The New York Times

August 7, 2013

A Family Consents to a Medical Gift, 62 Years Later

By CARL ZIMMER

Henrietta Lacks was only 31 when she died of cervical cancer in 1951 in a Baltimore hospital. Not long before her death, doctors removed some of her tumor cells. They later discovered that the cells could thrive in a lab, a feat no human cells had achieved before.

Soon the cells, called HeLa cells, were being shipped from Baltimore around the world. In the 62 years since — twice as long as Ms. Lacks's own life — her cells have been the subject of more than 74,000 studies, many of which have yielded profound insights into cell biology, vaccines, in vitro fertilization and cancer.

But Henrietta Lacks, who was poor, black and uneducated, never consented to her cells' being studied. For 62 years, her family has been left out of the decision-making about that research. Now, over the past four months, the National Institutes of Health has come to an agreement with the Lacks family to grant them some control over how Henrietta Lacks's genome is used.

"In 20 years at N.I.H., I can't remember something like this," Dr. Francis S. Collins, the institute's director, said in an interview.

The agreement, which does not provide the family with the right to potential earnings from future research on Ms. Lacks's genome, was prompted by two projects to sequence the genome of HeLa cells, the second of which was published Wednesday in the journal Nature.

Though the agreement, which was announced Wednesday, is a milestone in the saga of Ms. Lacks, it also draws attention to a lack of policies to balance the benefits of studying genomes with the risks to the privacy of people whose genomes are studied — as well as their relatives.

As the journalist Rebecca Skloot recounted in her 2010 best-seller, "The Immortal Life of Henrietta Lacks," it was not until 1973, when a scientist called to ask for blood samples to study the genes her children had inherited from her, that Ms. Lacks's family learned that their mother's cells were, in effect, scattered across the planet.

Some members of the family tried to find more information. Some wanted a portion of the profits that companies were earning from research on HeLa cells. They were largely ignored for years.

Ms. Lacks is survived by children, grandchildren and great-grandchildren, many still living in or around Baltimore.

And this March they experienced an intense feeling of déjà vu.

Scientists at the European Molecular Biology Laboratory published the genome of a line of HeLa cells, making it publicly available for downloading. Another study, sponsored by the National Institutes of Health at the University of Washington, was about to be published in Nature. The Lacks family was made aware of neither project.

“I said, ‘No, this is not right,’ ” Jeri Lacks Whye, one of Henrietta Lacks’s grandchildren, said in an interview. “They should not have this up unless they have consent from the family.”

Officials at the National Institutes of Health now acknowledge that they should have contacted the Lacks family when researchers first applied for a grant to sequence the HeLa genome. They belatedly addressed the problem after the family raised its objections.

The European researchers took down their public data, and the publication of the University of Washington paper was stopped. Dr. Collins and Kathy L. Hudson, the National Institutes of Health deputy director for science, outreach and policy, made three trips to Baltimore to meet with the Lacks family to discuss the research and what to do about it.

“The biggest concern was privacy — what information was actually going to be out there about our grandmother, and what information they can obtain from her sequencing that will tell them about her children and grandchildren and going down the line,” Ms. Lacks Whye said.

The Lacks family and the N.I.H. settled on an agreement: the data from both studies should be stored in the institutes’ database of genotypes and phenotypes. Researchers who want to use the data can apply for access and will have to submit annual reports about their research. A so-called HeLa Genome Data Access working group at the N.I.H. will review the applications. Two members of the Lacks family will be members. The agreement does not provide the Lacks family with proceeds from any commercial products that may be developed from research on the HeLa genome.

With this agreement in place, the University of Washington researchers were then able to publish

their results. Their analysis goes beyond the European study in several ways. Most important, they show precisely where each gene is situated in HeLa DNA.

A human genome is actually two genomes, each passed down from a parent. The two versions of a gene may be identical, or they may carry genetic variations setting them apart.

“If you think of the variations as beads on a string, you really have two strings,” said Dr. Jay Shendure, who led the Washington genome study. “The way we sequence genomes today, for the most part we just get a list of where the genes are located, but no information about which ones are on which string.”

Dr. Shendure and his colleagues have developed new methods that allow them to gather that information. By reconstructing both strings of the HeLa genome, they could better understand how Ms. Lacks’s healthy cells had been transformed over the past 60 years.

For example, they could see how Ms. Lacks got cancer. Cervical cancer is caused by human papillomavirus infections. The virus accelerates the growth of infected cells, which may go on to become tumors.

Dr. Shendure and his colleagues discovered the DNA of a human papillomavirus embedded in Ms. Lacks’s genome. By landing at a particular spot, Ms. Lacks’s virus may have given her cancer cells their remarkable endurance.

“That’s one of the frequent questions that I and the Lacks family get whenever we talk about this stuff,” Ms. Skloot said. “The answer was always, ‘We don’t know.’ Now, there’s at least somewhat of an answer: because it happened to land right there.”

Richard Sharp, the director of biomedical ethics at the Mayo Clinic, said he thought the agreement “was pretty well handled.” But he warned that it was only a “one-off solution,” rather than a broad policy to address the tension between genome research and the privacy of relatives, now that recent research has demonstrated that it is possible to reveal a person’s identity through sequencing.

Dr. Sharp considered it impractical to set up a working group of scientists and relatives for every genome with these issues. “There’s absolutely a need for a new policy,” he said.

Eric S. Lander, the founding director of the Broad Institute, a science research center at Harvard and M.I.T., said resolving these issues was crucial to taking advantage of the knowledge hidden in our genomes.

"If we are going to solve cancer, it's going to take a movement of tens of thousands, or hundreds of thousands, of patients willing to contribute information from their cancer genomes towards a common good," Dr. Lander said. "We are going to need to have ways to have patients feel comfortable doing that. We can't do it without a foundation of respect and trust."