

Genetic justice

The cells of Henrietta Lacks, crucial to medical research, were harvested without her consent – now her family are suing
By Semmi W.

When Johns Hopkins Hospital held a press conference in 1951 announcing its discovery of the HeLa cell line, the body of Henrietta Lacks was still lying in the hospital's morgue.

She had died of cervical cancer at the age of 31, leaving behind a husband and five children. Johns Hopkins took time to excitedly inform the world of a great medical advancement: these were the first human cells able to grow outside a body for more than 36 hours, opening up new paths for research. But they never told her grieving family.

It was only in 1975 that the family discovered the fate of the cells, which had been harvested from tumours in Henrietta's womb. Scientists hoping to map Henrietta's DNA called her husband in order to request permission to collect genetic samples from him and other relatives. Before that phone call, no efforts had been made to seek consent or inform the family. They tried to find out more, but the details were scarce. "She was systematically erased by Johns Hopkins, scientists, researchers and doctors – often incorrectly referred to as 'Helen Lane' or 'Henry Lawson,'" Alfred Lacks Carter, Henrietta's grandson, said.

The cells, which are remarkably durable and prolific, thriving in lab conditions, have since been reproduced

billions of times. The HeLa cell line has facilitated crucial research on viruses such as polio, zika, HIV, herpes and measles. Recently, it played an important role in the development of Covid-19 vaccines.

On 4 October, exactly 70 years since the day Henrietta died, the Lacks family estate filed a lawsuit against biotech giant Thermo Fisher Scientific Inc, one of the many companies making use of the HeLa cell line. Represented by civil rights attorney Benjamin Crump, who has fought for the rights of police brutality victims including Trayvon Martin and George Floyd, and Christopher Seeger, who led the \$1 billion National Football League concussion settlement, the suit accuses the company of selling HeLa cells without consent in a "racially unjust medical system".

For the family, the lawsuit is part of a long fight to have Henrietta's mistreatment recognised. *The Immortal Life of Henrietta Lacks* (2017), an HBO film starring Oprah Winfrey, based on Rebecca Skoolt's 2010 book of the same title, initially helped draw mainstream attention to the Lacks story and the impact of HeLa cells.

Seeger and Crump were drawn to the case partly due to its historical significance. They now plan to investigate at least 100 other pharmaceutical companies for their use of the cells.



The unveiling of a statue of Henrietta Lacks at Royal Fort House, Bristol, with her family in attendance, October 2021

“The continued exploitation of Mrs. Lacks’ genetic material is one of the greatest examples of corporate theft in history,” Seeger said. “Her story represents the unfortunately common exploitation of Black people by the medical industry throughout US history. When I learned about this case, I wanted to be a part of correcting that wrong, even if only for one family.”

Over 50 million metric tonnes of HeLa cells have been distributed around the world to date, while the cells have been involved in nearly 75,000 studies. Widely considered the industry standard tool for studying human biology, they have contributed to the development of drugs for HIV/Aids and Parkinson’s disease, as well as breakthroughs in reproductive health and research on chromosomal conditions, gene-mapping and precision medicine. As Carter, Henrietta’s grandson, has said: “Billions of dollars [are] being made without our consent.”

Should the Lacks family be compensated – and if so, how? This past October, Crump told Amy Goodman of *Democracy Now!* that the lawsuit is based “on the principle of not just simple justice, not just social justice,” but “genetic justice – the belief that justice should flow from one

generation to the next.”

Genetic justice recognises how past violations of disenfranchised communities have shaped science and medical education around the world. But will it hold up in a court of law? Experts in bioethics or law may simply counter that while informed consent matters, “genetic justice” is not a recognised legal theory. However, it is related to the doctrine of Unjust Enrichment, which occurs when one person is enriched at the expense of another in circumstances that the law sees as unjust.

Crump believes that the doctrine of Unjust Enrichment applies to this case. As he put it in the interview, “You should not be allowed to continue to benefit at the peril of the victim, which is Henrietta Lacks.” Seeger, meanwhile, has claimed that “research organisations and pharmaceutical companies are making a conscious choice to embrace the legacy of racial injustice embedded in the US research and medical systems.”

It is difficult, however, to provide concrete evidence of racial injustice. Its role in Henrietta Lack’s mistreatment is a point of legal dispute in the case. Back in the 1950s, there were no clear ethical standards for any patient, regardless of race, when it came to medical research. It was

common practice for biospecimens to be taken or analysed by doctors and researchers without their consent. Meanwhile, official health data related to race from the period is thin on the ground. However, it's important to look at the big picture.

Henrietta Lacks was born in 1920 in Virginia, at a time when the Jim Crow laws enforced racial segregation in most areas of life. Her mother died when Lacks was aged four, and she was sent to live with her grandfather in a log cabin on a tobacco farm that once housed slaves. Her cancer diagnosis came in early 1951, following her marriage to Daniel "Day" Lacks and the birth of her five children. She was sent to Baltimore for treatment but her options were limited. Most hospitals refused to take Black patients. Only teaching hospitals, like Johns Hopkins, had segregated wards.

Lacks died on such a ward. In the eight months before her death, doctors had been taking biopsies of her rapidly reproducing cancerous cells. Dr George Gey, a cell biologist and prominent cancer researcher at Johns Hopkins, created the HeLa cell line and sent it to a special facility at the Tuskegee Institute without patient knowledge or family consent, in order to manufacture more HeLa cells and distribute them worldwide.

"My great-grandmother experienced medical racism," said Victoria Baptiste, "and my family faced discrimination." This pattern, she says, has continued. "Today, we [the family] speak out against normalised malpractice and structural gaslighting to demand that historical injustices are acknowledged and addressed as the first step to building trust in research, science and medicine."

Johns Hopkins Hospital, however, denies targeting Black patients. "It was common practice at Johns Hopkins to collect tissue samples from cervical cancer patients, regardless of race or socio-economic status," it has stated on a special legacy site, devoted to clarifying their stance on the case. The hospital has admitted that it should have done more in the past to inform the Lacks family. However, it has emphasised that it has only ever "offered" HeLa cells for scientific research, not sold them.

But while the hospital may not have profited, its extraction of the cells has meant that others have. There are approximately 11,000 registered patents around the world using HeLa cells, owned by multiple companies. One of these is Thermo Fisher Scientific Inc. In the case brought by the Lacks family, the company has been accused of

profiting directly from the mass production of Lacks' cell tissue. It has also marketed at least 12 products, sold to labs across the globe, that contain the HeLa cell line.

This use of the cells, the lawsuit states, "can only be understood as a choice to embrace a legacy of racial injustice embedded in the US research and medical systems." The Lacks family want the company to release "the full amount of its net profits obtained by commercialising the HeLa cell line". They also want Thermo Fisher Scientific Inc. to stop using HeLa cells without permission and to create a trust for the Henrietta Lacks Estate.

In December, the company filed a Motion to Dismiss, stating: "Thermo Fisher is left in the untenable position of defending itself for the downstream effects of 70-year-old acts in which Thermo Fisher had no part, which took place in a different time, under different norms than today, with no known physician or family witnesses still living."

They added: "A plaintiff cannot wait decades to bring a claim while the scientific community – including companies that serve it like Thermo Fisher – makes use of a resource that has been freely and publicly available for the better part of a century." This would, it states, place "every researcher

(not just Thermo Fisher) who uses HeLa cells . . . under a cloud of potential liability".

What might unnerve those companies still using the HeLa line is the precedent set by another case nearly four decades ago.

John Moore was an entrepreneur who learned that he had cancer – a rare form known as hairy cell leukaemia – in 1976. Like Lacks, his diagnosis came at the age of 31. Born in Seattle, Moore had an eclectic career which included stints working in Alaska as a survey engineer and alcohol counsellor, establishing a college in Guadalajara, Mexico, becoming a beverage distributor and even a worm farmer.

The condition Moore was diagnosed with caused his spleen to fill with defective lymphocytes (a type of white blood cell) and doctors grew fearful that his spleen might burst. He underwent treatment at UCLA's Medical Center, where his spleen was removed. Later, one Dr David Golde, a cancer researcher at the medical centre, realised that the spleen contained unique blood cells of a kind that stimulated white blood cell development. This find was remarkable: white blood cells are needed to fight infection. From the extracted cells, Golde created a replicating cell, which the university then patented under the name "Mo".

*Roughly 11,000
patents use HeLa
cells today*

John Moore survived the treatment. But when he learned of the patent, he filed a lawsuit against the University of California and Dr Golde, who had not obtained consent to replicate the cells. Moore felt he had been duped. Between 1976-83 he was asked to make frequent trips to Los Angeles from Seattle, believing he was doing so for treatment. In reality, Golde was taking more specimens for the “Mo” cell line, and by the mid-1980s, he had established contracts with Sandoz Pharmaceuticals and Genetics Institute, Inc. to turn it into a commercial product.

Moore sued for lack of informed consent, fraud and deceit. His legal team argued that he had a right to a portion of the profits made from the “Mo” line. The case was initially dismissed, before the California Court of Appeal ruled in favour in 1988, stating that a patient’s blood and tissue was personal property, meaning that they could take a share in resulting profits.

In 1990, however, the Supreme Court of California reversed the decision. They considered cells to be similar to donated or discarded organs, and believed that laboratories with large amounts of bio materials could not always be expected to know if everything was obtained ethically. At the time, the “Mo” cell line was valued at \$3 billion. Today, it is worth more than \$6 billion.

In 1991, Moore took his case to the US Supreme Court, but he was denied again on similar grounds. However, he did negotiate a settlement with UCLA, which covered all of his legal fees, based on the fact that he was an uninformed patient and research subject. The Supreme Court also acknowledged his mistreatment, stating that “a physician who is seeking a patient’s consent for a medical procedure must . . . disclose personal interest unrelated to the patient’s health, whether research or economic, that may affect his medical judgment.”

Moore was a white man who had access to medical treatment without prejudice. He was also alive when his cells were being harvested. Yet, while medical standards and the law had progressed significantly in the decades between, there is still a connection between him and Henrietta Lacks. Both were desperate for treatment, and sought care for rare forms of cancer at teaching hospitals. Both were not informed about the basic fact that their bodies were being harvested, creating cell lines which are now worth billions.

Although Moore ultimately lost the case, legal scholars have noted the precedent set by it. “He was able to show how his doctors violated their ethical duties to him, which

is very serious,” says Jorge L. Contreras, an expert in science and technology law at the American Bar Association and a member of the advisory board of the American Antitrust Institute. “Even so, the court didn’t go as far as he wanted . . . The theory is that (in the hospital) as part of your treatment, you discard cells all the time . . . when you give that vial of blood to the hospital, you can’t give it back. It’s gone. You give up ownership when you give it to the hospital.”

Moore lost when it came to ownership over his cells, but he won when it came to the question of whether doctors breached their ethical duties towards him.

What will happen if the Lacks family win? Thermo Fisher Scientific Inc. has an estimated annual revenue of \$40 billion. In December 2021, it acquired PPD, a renowned global research organization, for \$17.4 billion.

PPD provides clinical research services to biopharma and biotech companies, all of which require, or have required, HeLa cells to expand their own growth and innovation.

The Lacks family are clear that the lawsuit should not be understood as a threat to the future of scientific enquiry.

“The Lacks family does not want to stop innovation or research. Instead, we want to end injustice,” said Alfred Lacks Carter. “We want what is rightfully ours – the Henrietta Lacks Estate having a say in how her cells and genetic materials are used, to be compensated, and to ensure equitable access to the innovations made possible by the HeLa cells.”

The research community is already paying attention. The Henrietta Lacks Foundation, established by Skoolt in 2010 using proceeds from her book, has received large donations from institutions including the UK biotech firm Abcam and the University of California (San Diego) and a six-figure sum from the Howard Hughes Medical Institute in 2020. The foundation has thus far awarded 90 grants to over 30 members of Henrietta Lacks’s immediate family.

While the foundation is separate from the case against Thermo Fisher, the donations show that there is a strong institutional interest in the story.

Meanwhile, Seeger has confirmed that more claims against other companies are likely to be filed soon. “What happened to [Henrietta] cannot be changed,” he said, “but by returning to her family what is rightfully theirs and acknowledging the Lacks family’s contribution to scientific advancement, these companies can demonstrate that Black lives are valued and respected.” ●

“The lawsuit is not a threat to the future of scientific enquiry”