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Client Alert: In Honor of Martin Luther King Jr. Day: Appreciating the Genomic Legacy of Henrietta Lacks

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Appreciating the Genomic Legacy of Henrietta Lacks

On January 29, 1951, Henrietta Lacks, a 31-year-old, black mother of 5, was admitted into the racially segregated ward at John Hopkins Hospital. She had a cervical lump and complained of intense pain and abnormal bleeding. The biopsy result was not good. The culture was malignant, and Lacks was diagnosed with epidermoid carcinoma of the cervix. The standard treatment at Hopkins was to take strips of radium and place them over the cancerous growth. Radium is a radioactive metal, deadly to *all* cells, including cancerous ones. Lacks arrived the following week for treatment. While anesthetized and unconscious, her doctor sliced two samples from her cervix: one healthy and the other cancerous. As she had already been biopsied, the procedure was unnecessary medically. Lacks never assented to the excision, nor would she ever learn of it in the few remaining months of her life. This was not unusual. Tissue samples were being taken from numerous black women at John Hopkins, frequently without their approval or knowledge. But Henrietta Lacks' cancerous cells—dubbed "HeLa cells"—turned out to be singularly different from all others. In fact, they were extraordinary. Nearly 11,000 patents, 5 Nobel prizes, advances in cloning, gene therapy, as well as vaccines for everything from polio to HIV can be linked to research conducted with HeLa cell lines. And yet, while millions of lives have been saved thanks to Henrietta Lacks, the legal circumstances under which bodily tissue may be taken without "informed consent" remain unresolved. The needs of science and public welfare are often in tension with patient rights to privacy, foreknowledge, and consent. Police scan DNA databases to solve crimes. Amidst the Covid-19 pandemic, HIPAA requires laboratories to report the identities of those who test positive for Covid to health authorities. It was only this year that California passed a law to protect genetic information privacy. So perhaps some lessons may be learned from how it happened that Henrietta's cells were taken in the first place…

Scientists require an endless supply of human cells to advance research. Cellular biospecimens are essential to study disease, develop cures, and test new drugs. They are as vital to the field of genetics as they are to forensics. Today, human cell lines are mass-produced and sold to laboratories across the globe. But to get human cells to survive and replicate outside the body was no small achievement. By the mid-20th century, researchers had strived for decades to keep human cell cultures alive and replicating under laboratory conditions. All attempts ended in failure. Furthermore, such work suffered from an obvious supply challenge. As cell cultures constantly perished, new biospecimens had to be continuously acquired. In constant need of new, living tissue samples, researchers sought out hospital surgeons as suppliers.

In 1951, Dr. Richard Wesley TeLinde, chair of gynecology at John Hopkins, found himself in an interesting predicament. TeLinde believed that vaginal carcinoma in situ (CIS) was a deadly form of cancer. Accordingly, he regularly removed the cervix, uterus, and portions of the vagina of patients with this condition. While today CIS is considered a 'Stage 0' form of cancer, even in 1951, TeLinde faced vociferous criticism from colleagues who questioned why a stationary cancer required such aggressive treatment. To prove his surgeries justified, TeLinde wanted to demonstrate that, left untreated, CIS would inevitably spread and decimate the removed organs. What he needed was a way to observe the long-term progression of the cancer under laboratory conditions, but that could not be done if human tissue could not survive detached from the body. Desperate to restore his tarnished reputation, TeLinde turned to the head of tissue research at John Hopkins, Dr. George Gey, who was obsessively attempting to solve the in vitro cellular survivability problem. In exchange for his help, TeLinde offered Gey a steady stream of samples, something that suited the researcher perfectly. Thereafter, TeLinde instructed doctors treating black patients in John Hopkins segregated ward to remove tissue samples from women diagnosed with cervical cancer and give them to Gey for his experiments in cell line regeneration. The patients were neither informed nor did they consent to the use of their removed tissue and organs for research.

In Gey's laboratory, Henrietta's cells were cultivated no differently than his prior failings. However, Lacks' cancerous cells thrived, doubling every 24 hours. It would take decades for the scientific community to come to understand the unique properties that allowed the cell line to survive. Meanwhile, Gey boasted of his success to

colleagues. Word spread. Very soon vials of HeLa cells were being sent to labs in New York, Amsterdam, Chile, and India. They, in turn, shared the undying cell line with other labs. So began a revolution in medical research leading to treatments for sickle cell anemia and advancing the science of genomics. The commercial wealth created by the existence of HeLa cells is in the billions. Remarkably, it was not till 1975 that Lacks' family was informed that Henrietta's cells not only remained alive, but existed in the order of millions of metric tons in laboratories around the world. Ironically, zealous researchers, curious about origins of HeLa cells, wanted to study biological samples of Henrietta's descendants. Lacks' family responded with attempts to gain control over her genetic legacy. Their efforts were futile. In 2010, a New York Times best seller, *The Immortal Life of Henrietta Lacks,* finally managed to draw global attention to the Lacks' family. The popularity of the book, however, did not prevent a team of researchers from publishing Henrietta's entire genome on the internet in 2013. The information was only removed when John Hopkins University intervened on behalf of the family.

In the last decade, recognition of Henrietta Lack's contributions to science have steadily gained momentum. She has been inducted into the National Women's Hall of Fame, a painting of her hangs in the National Gallery, a medical campus and a high school were named for Lacks. Sculptures and statues have been commissioned. There has even been a film about her starring Oprah Winfrey and Reneé Elise Goldsberry. However, Lacks' descendants have not benefitted financially from the commercial use of HeLa cell lines. But that may soon change.

On October 4, 2021, The Estate of Henrietta Lacks filed suit against Thermo Fischer Scientific for profiting from the HeLa cell line without Lacks' consent. It is a one count action for unjust enrichment. The plaintiff asks for the "full amount" of Thermo's net profits obtained from HeLa cells. To appreciate the magnitude of the plaintiff's demand for relief, one might consider the litany of HeLa product lines available for sale on the company's website:

1. Pierce HeLa Protein Digest Standard
2. Pierce HeLa Digest/PRTC Standard
3. T-REx HeLa Cell Line
4. Cervical Adenocarcinoma (HeLa-S3) Total RNA
5. Human Cervical Adenocarcinoma (HeLa-S3) Total RNA
6. Cell Sensor ESRE-bla HeLa Cell Line
7. Cell Sensor HSE-bla HeLa Cell Line
8. LanthaScreen c-Jun (1-79) HeLa Cell Line
9. Cell Sensor T-REx NICD CSL-bla HeLa Cell Line
10. Cell Sensor T-REx FOXO3 DBE-bla HeLa Cell Line
11. 1-Step Human Coupled IVT Kit – DNA

This trial or settlement will be closely watched by many different stakeholders in the life sciences and healthcare industry. The rights of patients, researchers, medical institutions, research sponsors, funders, and others seeking to commercialize research advances are often in tension with each other in respect to the issues litigated in this case.

It is worth contemplating that the millions of people saved by Covid vaccinations may also owe a profound debt to Henrietta Lacks. In September 2020, Harvard University reported that HeLa cells were instrumental to researchers trying to understand the virus. For one thing, HeLa cells were remarkably resistant to Covid infection, which was vital to discovering the virus's infectivity properties and the development of effective vaccines.

In light of her impact on modern science, it is astonishing that, for almost 60 years, Henrietta Lacks lay in an unmarked grave. But in May 2010, she finally received a tombstone:

Henrietta Lacks
August 01, 1920-October 04, 1951.
In loving memory of a phenomenal woman, wife and mother who touched the lives of many.
Here lies Henrietta Lacks (HeLa). Her immortal cells will continue to help mankind forever.
Eternal Love and Admiration, From Your Family

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