Henrietta Lacks in the 1940s. (Science Source)

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Next year will mark 75 years since the death of Henrietta Lacks, whose "immortal" HeLa cells have proved nearly indispensable to modern medicine. Their use was crucial for the development of vaccines for polio, HPV, and COVID-19, and has generated billions in profits for the life sciences industry. Central to Lacks' story, however, is that these cells were used for medical research not only without her consent, but against her family's express wishes.

This year, family members and advocates are aiming to correct the record and achieve recognition from one of the first entities to overlook her medical rights: the Maryland State Anatomy Board, which will commemorate her for the first time at an event on Saturday, Oct. 4, near her final place of residence in Turner Station, Maryland.

"We have a theme called the liberation of Henrietta Lacks," said David Sanders, a Utah Black Catholic and cancer survivor who has benefitted from the HeLa cells. He is assisting members of the Lacks family in gaining full recognition for their ancestor's contributions to science.

"Part of that comes from liberation theology and how you use health issues for social justice. They're tied hand-in-hand. We recognize that now… Henrietta Lacks is the great thread that ties us all together."

The October event, taking place on the anniversary of Lacks' death, will mark a closing of the circle for her memory, which has undergone several permutations since being popularized in 2010 with the bestselling book "The Immortal Life of Henrietta Lacks" by Rebecca Skloot. It was later adapted into an HBO film released in 2017, starring and produced by Black billionaire Oprah Winfrey.

They follow the story of Lacks, who was born in rural Virginia and diagnosed with cervical cancer in 1951 after moving to the Baltimore area. She died the same year at age 31 after receiving treatment at Johns Hopkins Hospital in Baltimore, where scientists collected her cancer cells during a biopsy and kept them for testing. They were passed on to Johns Hopkins researcher Dr. George Otto Gey, who quickly discovered their uniqueness and helped them become the popular—and lucrative—HeLa cells known today.

Since it was first reported in the Black press in the 1970s, it has been known that Lacks' husband, David "Day" Lacks, refused permission for the collection of her cells, which took place on several occasions. The final violations of her body occurred postmortem, after Day gave permission for an autopsy—during which Gey collected more HeLa cells for his own purposes without proper authorization. The family was not informed about the use of Lacks' cells until the 1970s.

Contrary to the idea that the confiscation of HeLa cells occurred due to loopholes in medical law, it directly violated existing state regulations in the 1950s, according to Sanders and Lacks' grandson, Alfred Lacks-Carter Jr., who first met last year. In 1947—around the same time as the enactment of the Nuremberg Code following the medical abuses of World War II—the Maryland State Anatomy Board was established, including under its purview the fate of cadavers in medical research. It is not known whether the board was aware of the use of Lack's body following her death, but they certainly did not intervene.

In the decades since, the board has regularly commemorated Marylanders whose bodies contributed to scientific research. Lacks has never been among them. Sanders and Lacks-Carter filed a complaint with the Maryland State Prosecutor in November to address the original negligence of the board in 1951 and the continued erasure of Lacks' legacy.

Part of the outcome of that complaint is the board's decision to finally honor Lacks at the event in October, a shift that Lack-Carter describes as a welcome development.

"I'm a living testimony that people can change," said Lacks-Carter, whose mother Deborah "Dale" Lacks was a principal contributor to Skloot's "Immortal Life" book, which was released three years after Dale's death.

"So that's why we're doing this. God is just making sure that the legacy is protected and he is surrounding us with like-minded people."

The event comes years after the success of the book and film, which brought Lacks' story to a wider audience, though with little recompense for her descendants. According to Sanders and Lacks-Carter, Dale did not receive due payment for her services with Skloot, who has largely been off the radar in recent years.

Around the time of her book's release, several members of the Lacks family spoke out against her, calling the book inaccurate, inappropriate, and largely misrepresentative of the family. Dale's passing in 2009 left little in the way of its release, though, and it received rave reviews from critics and other family members. Some, however, like Lacks-Carter, his cousin Ron, and his uncle Lawrence Sr., maintained that the media cash-in on Lacks' legacy enriched everyone but those most connected to it.

Lawrence, Henrietta's last surviving child and the former executor of her estate, died in 2023—the same year the family settled a lawsuit against Thermo Fisher Scientific over its use of her HeLa cells. The national civil rights attorney Ben Crump served as the family's legal counsel and the amount received in the settlement was kept confidential.

Skloot herself has maintained that she is fulfilling the expressed wishes of Dale that she contribute to the Lacks family with funds from her book, which has sold more than 2.5 million copies. Skloot's method? Creating the Henrietta Lacks Foundation in 2011, which is not led by or centered on Lacks' descendants. According to its website, "the foundation is not affiliated with the Lacks family and has been established to benefit the general public." (The nonprofit makes grants generally to those affected by medical experimentation, and recipients have included Lacks' relatives.)

According to Sanders and Lacks-Carter, Henrietta Lacks' estate—opened by Dale in 2000—never received proceeds from the book or adapted film, the latter of which was nominated for an Emmy (among numerous other awards). HBO, Oprah, and other involved parties reportedly refused requests from family members for direct contributions apart from individual consulting fees. Skloot, on the other hand, negotiated a "significant HBO contribution" in 2017 for her foundation. She did not respond to an emailed list of questions from BCM.

For these and other reasons, Skloot will not be welcome at this October's event, which will take place at Dundalk High School in Baltimore. On the schedule are acknowledgements from the World Health Organization and Gov. Wes Moore, as well as remarks from a John Hopkins scientist, Maryland State Delegate Richard W. Metzgar, the State Anatomy Board, and Dr. Michele Goodwin, a law professor at Georgetown University's O'Neill Institute for National and Global Health Law.

"[Skloot] is not invited, and if she shows up, she'll be escorted out," Sanders said. "She's barred."

Lacks-Carter, who is not directly affiliated with the estate of Henrietta Lacks (now run by his cousin Ron), has trademarked his grandmother's name and also opened his mother Dale's estate this summer. He plans to continue his push for what he says is owed to his family's legacy—both symbolic and material.

"They didn't witness the victory of Henrietta Lacks. All they heard was the agony and the defeat and disrespect, the circumvention of the estate, all the negative things," he said.

"I'm doing this to immortalize not only my grandmother, but my mother as well."

He and Sanders also describe the Dundalk event as a launching point for a more global effort to both honor Lacks and prevent further medical abuses, including through Lacks-Carter's nonprofit, the Henrietta Lacks House of Healing, founded in 2016. The keynote speaker for the gathering, Dr. Goodwin, is also assisting the family in filing an official complaint with the U.N. Human Rights Council.

Sanders has also requested an official acknowledgement for the October event from the Vatican, as Lacks reportedly converted to Catholicism after her move to Maryland. Sanders notes that a Catholic element at the October event could be a first for commemorations with the State Anatomy Board, and a timely bridge between the Church and a global health initiative.

With several separate lawsuits ongoing in Maryland from the Lacks family against pharmaceutical outfits, a class-action case may also be in the works, in view of comprehensive redress from companies that continue to enrich themselves through the HeLa cells.

"We're trying to do a corrective, definitive work," said Sanders.

"They took [Henrietta Lacks' cells] illegally. They didn't ask her permission, but nonetheless, when they did that, they made her an organ donor. It was an involuntary organ donation, if you want to call it that. Now it's time to correct that and for people to fess up."

This story was originally published in Black Catholic Messenger.