

1976-1988

25

"Who Told You You Could Sell My Spleen?"

In 1976—the same year Mike Rogers published his article in *Rolling Stone* and the Lacks family found out people were buying and selling Henrietta's cells—John Moore was working twelve-hour days, seven days a week, as a surveyor on the Alaska Pipeline. He thought the job was killing him. His gums bled, his belly swelled, bruises covered his body. It turned out that at the age of thirty-one, Moore had hairy-cell leukemia, a rare and deadly cancer that filled his spleen with malignant blood cells until it bulged like an overfilled inner tube.

Moore's local doctor referred him to David Golde, a prominent cancer researcher at UCLA, who said that removing his spleen was the only way to go. Moore signed a consent form saying the hospital could "dispose of any severed tissue or member by cremation," and Golde removed his spleen. A normal spleen weighs less than a pound; Moore's weighed twenty-two.

After the surgery, Moore moved to Seattle, became an oyster salesman, and went on with his life. But every few months between 1976 and 1983, he flew to Los Angeles for follow-up exams with

Golde. At first Moore didn't think much of the trips, but after years of flying from Seattle to L.A. so Golde could take bone marrow, blood, and semen, he started thinking, *Can't a doctor in Seattle do this?* When Moore told Golde he wanted to start doing his follow-ups closer to home, Golde offered to pay for the plane tickets and put him up in style at the Beverly Wilshire. Moore thought that was odd, but he didn't get suspicious until one day in 1983—seven years after his surgery—when a nurse handed him a new consent form that said:

I (do, do not) voluntarily grant to the University of California all rights I, or my heirs, may have in any cell line or any other potential product which might be developed from the blood and/or bone marrow obtained from me.

At first, Moore circled "do." Years later, he told *Discover* magazine, "You don't want to rock the boat. You think maybe this guy will cut you off, and you're going to die or something."

But Moore suspected Golde wasn't being straight with him, so when the nurse gave him an identical form during his next visit, Moore asked Golde whether any of the follow-up work he was doing had commercial value. According to Moore, Golde said no, but Moore circled "do not," just in case.

After his appointment, Moore went to his parents' house nearby. When he got there, the phone was ringing. It was Golde, who'd already called twice since Moore left the hospital. He said Moore must have accidentally circled the wrong option on the consent form, and asked him to come back and fix it.

"I didn't feel comfortable confronting him," Moore told a journalist years later, "so I said, 'Gee, Doctor, I don't know how I could have made that mistake.' But I said I couldn't come back, I had to fly to Seattle."

Soon the same form appeared in Moore's mailbox at home with a sticker that said "Circle I do." He didn't. A few weeks later he got a letter from Golde telling him to stop being a pair and sign the form.

That's when Moore sent the form to a lawyer, who found that Golde had devoted much of the seven years since Moore's surgery to developing and marketing a cell line called Mo.

Moore told another reporter, "It was very dehumanizing to be thought of as Mo, to be referred to as Mo in the medical records: 'Saw Mo today.' All of a sudden I was not the person Golde was putting his arm around, I was Mo, I was the cell line, like a piece of meat."

Weeks before giving Moore the new consent form—after years of "follow-up" appointments—Golde had filed for a patent on Moore's cells, and several extremely valuable proteins those cells produced. Golde hadn't yet sold the rights to the patent, but according to the lawsuit Moore eventually filed, Golde had entered into agreements with a biotech company that gave him stocks and financing worth more than \$3.5 million to "commercially develop" and "scientifically investigate" the Mo cell line. At that point its market value was estimated to be \$3 billion.

Nothing biological was considered patentable until a few years before Moore's lawsuit, in 1980, when the Supreme Court ruled on the case of Ananda Mohan Chakrabarty, a scientist working at General Electric who'd created a bacterium genetically engineered to consume oil and help clean up oil spills. He filed for a patent, which was denied on the grounds that no living organism could be considered an invention. Chakrabarty's lawyers argued that since normal bacteria don't consume oil, Chakrabarty's bacteria weren't naturally occurring—they only existed because he'd altered them using "human ingenuity."

Chakrabarty's victory opened up the possibility of patenting other living things, including genetically modified animals and cell lines, which didn't occur naturally outside the body. And patenting cell lines didn't require informing or getting permission from the "cell donors."

Scientists are quick to point out that John Moore's cells were

exceptional, and few cell lines are actually worth patenting. Moore's cells produced rare proteins that pharmaceutical companies could use to treat infections and cancer. They also carried a rare virus called HTLV, a distant cousin of the HIV virus, which researchers hoped to use to create a vaccine that could stop the AIDS epidemic. Because of this, drug companies were willing to pay enormous sums to work with his cells. Had Moore known this before Golde patented them, he could have approached the companies directly and worked out a deal to sell the cells himself.

* In the early 1970s a man named Ted Slavin had done precisely that with antibodies from his blood. Slavin was born a hemophiliac in the 1950s, when the only available treatment involved infusions of clotting factors from donor blood, which wasn't screened for diseases. Because of that, he'd been exposed to the hepatitis B virus again and again, though he didn't find out until decades later, when a blood test showed extremely high concentrations of hepatitis B antibodies in his blood. When the results of that blood test came back, Slavin's doctor—unlike Moore's—told him his body was producing something extremely valuable.

Researchers around the world were working to develop a vaccine for hepatitis B, and doing so required a steady supply of antibodies like Slavin's, which pharmaceutical companies were willing to pay large sums for. This was convenient, because Slavin needed money. He worked odd jobs waiting tables and doing construction, but he'd eventually have another hemophilia attack and end up unemployed again. So Slavin contacted laboratories and pharmaceutical companies to ask if they wanted to buy his antibodies. They said yes in droves.

Slavin started selling his serum for as much as ten dollars a milliliter—at up to 500 milliliters per order—to anyone who wanted it. But he wasn't just after money. He wanted someone to cure hepatitis B. So he wrote a letter to Nobel Prize-winning virologist Baruch Blumberg, who'd discovered the hepatitis B antigen and created the blood test that found Slavin's antibodies in the first place. Slavin offered Blumberg unlimited free use of his blood and tissues for his research,

which began a years-long partnership. With the help of Slavin's serum, Blumberg eventually uncovered the link between hepatitis B and liver cancer, and created the first hepatitis B vaccine, saving millions of lives.

Slavin realized he probably wasn't the only patient with valuable blood, so he recruited other similarly endowed people and started a company, Essential Biologicals, which eventually merged with another, larger biological-product corporation. Slavin was only the first of many who have since turned their bodies into businesses, including nearly two million Americans who currently sell their blood plasma, many of them on a regular basis.

Moore, however, couldn't sell the Mo cells because that would have violated Golde's patent. So in 1984, Moore sued Golde and UCLA for deceiving him and using his body in research without consent; he also claimed property rights over his tissues and sued Golde for stealing them. With that, he became the first person to legally stake a claim to his own tissue and sue for profits and damages.

When Judge Joseph Wapner, most famous for being the judge on *The People's Court* television show, ended up refereeing the depositions, Moore figured no one would take the case seriously. But scientists worldwide panicked. If tissue samples—including blood cells—became patients' property, researchers taking them without getting consent and property rights up front would risk being charged with theft. The press ran story after story quoting lawyers and scientists saying that a victory for Moore would "create chaos for researchers" and "[sound] the death knell to the university physician-scientist." They called it "a threat to the sharing of tissue for research purposes," and worried that patients would block the progress of science by holding out for excessive profits, even with cells that weren't worth millions like Moore's.

But plenty of science was already on hold while researchers, universities, and biotech companies sued one another over ownership of various cell lines. Only two of those cases mentioned the people those cells came from: the first, in 1976, involved ownership of an important human-fetal-cell line. Leonard Hayflick, the researcher who'd originally grown the cells, argued that there were numerous parties with

legitimate property interests in any cultured cells, including the scientist who grew them, the financiers of any related work, and the "donors" of the original samples. Without any one of those contributions, he said, the cultured cells wouldn't exist, and neither would any money resulting from their sale. That case set no precedent because it settled out of court, with rights to the cells being divided between the parties involved in the lawsuit, which didn't include the cell "donor." The same was true of another case soon after, in which a young scientist took a cell line he'd helped develop in the United States and fled with it to his native Japan, claiming ownership because the original cells had come from his mother.

The public didn't realize there was big money in cell lines until news of the Moore case hit, and headlines nationwide said things like:

OWNERSHIP OF CELLS RAISES STICKY ISSUES . . .

WHO SHOULD HAVE RIGHTS TO A PATIENT'S CELLS? . . .

WHO TOLD YOU YOU COULD SELL MY SPLEEN?

Scientists, lawyers, ethicists, and policymakers debated the issues: some called for legislation that would make it illegal for doctors to take patients' cells or commercialize them without consent and the disclosure of potential profits; others argued that doing so would create a logistical nightmare that would put an end to medical progress.

Ultimately the judge threw Moore's suit out of court, saying he had no case. Ironically, in his decision, the judge cited the HeLa cell line as a precedent for what happened with the Mo cell line. The fact that no one had sued over the growth or ownership of the HeLa cell line, he said, illustrated that patients didn't mind when doctors took their cells and turned them into commercial products. The judge believed Moore was unusual in his objections. But in fact, he was simply the first to realize there was something potentially objectionable going on.

Moore appealed, and in 1988 the California Court of Appeals ruled in his favor, pointing to the Protection of Human Subjects in Medical Experimentation Act, a 1978 California statute requiring that research

on humans respect the "right of individuals to determine what is done to their own bodies." The judges wrote, "A patient must have the ultimate power to control what becomes of his or her tissues. To hold otherwise would open the door to a massive invasion of human privacy and dignity in the name of medical progress."

But Golde appealed and won. And with each new decision in the suit, headlines flip-flopped:

COURT RULES CELLS ARE THE PATIENT'S PROPERTY . . .
COURT BACKS DOCTORS' RIGHT TO USE PATIENT TISSUES

Nearly seven years after Moore originally filed suit, the Supreme Court of California ruled against him in what became the definitive statement on this issue: When tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes. When you leave tissues in a doctor's office or a lab, you abandon them as waste, and anyone can take your garbage and sell it. Since Moore had abandoned his cells, they were no longer a product of his body, the ruling said. They had been "transformed" into an invention and were now the product of Golde's "human ingenuity" and "inventive effort."

Moore wasn't awarded any of the profits, but the judge did agree with him on two counts: lack of informed consent, because Golde hadn't disclosed his financial interests, and breach of fiduciary duty, meaning Golde had taken advantage of his position as doctor and violated patient trust. The court said researchers should disclose financial interests in patient tissues, though no law required it. It also pointed out the lack of regulation and patient protections in tissue research, and called on legislators to remedy the situation. But it said that ruling in Moore's favor might "destroy the economic incentive to conduct important medical research," and that giving patients property rights in their tissues might "hinder research by restricting access to the necessary raw materials," creating a field where "with every cell sample a researcher purchases a ticket in a litigation lottery."

Scientists were triumphant, even smug. The dean of the Stanford

University School of Medicine told a reporter that as long as researchers disclosed their financial interests, patients shouldn't object to the use of their tissues. "If you did," he said, "I guess you could sit there with your ruptured appendix and negotiate."

Despite the widespread media coverage of the Moore suit, the Lacks family had no idea any of this was happening. As the debate over ownership of human tissues played out around the country, the Lacks brothers continued to tell anyone who'd listen that Johns Hopkins had stolen their mother's cells and owed them millions of dollars. And Deborah started handing out newsletters about her mother and the cells, saying, "I just want y'all read what's on this paper! And tell everybody! Bring it around. We want everybody in the world to know about my mother."