

Henrietta Lacks and Her Remarkable Cells Will Finally See Some Payback

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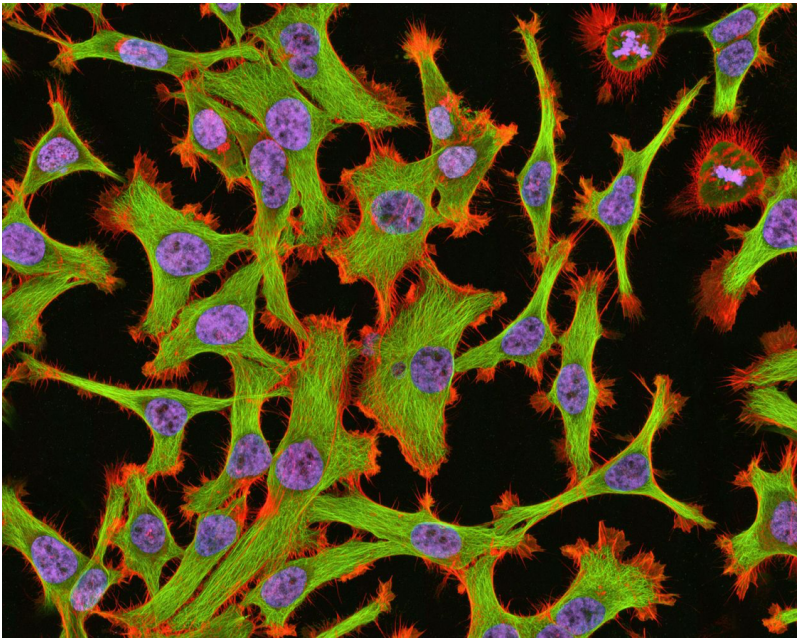
In 1951, scientists took a Black woman's cancer cells without her consent. The cells of Henrietta Lacks proved invaluable for research, and labs and companies gained financially from using them for decades, with nothing for her or her family.

Now, two entities that benefited say they are giving back.

[Abcam ABC -0.08%](#) PLC, a 1,400-person life-sciences company with headquarters in the U.K., is making a gift to the Henrietta Lacks Foundation to support higher-education scholarships in science, technology, engineering and mathematics for descendants of Ms. Lacks. The foundation and company aren't disclosing the amount of the gift.

The lab of Samara Reck-Peterson, an investigator at the Howard Hughes Medical Institute and professor of cellular and molecular medicine and of biological sciences at the University of California San Diego, said it utilizes the cells, commonly known as HeLa cells after Ms. Lacks, to study and ask research questions. The lab will donate \$100 to the foundation for each of the four cell lines that lab members created in the past by making changes to the HeLa cells, and for any cell lines they make in the future.

"This is a small part, but we want to encourage other labs to do something similar," Dr. Reck-Peterson said. If every lab that uses the cells donated money, she added, it could have a sizable impact.



A picture of HeLa cells, which have contributed to medical breakthroughs such as the polio and HPV vaccines.

Photo: Tom Deerinck

“The symbolism of the donations is powerful,” said Blair Kelley, associate professor of history at North Carolina State University and a member of the board of the Henrietta Lacks Foundation. “A company and a research institution, two of the most important spaces that have benefited from the HeLa lines, are acknowledging what happened and what should be made right.”

The story of Ms. Lacks, who would have turned 100 years old on Saturday, has become a powerful symbol of the need for transparency in science, and the [legacy of mistrust of the scientific and medical establishment](#) within minority communities whose bodies have historically been used without their consent.

The [case was detailed in the 2010 bestselling book](#) “The Immortal Life of Henrietta Lacks,” by Rebecca Skloot, who set up the Henrietta Lacks Foundation and has primarily funded it with proceeds from the book and an HBO adaptation that starred Oprah Winfrey.

Ms. Lacks sought treatment for cervical cancer at Johns Hopkins Hospital in Baltimore in 1951. She died later that year. Cells taken from her tumor sample without her knowledge and consent were sent to the lab of a researcher. Growing human cells in a lab is often difficult. The researcher was amazed that the cells remained alive and kept replicating. He shared them with scientists around the world. Scientists today buy HeLa cells and cells with

modifications for anywhere from \$400 to thousands of dollars per vial.



The Lacks family gathering at a highway marker honoring Henrietta Lacks near her childhood home in Clover, Va.

Photo: The Lacks family

The cells contributed to medical breakthroughs such as the polio and HPV vaccines and in vitro fertilization, and to study and ask research questions about cancer and AIDS.

Ms. Lacks's family didn't learn about the cells until the 1970s, when scientists tracked down and took blood samples from her children for additional studies. The family didn't understand they were part of research, Ms. Skloot said.

Over the past decade, Johns Hopkins has worked with several members of the Lacks family to "recognize and honor Henrietta Lacks," a spokeswoman for the university said. There are now named scholarships, annual symposia, a historical exhibit on the medical campus and plans to name a building after Ms. Lacks, as well as continuing discussions about informed consent, medical privacy, and how to communicate with research participants.

"Johns Hopkins has never sold or profited from the discovery or distribution of the HeLa cells and does not own the rights to the HeLa cell line," the spokeswoman said.

Scientists have improved ethical rules in the wake of public attention about the Lacks case. In 2013, the National Institutes of Health announced an agreement that requires [scientists to seek permission to use the genetic code](#) of the HeLa cells in NIH-funded research and to acknowledge gratitude for the family's contributions. The committee includes members of the

Lacks family.



Members of the Lacks family at a book signing at Charles R. Drew University of Medicine and Science in Los Angeles.

Photo: Rebecca Skloot

Ruha Benjamin, an associate professor of African American Studies at Princeton University, said the discussion about compensation for the HeLa cells echoes issues raised by the current protests about racial and social justice. Prof. Benjamin said that Henrietta Lacks's story is now known, but that **health inequities remain and need to be addressed**. "With racism, we are taught to look at who it harms, but we often fail to understand that people benefit materially from the ongoing perpetuation of racism," she said.

The Lacks case also raises broad questions about research subjects that still remain unaddressed, says Clyde W. Yancy, professor and chief of cardiology at Northwestern University, a member of the foundation's board and former chairman of the NIH HeLa committee.

"Are they or anyone else owed anything when a discovery is made from their biological material?" Dr. Yancy said. The question is especially sharp when it involves minority communities, who have historically been used in scientific experiments without their consent or knowledge. The field of gynecology was developed in part on experiments performed on enslaved women, according to historians of science. Black men with syphilis had treatment withheld from them during a 40-year U.S.-run syphilis study in Tuskegee, Ala. President Bill Clinton issued a formal apology in 1997.

Dr. Yancy said that scientists have a duty to ensure that biological materials such as cells aren't taken or used without people's understanding and consent as well as an obligation to maintain patient anonymity to the extent possible. But what, if any, financial compensation should be given to people when scientific creativity is involved in taking cells and turning them into important discoveries "remains an unresolved question. There is a lot of gray area around what happens there," he said.

Yolonda Wilson, a professor of philosophy and bioethicist at Howard University, said the answer is clear in the case of Henrietta Lacks. "You still have to pay for it. If a baker steals apples off the tree and says, 'I made the pie,' you still have to pay for the apples you took," Dr. Wilson said.

Alan Hirzel, CEO of Abcam, said that when he read about Henrietta Lacks, he was moved by "the story and the injustice of how her life played out." In 2018, the company started making more of its own cell lines and acquiring edited cell lines from other companies, many of which use HeLa cells. The company said that 60%-65% of the company's edited cell-line products are based on the HeLa cell line.

In recognition of the history of the cells, the company decided to set up a scholarship to help give family members access to STEM education.

"I don't think we have an obligation," Mr. Hirzel said. "It was a choice. I thought having our product lines gave us greater cause and reason for doing something." He said he hopes other companies will also consider the idea of a donation. "I think they have to want to do it. It has to come from a visceral desire to contribute and make an impact."

At the Reck-Peterson lab, the scientists saw a direct connection between what happened to Henrietta Lacks and to current demonstrations and struggles for racial and social justice.

Donté Alexander Stevens, a graduate student in the lab, said the idea that the lab should do something was born out of conversations after the [civil unrest following the killing](#) of George Floyd in May. "Racism is everywhere," Mr. Stevens said. "It got us thinking about how racism affects science."

Mr. Stevens, who is Black, said he didn't learn about the history of the Lacks cells until a professor in a biology class in college urged him to dig into the literature. "I remember having a sense of shock that the field I was trying to get into had a long history of exploitation of minorities."

Dr. Reck-Peterson and her team considered several options, including using other cell lines or making monetary donations. They ended up speaking with members of the Lacks family,

who told them the family wanted scientists to continue to use the cells to benefit science.

Ms. Skloot, the author, said that when she initially set up the foundation, she hoped businesses and research institutions that rely so heavily on HeLa cells would donate to help the family. But donations have mainly come from individuals rather than corporations or institutions.

“It is impossible to calculate how much money has been made in the world of science from the use of HeLa cells, whether it is selling HeLa cells or making a product using HeLa cells,” Ms. Skloot said. “People get tied up in knots trying to come up with a figure, what amount is owed to the family, and who owes the money.”

Jeri Lacks, granddaughter of Henrietta Lacks, said the donations recognizing that something is owed by those who use the cells “are a step in the right direction to recognize the sizable contribution Henrietta Lacks and HeLa cells have made.”

She said that the Lacks family is large and that different members hold various viewpoints on what should be done to rectify past injustices and how to move forward in a way that also ensures that future patients are protected. “More can be done,” she said, “and more will be done.”

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