

# Science nod to family of unwitting medical heroine

August 7 2013, by Mariette Le Roux

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This 1940s photo made available by the family shows Henrietta Lacks. In 1951, a doctor in Baltimore removed cancerous cells from Lacks without her knowledge or consent. Those cells eventually helped lead to a multitude of medical treatments and formed the groundwork for the multibillion-dollar biotech industry. On Wednesday, Aug. 7, 2013, under an agreement announced by the federal government, Lacks family members will have a say in how such research proceeds. (AP Photo/Lacks Family via The Henrietta Lacks Foundation)

Sixty-two years ago, scientists harvested cancer cells from an African American tobacco farmer which were used for some of the biggest breakthroughs in medical science—without her knowledge or consent.

The abnormally resilient cells were taken from Henrietta Lacks shortly before she died and used for decades without her family's knowledge, spawning Nobel-winning discoveries and a multi-million-dollar industry that yielded the polio vaccine, cloning, in-vitro fertilisation and many medicines.

It became the most widely used human cell line used by researchers and made Lacks a giant contributor to medical science, albeit unwittingly.

Now, six decades after her death, Lacks' descendents are paving the way yet again—this time helping to lay the groundwork for ethical use of genetic data obtained in the name of research.

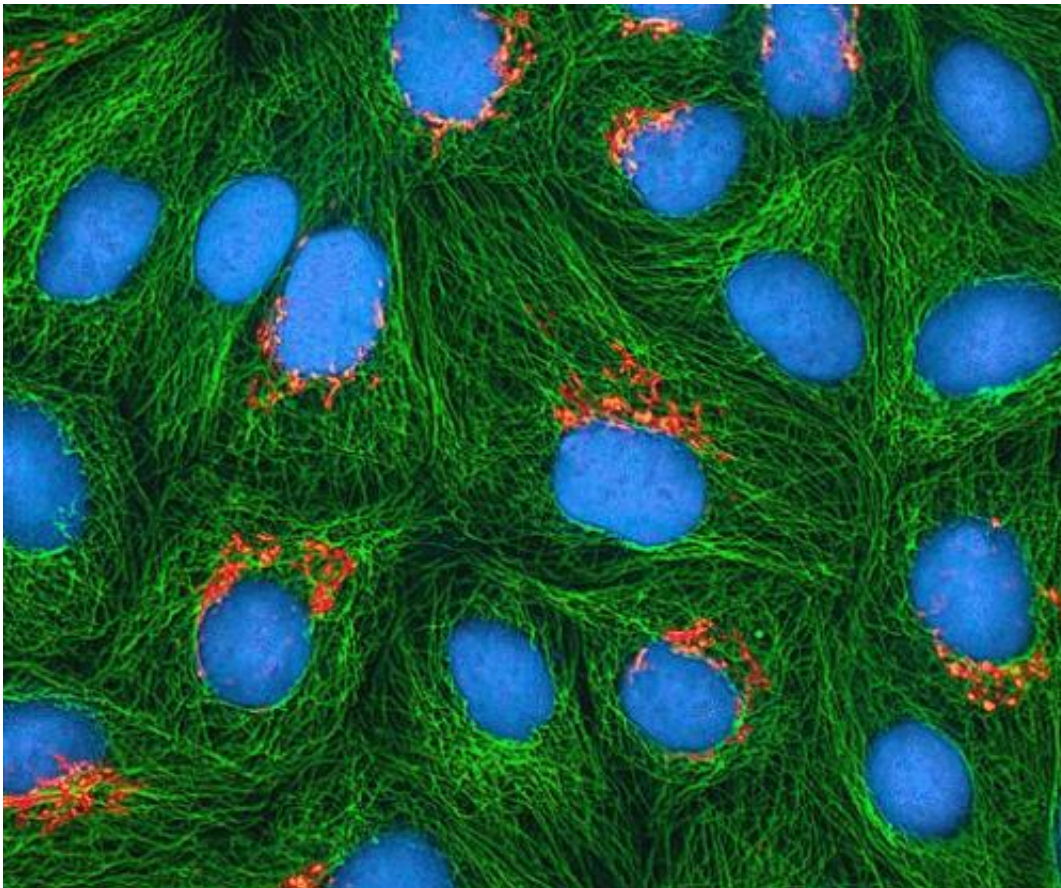
On Wednesday, authorities announced they had finally reached an agreement with Lacks' family for the continued, though controlled, use of the cells' genomic data, which was published on the same occasion.

"It is truly fitting, given the priceless contributions that Henrietta Lacks has made to science and medicine, that her story is now catalysing enduring changes in policy," Francis Collins, director of the US National Institutes of Health (NIH), told journalists.

"We should all count Henrietta Lacks and her family among the greatest philanthropists of our time if we consider how they have contributed to the advancement of science and human health."

Lacks, a mother of five, was 31 when she died of an aggressive cervical cancer at Johns Hopkins Hospital in Baltimore, Maryland in 1951.

At the time, US regulations did not require doctors to obtain a patient's consent to harvest cell specimens.



This undated image made available by the National Institutes of Health and National Center for Microscopy in Aug. 2013 shows HeLa cells. The cells were cultured with a fluorescent proteins targeted to the Golgi apparatus (orange), microtubules (green) and counterstained for DNA (cyan). The cancerous cells, originally taken from Henrietta Lacks in 1951 without her knowledge or consent, were the first human cells that could be grown indefinitely in a laboratory. These "HeLa" cells have been crucial for key developments in such areas as vaccines and cancer treatments. (AP Photo/National Institutes of Health, National Center for Microscopy, Tom Deerinck)

The cells taken from Lacks, dubbed HeLa for the first letters of her first and last names, caused great excitement in scientific circles: they were the first-ever human cells to grow endlessly in the lab—all others harvested up to this point eventually died.

"HeLa cells... are considered one of the biggest medical miracles in the last century," said a statement from the University of Washington in Seattle, which on Wednesday published a genome sequence of the cells in the journal *Nature* under the terms of the new agreement.

"The cells allowed scientists to perform experiments without using a living human and led to major medical breakthroughs", including a vaccine for certain types of cervical cancer and drugs for herpes, leukemia, influenza and Parkinson's disease.

Lacks' identity was revealed in a scientific journal in 1971, followed by a television documentary in 1997 and the publication in 2010 of a book, "The Immortal Life of Henrietta Lacks", now being made into a film.

Then in March this year, scientists from the European Molecular Biology Laboratory in Germany published a full genome of the cell line—including data that could divulge certain heritable traits of Lacks' descendants.

Such information, which may point to a propensity for diseases like alcoholism, Alzheimer's disease or bipolar disorder, could be used to deny people life insurance or disability coverage, and the data was removed from public fora within days after the family protested.

The incident resulted in talks between the Lacks family and the NIH, which in turn yielded Wednesday's deal in terms of which researchers must apply to the NIH to use the HeLa genomic data in a study, agree to terms defined by a panel that will include two Lacks family members,

and contribute their findings to a database.

"Today's release of the human genome sequencing is a historic, game-changing event," granddaughter and family spokeswoman Jeri Lacks Whye told a telephone conference.



In this July 30, 2013 photo made available by the National Institutes of Health, a researcher places HeLa cells in an incubator at 37 degrees Celsius at a lab at the National Cancer Institute in order for them to multiply. The cancerous cells, originally taken from Henrietta Lacks in 1951 without her knowledge or consent, were the first human cells that could be grown indefinitely in a laboratory. These "HeLa" cells have been crucial for key developments in such areas as vaccines and cancer treatments. (AP Photo/National Institutes of Health, Maggie Bartlett)

"In the past, the Lacks family has been left in the dark... For more than 60 years our family has been pulled into science without our consent and

researchers had never stopped to talk to us... or to give us a voice in the conversation about HeLa cells, until now."

Whye said the decision had been a complicated one, seeking to balance the needs of science with protecting her family's privacy.

"We are proud of what HeLa cells have done for science," she said, and welcomed a stipulation that will require researchers to recognise Henrietta Lacks and her cells' contribution to science.

The agreement covered only researchers funded by the NIH, and would not prevent others from "piecing together" large parts of the HeLa genome from data already in the public domain, or even sequencing it from scratch.

"Such actions would not be right and would not be respectful of the Lacks family," said NIH deputy director for science, outreach and policy, Kathy Hudson.

Collins stressed the agreement was not precedent-setting, and was necessary only because the HeLa cells were in such widespread use and the Lacks family was by now so widely known.

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