served years in various prisons for fraud, much of it involving bad checks, and he'd spent his jail time taking law courses and launching what one judge called "frivolous" lawsuits. Cofield sued guards and state officials connected to the prisons he'd been in, and was accused of calling the governor of Alabama from jail and threatening to murder him. Cofield sued McDonald's and Burger King for contaminating his body by cooking fries in pork fat, and he threatened to sue several restaurants for food poisoning—including the Four Seasons in New York City—all while he was incarcerated and unable to eat at any restaurants. He sued The Coca-Cola Company, claiming a bottle of soda he'd bought was filled with ground glass, though he was in a prison that only offered Pepsi products in aluminum cans. He'd also been convicted of fraud for a scam in which he got an obituary of himself published, then sued the newspaper for libel and damages up to \$100 million. He told the FBI that he'd filed at least 150 similar lawsuits.

In various court documents, judges described Cofield as a "con artist," "no more than a gadfly and an exploiter of the court system," and "the most litigious inmate in the system." By the time Cofield contacted the Lackses about suing Hopkins, he'd been banned from filing lawsuits in at least two counties.

But Deborah knew none of this. Cofield called himself doctor and lawyer, and seemed capable of getting and understanding more information from Hopkins than the family ever could. And his demeanor didn't hurt. When Courtney Speed described him to me a few years later, she said, "Charisma! Woo! I mean, cream of the smooth! Very well-versed and knew something about everything."

When Kidwell learned the truth about Cofield, the first thing he did was protect Deborah—something the Lacks family never would have expected from someone at Hopkins. He told her that Cofield was a con artist, and had her sign a document forbidding Cofield access

to her family's records. The way everyone I talked to at Hopkins remembers it, when Cofield came back and learned that the family had denied him access, he yelled and demanded copies of the records until a security guard threatened to physically remove him and call the police.

Cofield then filed a lawsuit against Deborah, Lawrence, Courtney Speed, the Henrietta Lacks Health History Museum Foundation, and a long list of Hopkins officials: the president, the medical records administrator, an archivist, Richard Kidwell, and Grover Hutchins, the director of autopsy services. He sued ten defendants in all, and several of the Hopkins employees involved had never heard of Cofield or Henrietta Lacks before their subpoenas arrived.

Cofield accused Deborah, Speed, and the museum foundation of breach of contract for entering into an agreement that required him to have access to Henrietta's medical records, then denying him access. He claimed that Deborah could not legally prohibit him from doing research for the Henrietta Lacks Health History Museum Foundation, because she was not a member of its board of directors, or officially involved with the foundation in any way. He also claimed racial discrimination, saying he was "harassed by negro security of Johns Hopkins, and staff at the archives," and that "the defendants and employees actions were all racially motivated and very anti-black." He demanded access to the medical records and autopsy reports of Henrietta and Deborah's sister, Elsie, as well as damages of \$15,000 per defendant, plus interest.

The most astonishing detail of Cofield's suit was his claim that the Lacks family had no right to any information about Henrietta Lacks because she'd been born Loretta Pleasant. Since there was no official record of a name change, Cofield argued, Henrietta Pleasant had never actually existed, and therefore neither had Henrietta Lacks. Whoever she was, he said, the family wasn't legally related to her. In a statement so filled with grammatical errors it's difficult to understand, Cofield called this an "obvious fraud and conspiracy" and claimed

that his lawsuit would "ultimately lead to the ends of justice for only Mrs. Henrietta Lacks, and now the plaintiff who has become the victim of a small, but big time fraud."

Piles of legal documents began arriving almost daily at Deborah's door: summonses and petitions and updates and motions. She panicked. She went to Turner Station and burst into Speed's grocery store screaming, demanding that Speed give her everything she'd gathered related to Henrietta: the documents Speed kept in a superhero pillowcase, the Henrietta Lacks T-shirts and pens, the video of Wyche interviewing Day in Speed's beauty parlor. Deborah yelled at Speed, accused her of conspiring with Cofield, and said she was going to hire O. J. Simpson's lawyer, Johnnie Cochran, and sue Speed for everything she had if she didn't shut down the foundation and stop all Henrietta-related activities.

But Speed had nothing and was just as scared as Deborah. She was a single mother with six sons, and she planned to put all of them through college using money she made cutting hair and selling chips, candy, and cigarettes. Her store was being robbed regularly, and she was getting just as many court mailings from Cofield as Deborah was. Soon, Speed stopped opening the letters and let them pile up in the backroom of her store until they stacked thirty envelopes high. Then she started a new pile. She prayed to God for the letters to stop, and wished her husband was still alive to deal with Cofield.

By this time the BBC documentary had aired, and reporters were calling Deborah, requesting photos of Henrietta and the family, and asking questions about her mother and how she died. But Deborah still didn't know anything beyond what she'd read in Gold's book. It was time, she decided, to find out what her mother's medical records said. So she requested a copy from Hopkins, along with a copy of her sister's records.

She also met with Kidwell, who told her not to worry and promised that Hopkins would fight Cofield. And it did. The case was eventually dismissed, but everyone involved was spooked. When the group

at Hopkins that had been working on a plan to honor Henrietta heard about Cofield's lawsuit, they quietly dropped the idea, never telling the Lackses they'd even considered it.

Years later, when I talked to Grover Hutchins, the pathologist listed in Cofield's lawsuit, he shook his head and said, "The whole thing was very sad. They wanted to have some kind of recognition for Henrietta, but then things got so hairy with Cofield and the crazy things he was saying the family thought about Hopkins, they decided it was best to let sleeping dogs lie and not get involved with anything having to do with the Lackses."

When I talked with Johns Hopkins spokesperson JoAnn Rodgers, she said there had never been an official effort by Hopkins to honor Henrietta. "It was an individual effort—maybe one or two people—and when they went away, it went away. It was never an institutional initiative."

Though the subpoena had finally stopped coming, Deborah didn't believe the lawsuit was truly over. She couldn't shake the idea that Cofield might send people to her house to steal her mother's Bible or the lock of hair she kept tucked inside it. Or maybe he'd try to steal her cells, thinking they might be valuable like her mother's.

She stopped checking her mail and rarely left the house except to work her shifts driving a school bus for disabled children. Then she was in a freak accident: a teenager on the bus attacked her, throwing himself on top of her, biting and scratching until two men ran onto the bus and pulled him off. A few days later the same boy attacked her again, this time permanently damaging several discs in her spine.

Deborah had her husband hang dark curtains on their windows and stopped answering her phone. Then, sitting in her dark living room a year and a half after Cofield's lawsuit ended, she finally began reading and rereading the full details of her mother's death in her medical records. And for the first time, she learned that her sister had been committed to a mental institution called Crownsville.

She began worrying that something bad had happened to her sister in that hospital. *Maybe she was used in some kind of research like*

*our mother*, she thought. Deborah called Crownsville for a copy of Elsie's records, but an administrator said most of Crownsville's documents from before 1955, the year Elsie died, had been destroyed. Deborah immediately suspected that Crownsville was hiding information about her sister, just as she still believed Hopkins was hiding information about Henrietta.

Within hours of her call to Crownsville, Deborah became disoriented and had trouble breathing. Then she broke out in hives—red welts covering her face, neck, and body, even the soles of her feet. When she checked herself into a hospital, saying, "Everything going on with my mother and sister is making my nerves break down," her doctor said her blood pressure was so high she'd nearly had a stroke.

A few weeks after Deborah came home from the hospital, Roland Pattillo left a message on her answering machine saying he'd been talking to a reporter who wanted to write a book about Henrietta and her cells, and he thought Deborah should talk to her. That reporter was me.