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*1975*

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# "Least They Can Do"

The Lackses didn't know anything about the HeLa contamination problem that led McKusick and Hsu to them until Michael Rogers, a young reporter for *Rolling Stone*, showed up at their house with long hair and rock-and-roll clothes.

Rogers was something of a journalism prodigy. By his nineteenth birthday he'd gotten a degree in creative writing and physics and published his first story in *Esquire;* by his early twenties, when he started looking into the HeLa story, he'd already published two books and joined the staff of *Rolling Stone.* In coming years he'd go on to be an editor at *Newsweek*, and later the *Washington Post.*

Rogers first learned about HeLa cells after seeing "Helen Lane Lives!" written over a urinal in a medical school bathroom. He started reading news reports about HeLa cells and the contamination problem and realized it would make a great story for *Rolling Stone*—the perfect mix of science and human interest. So Rogers set out to find this mysterious Helen Lane.

He called Margaret Gey, who was friendly and talkative until Rogers asked about Helen Lane. Then she told him it wouldn't be a good

idea for them to meet and hung up. Eventually Rogers found his way to Walter Nelson-Rees, who mentioned as an aside that Henrietta Lacks was the real name of the woman behind the cells. Soon, while sitting on his Baltimore hotel bed with the view of the B-R-O-M-O-S-E-L-T-Z-E-R clock, Rogers found Lawrence Lacks in the phone book.

It was the winter of 1975, the streets were icy, and on his way to Lawrence's house, Rogers's taxi was hit by another car in the middle of an intersection. The cab spun in the road, doing five, then six full circles, as if some giant hand had reached down and spun it like a bottle. Rogers had done risky reporting all over the world; now he was sitting in the back of a cab, gripping the door handle, thinking, *Damn it! It would be really stupid if I got killed in Baltimore working on this of all assignments. It's not even a dangerous story!*

Decades later, as I talked with Rogers in his Brooklyn apartment, we agreed, only half joking, that the spinning cab was probably no accident. Deborah would later say that it was Henrietta warning him to leave her family alone, because he was about to tell them something upsetting. She'd also say that Henrietta started the famous Oakland, California, fire that later burned Rogers's house, destroying all the notes and documents he'd collected about HeLa and Henrietta's family.

When Rogers made it to Lawrence's house, he expected to interview the Lackses about Henrietta, but found himself bombarded with questions instead.

"It was so clear they hadn't been treated well," Rogers told me. "They truly had *no* idea what was going on, and they really wanted to understand. But doctors just took blood samples without explaining anything and left the family worrying."

Lawrence asked, "What I was wondering was, about these cells . . . They say they're stronger, they're taking over—is that bad or good? Does that mean if we get sick, we'll live longer?"

Rogers told the Lackses that no, the cells being immortal didn't mean they'd become immortal too, or that they'd die of cancer. But he wasn't sure they believed him. He explained the concept of cells as best he could, told them about the media reports that had already appeared about HeLa, and promised he'd send them copies to read.



At that point no one in Henrietta's immediate family except Deborah seemed particularly upset about Henrietta's story or the existence of those cells.

"I didn't feel too much about the cells when I first found they was livin," Sonny told me years later. "Long as it's helpin somebody. That's what I thought."

But that changed when he and his brothers read Rogers's article and learned this:

> Cell lines are swapped, traded, forwarded, begged and borrowed among research institutions around the world. . . . The institutional sources of cells now range from [government]-supported facilities like Nelson-Rees's to commercial outfits with toll-free 800 numbers, from whom one can order, for about $25, a tiny glass vial of HeLa cells.

With that paragraph, suddenly the Lacks brothers became very interested in the story of HeLa. They also became convinced that George Gey and Johns Hopkins had stolen their mother's cells and made millions selling them.

But in fact, Gey's history indicates that he wasn't particularly interested in science for profit: in the early 1940s he'd turned down a request to create and run the first commercial cell-culture lab. Patenting cell lines is standard today, but it was unheard of in the fifties; regardless, it seems unlikely that Gey would have patented HeLa. He didn't even patent the roller drum, which is still used today and could have made him a fortune.

In the end, Gey made a comfortable salary from Hopkins, but he wasn't wealthy. He and Margaret lived in a modest home that he bought from a friend for a one-dollar down payment, then spent years fixing up and paying off. Margaret ran the Gey lab for more than a decade without pay. Sometimes she couldn't make their house payments

or buy groceries because George had drained their account yet again buying lab equipment they couldn't afford. Eventually she made him open a separate checking account for the lab, and kept him away from their personal money as much as she could. On their thirtieth wedding anniversary, George gave Margaret a check for one hundred dollars, along with a note scribbled on the back of an aluminum oxide wrapper: "Next 30 years not as rough. Love, George." Margaret never cashed the check, and things never got much better.

Various spokespeople for Johns Hopkins, including at least one past university president, have issued statements to me and other journalists over the years saying that Hopkins never made a cent off HeLa cells, that George Gey gave them all away for free.

There's no record of Hopkins and Gey accepting money for HeLa cells, but many for-profit cell banks and biotech companies have. Microbiological Associates—which later became part of Invitrogen and BioWhittaker, two of the largest biotech companies in the world—got its start selling HeLa. Since Microbiological Associates was privately owned and sold many other biological products, there's no way to know how much of its revenue came specifically from HeLa. The same is true for many other companies. What we do know is that today, Invitrogen sells HeLa products that cost anywhere from $100 to nearly $10,000 per vial. A search of the U.S. Patent and Trademark Office database turns up more than seventeen thousand patents involving HeLa cells. And there's no way to quantify the professional gain many scientists have achieved with the help of HeLa.

The American Type Culture Collection—a nonprofit whose funds go mainly toward maintaining and providing pure cultures for science—has been selling HeLa since the sixties. When this book went to press, their price per vial was $256. The ATCC won't reveal how much money it brings in from HeLa sales each year, but since HeLa is one of the most popular cell lines in the world, that number is surely significant.

Lawrence and Sonny knew none of this. All they knew was that Gey had grown their mother's cells at Hopkins, someone somewhere



was making money off of them, and that someone wasn't related to Henrietta Lacks. So, in an attempt to get Hopkins to give them what they saw as their cut of the HeLa profits, they made handouts about Henrietta Lacks's family being owed their due, and gave them to customers at Lawrence's store.

Deborah wanted nothing to do with fighting Hopkins—she was too busy raising her children and trying to teach herself about her mother's cells. She got herself some basic science textbooks, a good dictionary, and a journal she'd use to copy passage after passage from biology textbooks: "Cell is a minute portion of living substance," she wrote. "They create and renew all parts of the body." But mostly she wrote diary entries about what was happening:

> *going on with pain*
> *. . . we should know what's going on with her cells from all of them that have her cells. You might want to ask why so long with this news, well its been out for years in and out of video's papers, books, magazines, radio, tv, all over the world. . . . I was in shock. Ask, and no one answers me. I was brought up to be quiet, no talking, just listen. . . . I have something to talk about now, Henrietta Lacks what went out of control, how my mother went through all that pain all by her self with those cold hearted doctor. Oh, how my father, said how they cooked her alive with radiation treatments. What went on in her mind in those short months. Not getting better and slipping away from her family. You see I am trying to relive that day in my mind. Youngest baby in the hospital with TB oldest daughter in another hospital, and three others at home, and husband got to, you hear me, got to work through it all to make sure he can feed his babies. And wife dying . . . Her in that cold looking ward at John Hopkin Hospital, the side for Black's only, oh yes, I know. When that day came, and my mother died, she*

*was Robbed of her cells and John Hopkins Hospital learned of those cells and kept it to themselfs, and gave them to who they wanted and even changed the name to HeLa cell and kept it from us for 20+ years. They say Donated. No No No Robbed Self.*

*My father have not signed any paper. . . . I want them to show me proof. Where are they.*

The more Deborah struggled to understand her mother's cells, the more HeLa research terrified her. When she saw a *Newsweek* article called PEOPLE-PLANTS that said scientists had crossed Henrietta Lacks's cells with tobacco cells, Deborah thought they'd created a human-plant monster that was half her mother, half tobacco. When she found out scientists had been using HeLa cells to study viruses like AIDS and Ebola, Deborah imagined her mother eternally suffering the symptoms of each disease: bone-crushing pain, bleeding eyes, suffocation. And she was horrified by reports of a "psychic healer" who, while conducting research into whether spiritual healing could cure cancer, attempted to kill HeLa cells by a laying on of hands. He wrote:

> As I held the flask, I concentrated on the picture I'd formed in my mind of the cells, visualizing a disturbance in the cell fields and the cells blowing up. . . . While I worked, I could feel a virtual tug-of-war going on between my hands and the cells' powerful adhesive ability. . . . Then I felt the field give way, as I had broken through . . . the cells looked as though someone had put a tiny hand grenade into each one—the whole culture had just blown apart! The number of dead floating cells had increased twenty times!

To Deborah, this sounded like a violent assault on her mother. But what bothered her most was the fact that so many scientists and journalists around the world continued to call her mother Helen Lane.



*Since they gone ahead and taken her cells and they been so important for science*, Deborah thought, *least they can do is give her credit for it.*

On March 25, 1976, when Mike Rogers's *Rolling Stone* article hit newsstands, it was the first time anyone had told the true story of Henrietta Lacks and her family, the first time the mainstream media had reported that the woman behind HeLa was black. The timing was explosive. News of the Tuskegee study was still fresh; the Black Panthers had been setting up free clinics for black people in local parks and protesting what they saw as a racist health-care system; and the racial story behind HeLa was impossible to ignore. Henrietta was a black woman born of slavery and sharecropping who fled north for prosperity, only to have her cells used as tools by white scientists without her consent. It was a story of white selling black, of black cultures "contaminating" white ones with a single cell in an era when a person with "one drop" of black blood had only recently gained the legal right to marry a white person. It was also the story of cells from an uncredited black woman becoming one of the most important tools in medicine. This was big news.

Rogers's article caught the attention of several other journalists, who contacted the Lackses. In the three months following Rogers's story, *Jet, Ebony, Smithsonian,* and various newspapers published articles about Henrietta, "one of the pivotal figures in the crusade against cancer."

Meanwhile, Victor McKusick and Susan Hsu had just published the results of their research in *Science*: in a table that took up about half of a page, under the headings "Husband," "Child 1," "Child 2," "H. Lacks," and "HeLa," McKusick, Hsu, and several coauthors mapped forty-three different genetic markers present in DNA from Day and two of the Lacks children, and used those to create a map of Henrietta's DNA that scientists could use to help identify HeLa cells in culture.

Today, no scientist would dream of publishing a person's name with any of their genetic information, because we know how much can be deduced from DNA, including the risks of developing certain

diseases. Publishing personal medical information like this could violate the 1996 Health Insurance Portability and Accountability Act (HIPAA) and result in fines up to $250,000 and up to ten years in jail. It could also violate the 2008 Genetic Information Nondiscrimination Act, created to protect people from losing their health insurance or employment due to genetic discrimination. But there was no such federal oversight at the time.

A lawyer might have told the Lackses they could sue on the grounds of privacy violation or lack of informed consent. But the Lackses didn't talk to a lawyer—they didn't even know anyone had done research on their DNA, let alone published it. Deborah was still waiting to hear the results of what she thought was her cancer test, and Sonny and Lawrence were still busy trying to figure out how to get money from Hopkins. They didn't know that on the other side of the country, a white man named John Moore was about to begin fighting the same battle. Unlike the Lacks family, he knew who'd done what with his cells, and how much money they'd made. He also had the means to hire a lawyer.