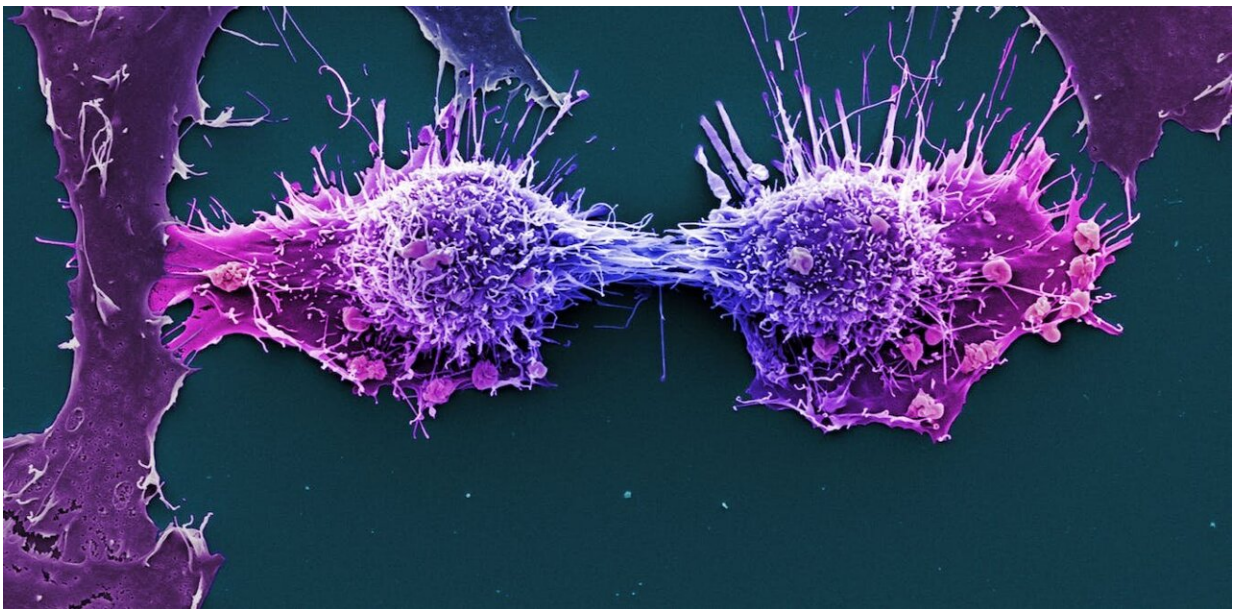


Settlement with family of Henrietta Lacks is an opportunity to reflect on inequalities in genetic research

August 4 2023, by Aileen Editha



The HeLa line of immortal human epithelial cancer cells was derived from cells taken from Henrietta Lacks when she was a cancer patient in 1951. Credit: [\(Wellcome Collection: Anne Weston, Francis Crick Institute\)](#), [CC BY-NC](#)

Aug. 1, 2023 would have been Henrietta Lacks's 103rd birthday. It was also the day the Lacks family [reached a settlement](#) with Thermo Fisher Scientific, the biotech company that used and profited from her ["HeLa" cells](#).

Though the details remain confidential, this settlement is a long-awaited moment of justice and victory for Lacks and her family.

Lacks's [story](#) is well known and [has since been popularized](#) in an HBO film, but it is viewed as a tale of the past. However, the inequalities suffered by Lacks remain problems of the present. As a legal researcher and woman of color, I have found that these problems are still alive and kicking today.

Genetic research (and [medical practice](#) more generally) are filled with [systemic racism](#), [racial discrimination](#) and [unconscious biases](#). For many Black, Indigenous and Peoples of Color (BIPOCs), [the battle for an equitable framework](#) is not over yet.

Henrietta Lacks' story

[Lacks](#) was a Black tobacco farmer living in Baltimore, Md. and undergoing treatment in 1951 for [cervical cancer](#) at Johns Hopkins University Hospital, one of the only hospitals that treated Black patients from lower socioeconomic backgrounds.

Her cells were taken and retained for research purposes by white physicians and researchers at the hospital. Lacks's cells, unlike others, had the innate ability to survive, divide and grow indefinitely. Viewed as extremely valuable in research, the researchers patented "HeLa," the first immortalized human cell line.

"HeLa"—derived from the first two letters of her first and last names—is the [oldest and most commonly used human cell line](#). It has since contributed to many lifesaving endeavors, including [the development of polio and COVID-19 vaccines](#).

Although Lacks passed away from cervical cancer in 1951, her story has

only been widely told in recent years. It was [Rebecca Skloot's 2010 book *The Immortal Life of Henrietta Lacks*](#) that drew attention to Lacks's story and highlighted the racialized and patriarchal nature of medical ethics and research practices.

Since then, Johns Hopkins University has established [a memorial award](#) and [university building](#) in her name. The World Health Organization has also [bestowed a posthumous award](#) to Lacks for her contributions to medical science.

These actions, however, have only recently been taken. Advocates—mainly people of color—used the pandemic and subsequent COVID-19 vaccine developments to [bring Lacks's story back to life](#).

Not just her: Other stories of inequality

Another story often told alongside Lacks's is that of John Moore, who [fought for property rights over his cells](#). Moore had hairy cell leukemia and, as part of his treatment, underwent a splenectomy at the University of California Los Angeles Medical Center in 1976. Like Lacks's, Moore's cells had been [unknowingly and unlawfully processed and patented as the "Mo" cell line](#).

But unlike Lacks—at least, until now—Moore received damages. In 1990, the Supreme Court of California decided that, although Moore did not have a property claim, his doctor breached a fiduciary duty to Moore by not obtaining proper informed consent. This decision has since been taught in [property law classes](#) across Canada and the United States.

These stories were covered and received in starkly different ways. Though [Moore's story was told in a timely manner](#), Lacks's story was not. But for her family and Skloot's journalism, the injustices experienced by a Black woman would have been easily overlooked.

Another case is the [Havasupai tribe's lawsuit against the Arizona Board of Regents](#). Blood samples from the tribe were obtained for research on [inherited diabetes](#). The samples were later [unlawfully used for other research](#), including studies on inbreeding and schizophrenia. This violated the Havasupai's consent agreement and had deeper repercussions, as these topics were considered taboo by the tribe.

The fight isn't over yet

News of the Lacks family's settlement should be celebrated. But it should also serve as a reminder that the fight for a fairer and more equitable framework of medical ethics and [genetic research](#) is not over.

Genetic materials are generally [treated like any other objects](#) and [little to no consideration is given to the person](#). This perpetuates existing systemic inequalities and racial harm in the fields of medicine and scientific research.

Ben Crump, attorney for the Lacks family, said in a [news conference](#) [that](#) "not only were the HeLa cells derived from Henrietta Lacks—the HeLa cells are Henrietta Lacks." We can continue Lacks's fight by continuing to raise awareness and advocating for the *people*, and not just the [cells](#).

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