



**Office of Clinical Research
First Friday**

 **Health**™ IN SCIENCE LIVES HOPE.

**The Immortal Life of
Henrietta Lacks**

Friday, February 5th, 2021

Learning Objectives:

- 1) Introduce and discuss the story of Henrietta Lacks and the HeLa cell line.
- 2) Discuss medical ethics, and the race and economic injustices that occurred in the development of the HeLa cell line, regarding how it was established and used for many years without Mrs. Lacks' consent, or her family's knowledge
- 3) Explain the magnitude of the HeLa cell line in advancing science and how none of it would be possible without HeLa Cells.
- 4) Identify the importance of communication and transparency between researchers and donors.

Target Audience:

Clinical Research Professionals (CRPs) at UC/H and Cincinnati Children's Hospital Medical Center (CCHMC): including Principal Investigators (PIs), Research Nurses (RNs), Critical Care Unit Nurses (RNs), Pharmacy Technicians and Regulatory Specialists.

Off-Label Disclosure Statement:

Faculty members are required to inform the audience when they are discussing off-label, unapproved uses of devices and drugs. Physicians should consult full prescribing information before using any product mentioned during this educational activity.

Learner Assurance Statement

The University of Cincinnati is committed to resolving all conflicts of interest issues that could arise as a result of prospective faculty members' significant relationships with drug or device manufacturer(s). The University of Cincinnati is committed to retaining only those speakers with financial interests that can be reconciled with the goals and educational integrity of the CME activity.

Accreditation Statement for Directly Sponsored Activity

The University of Cincinnati is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The University of Cincinnati designates this live activity for a maximum of 1 *AMA PRA Category 1 Credit*[™]. Participants should claim only the credit commensurate with the extent of their participation in the activity.

CRPs, NPs, PAs, and RNs can count activities certified for *AMA PRA Category 1 credit*[™] for professional credit reporting purposes. Other healthcare professionals should inquire with their certifying or licensing boards.

Disclaimer Statement

The opinions expressed during the live activity are those of the faculty and do not necessarily represent the views of the University of Cincinnati. The information is presented for the purpose of advancing the attendees' professional development.

Speaker Disclosure:

In accordance with the ACCME Standards for Commercial Support of CME, the speakers for this course have been asked to disclose to participants the existence of any financial interest and/or relationship(s) (e.g., paid speaker, employee, paid consultant on a board and/or committee for a commercial company) that would potentially affect the objectivity of his/her presentation or whose products or services may be mentioned during their presentation. The following disclosures were made:

Planning Committee Members:

- Brett Kissela, MD, Course Director – No Relevant Relationships
- Maria Stivers, MS – No Relevant Relationships
- Justin Osborne – No Relevant Relationships
- Nate Harris, BS, Course Coordinator – No Relevant Relationships
- Brandon Armstrong, CME Program Coordinator – No Relevant Relationships

Speaker:**Rebecca Ingledue, CCRC**

UC Physicians

Department of Internal Medicine

Pulmonary, Critical Care & Sleep Medicine

No Relevant Relationships

Study of the Month

FASTEST Trial Survey

We need your input on an emergency care Exception From Informed Consent (EFIC) research study of bleeding in the brain.

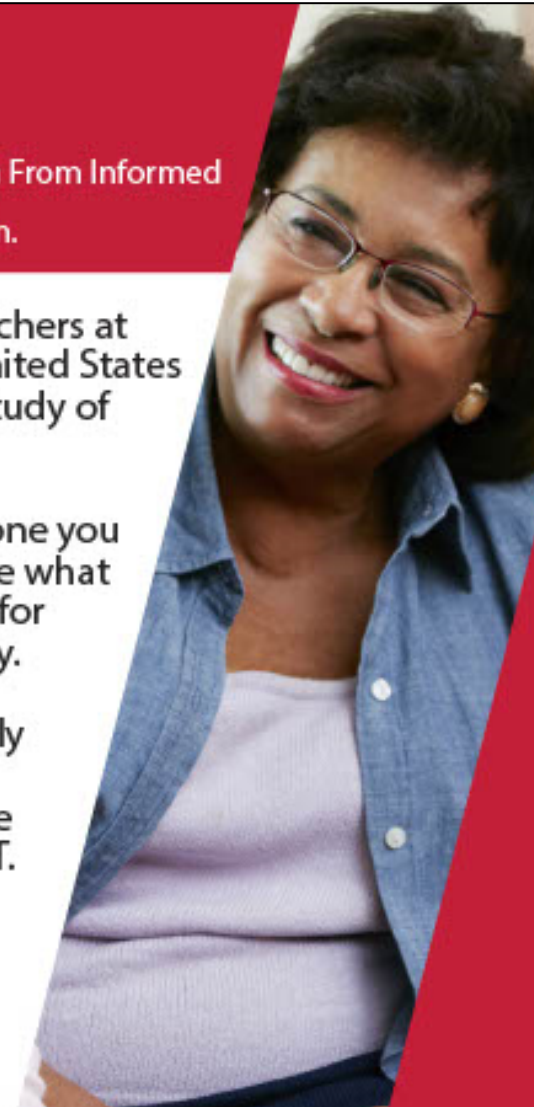
The University of Cincinnati is joining researchers at more than 100 other hospitals across the United States and other countries to conduct a research study of bleeding in the brain called FASTEST.

This research study may affect you or someone you know, and we need to find out ahead of time what the community thinks about it. **THANK YOU** for your help and time in completing this survey.

Your participation in this survey is completely voluntary. To complete the survey, contact Stephanie Thomas at 513-558-4536, scan the QR Code, or visit <https://redcap.link/FASTEST>.



01-21 Advarra IRB # 55U00117646



Compliance Corner

Searching Office of Clinical Research SOPs and Policies

All UC Health policies and SOPs, including all Office of Clinical Research SOPs and policies are accessible from the UC Health intranet home page utilizing the Compliance 360 policy portal search function.

The Policy Office now offers a MyKnowledge training on navigating Compliance 360:
ACCESSING UC HEALTH POLICIES THROUGH THE POLICY PORTAL:

<https://uchealth.sumtotal.host/Core/pillarRedirect?relyingParty=LM&url=core%2Factivitydetails%2FViewActivityDetails%3FActivityId%3D99389%26UserMode%3D0>

In this short MyKnowledge course you will learn how to:

- Access the UC Health Policy portal
- Find and open a policy using the catalog on the portal
 - Find and open a policy using keyword search

Always feel free to reach out to the Office of Clinical Research with any questions or concerns.



**Thursday, February 18th, 2021
12:00 noon - 1:00 pm
Virtual Presentation**

Epic Recruitment tools

Please join us for a detailed overview of the various research participant recruitment tools available in Epic. This presentation will also discuss how to decide on the best recruitment tool for each study, the process of submitting requests for Epic recruitment tools, as well as best practices and tips.

**Akke Wheatley, Miranda Gulasy, Emily Ledney, &
Zachary Johnson**

Today's Presentation:

The Immortal Life of Henrietta Lacks

Becky Ingledue, CCRC

UC Physicians

Department of Internal Medicine

Pulmonary, Critical Care & Sleep Medicine

The Immortal Cells of Henrietta Lacks



UIC Health™

Who was she and how did Henrietta change the world?



The story of Henrietta Lacks points to several important bioethical issues, including informed consent, medical records privacy, and communication with tissue donors and research participants.

Imagine a small number of your cells were harvested while seeking medical care. But instead of just being used for research into your own health, those cells are used for almost 70 years and in over 74,000 studies.

Meanwhile, you and your descendants are never told by the researchers about the use of your family's genetic material, and none of you ever receive even a fraction of the millions of dollars made from it.

That's exactly what happened to Henrietta Lacks and her descendants. In 1951 when Lacks was 31-years-old, doctors harvested her cells and researchers have been using them ever since—while giving none of the profits to the Lacks family.


Henrietta Lacks' contributions to science were not widely known until the 2010 release of the book *The Immortal Life of Henrietta Lacks* by Rebecca Skloot, which explored Lacks' life story, her impact on medical science and important bioethical issues.



In 2017, HBO and Harpo Studios released a movie based on the book, with Oprah Winfrey starring as Deborah Lacks, Henrietta Lacks' daughter.

"Like I'm always telling my brothers,
if you gonna go into history,
you can't do it with a hate attitude.
You got to remember, times was different."

REBECCA SKLOOT
The Immortal Life of Henrietta Lacks




Libro.fm

Who was Henrietta?

- Henrietta Lacks (born Loretta Pleasant) was born August 1, 1920
- Henrietta's mother died when she was only 4 years old while giving birth to her tenth child.
- After the death of her mother in 1924, Henrietta was sent to live with her grandfather in a log cabin. It is here that Henrietta shared a room with her first cousin, David "Day" Lacks who later became her husband.
- She left school in the 6th or 7th grade.
- Spent her days picking tobacco and caring for the animals on her grandparents farm.
- Mother of 5 children, first child at age 14
- She had 9 siblings
- Family and friends say she was meticulous about her appearance, despite hands roughened from years of fieldwork
- She never wore pants, and rarely left the house without pulling on a carefully pressed shirt and skirt
- She's a giver and protector. She takes care of cousin Cootie when he's recovering from polio and makes sure that no one ever goes hungry on her watch
- Her generosity inspires affection and loyalty from almost everyone around her
- She loved dancing-often with one of her five children in her arms
- She loved to cook-spaghetti was her favorite



Henrietta Pleasant married her cousin David Day Lacks on April 10, 1941 in Halifax County, Virginia.



SECTION

Referral to John Hopkins

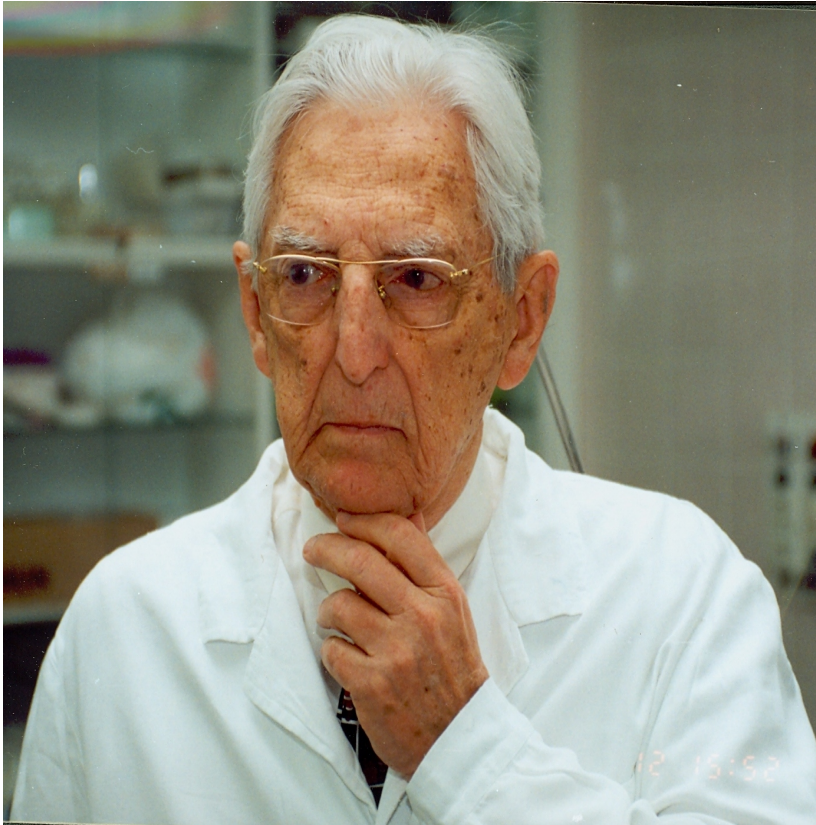
- On January 29, 1951, Lacks went to Johns Hopkins, the only hospital in the area that treated black patients, because she felt a "knot" in her womb
- She had told her cousins about the "knot" and they assumed correctly that she was pregnant
- After giving birth she had a severe hemorrhage. Her PCP tested her for syphilis, which was negative. He then referred her back to John Hopkins

Cancer treatment

- There her doctor, Howard Jones took a biopsy from a mass on her cervix.
- These samples were taken from Lacks' cervix without her permission or knowledge; one sample was of healthy tissue and the other was cancerous.
- Soon after, she was told she had malignant epidermoid carcinoma of the cervix.
- In 1970 physicians discovered that she had been misdiagnosed and actually had adenocarcinoma. This was a common mistake at the time and the treatment would not have differed

Treatment

- Lacks was treated with radium tube inserts as an inpatient and discharged a few days later with instructions to return for X-ray treatments as a follow-up
- On August 8, 1951, Lacks went to Johns Hopkins for a routine treatment session and asked to be admitted due to continued severe abdominal pain
- For a little over a month after her diagnosis in 1951, Lacks's family did not know of her cancer.



"I never saw anything like it before or after. And this didn't look like a normal tumor. It was deep purple and about as big as a quarter, sort of shiny. Very soft. That was another thing about it. When you touched it, you might think it was red and jello. There was something really strange about the way it looked."

- Dr. Howard Jones

Dr. Jones decided to take a sample or in this case two.

Teeny tiny pieces were cut off and put it in a tube. One went to the lab for diagnosis. And in this case, since it was Hopkins, they took an extra piece and give it to a man named George Gey.

He was a researcher who worked at Hopkins.

George and Margaret Gay

George had a deal with the clinic that anytime they got a patient with cervical cancer, they'd give him a tiny piece of the tumor.

His main mission--actually not just his, scientists everywhere were trying to do this, they wanted to find a way to grow human cells outside of a human being in a dish. George Gey had been trying to do this, working on this for decades.

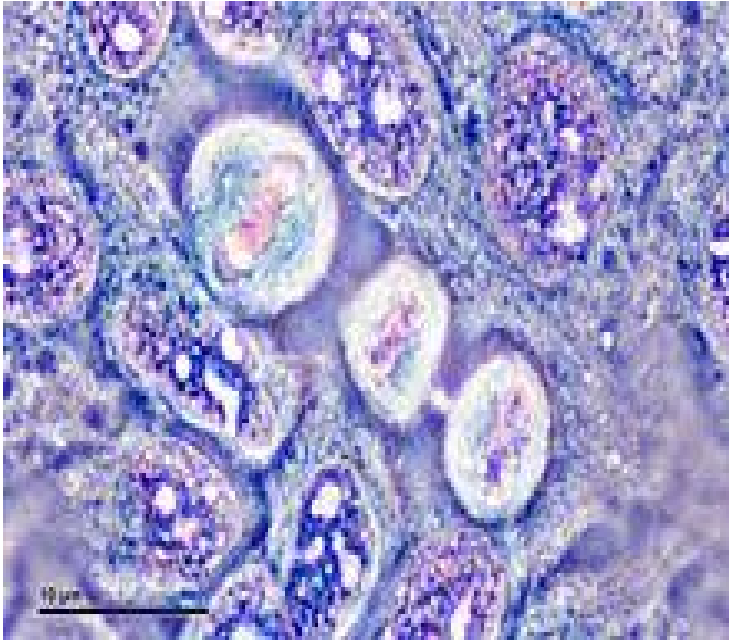
So, later that day, George Guy walked in and handed Margaret, his wife and lab assistant, a tube of a little chunk of a nameless woman's cervical cancer inside.

She put them in a dish, gave the some food, and turned on all the machines and left. When checked on them the next day, they hadn't died. So she came back the next day. And they were growing. And then the next day. Still growing.

They allegedly doubled in size every 24 hours. Margaret had to keep transferring them into new containers because they never stopped growing.



Discovery

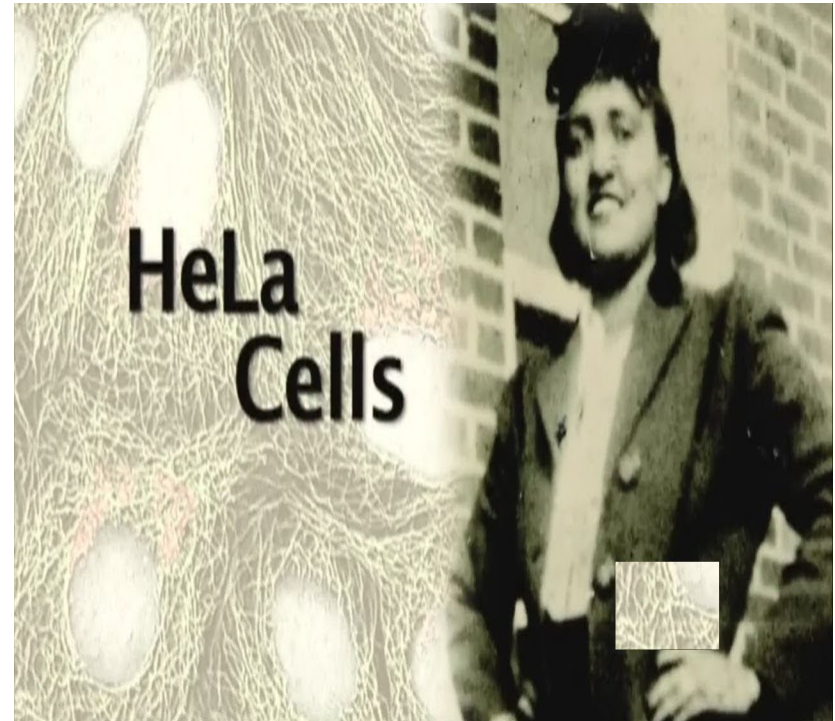


- George Gay observed that these cells were unusual in that they reproduced at a very high rate
- Gay was able to start a cell line from Lacks's sample by isolating one specific cell and repeatedly dividing it, meaning that the same cell could then be used for conducting many experiments
- Lacks's cells were the first to be observed that could be divided multiple times without dying, which is why they became known as "immortal".
- They could be kept alive long enough to allow more in-depth examination. (Until then, cells cultured for laboratory studies survived for only a few days at most)

Discovery

- They became known as HeLa cells, because Gey's standard method for labeling samples was to use the first two letters of the patient's first and last names
- Gey – who died in 1970 – did not make money from HeLa, however, is credited with being interested mainly in using them as a research tool.

The cells from this one tumor would spawn a multi-billion dollar industry



Death

- Her treatment was provided in a ward designated for "coloureds" she died in excruciating pain

Lacks died on 4 October 1951, with the official cause of her death being terminal uremia.

Terminal uremia occurs when the kidneys are unable to filter blood the way that they should, and consequently, high levels of toxins build up in the blood.

Though there was no obituary for Lacks, Gey's lab came to know of her death, according to Skloot, and Gey requested an autopsy to validate the potential for further samples from Lacks's various organs.

However, to comply with the law, which held that an autopsy could not be completed without permission, Gey needed permission from Lacks's family.

According to Skloot, physicians only convinced Lacks's husband to authorize the autopsy after claiming they would run medical tests on Lacks that could produce beneficial health information for his children.

Operation permit

The only form of consent that The John Hopkins Hospital had Lacks sign was titled, "Operation Permit," which stated that she consented to the hospital performing any operative procedures and anesthetic deemed necessary for proper surgical care.

THE JOHNS HOPKINS HOSPITAL

HISTORY NO. _____
 PATIENT'S NAME _____
 SERVICE _____

Admission note

2-6-51
Lack

Form 2042

OPERATION PERMIT

Date 2/6/51 19__

I hereby give consent to the staff of The Johns Hopkins Hospital to perform any operative procedures and under any anaesthetic either local or general that they may deem necessary in the proper surgical care and treatment of:

Henrietta Lack History No. 722410 My self Relationship

Name _____

While a patient in that hospital on Ar Ward

D. Paul Witness Henrietta Lack Signature



Gey began sending samples around the world and ordered his 21-year-old assistant, Mary Kubicek, to take more cells from Henrietta while her body lay in the hospital's autopsy room.

No one consulted the dead woman's family.

In the mortuary, Kubicek looked down at Henrietta's body and noticed her toenails were covered in chipped, bright red polish.

"I nearly fainted," she told Skloot during the author's research for the book. "I thought, 'Oh Jeez, she's a real person'. I started imagining her sitting in her bathroom painting those toenails and it hit me for the first time that those cells we'd been working with all this time and sending all over the world, they came from a live woman."



This cell line has contributed to many medical breakthroughs

- Research on the effects of zero gravity in outer space
- Development of the polio vaccine
- study of leukemia
- AIDS virus
- Used by scientists to develop a cancer research method that tests whether a cell line is cancerous or not. This method proves so reliable that scientists use it to this day.
- *in vitro* fertilization
- Effects of radiation and toxic substances
- Gene mapping
- Mailed to scientists around the globe for "research"
- HeLa cells were the first human cells successfully cloned in 1955, and have since been used to test human sensitivity to tape, glue, cosmetics, and many other products
- There are almost 11,000 patents involving HeLa cells
- Once HeLa cells started being mass produced, they infected HeLa cells with every kind of virus. Hepatitis, encephalitis virus. Yellow fever. Herpes. Measles, mumps, rabies, whatever
- By the late 60s, HeLa has led to a revolution in science and now there are hundreds of cell lines, not just HeLa, but hundreds. And somewhere along the way, scientists discover that HeLa is so aggressive that they're actually contaminating and taking over other cell lines because they can float on dust particles

Disclosure to family

In the early 1970s, a large portion of other cell cultures became contaminated by HeLa cells. As a result, members of Henrietta Lacks's family received solicitations for blood samples from researchers hoping to learn about the family's genetics in order to differentiate between HeLa cells and other cell lines.

Alarmed and confused, several family members began questioning why they were receiving so many telephone calls requesting blood samples.

The family had never discussed Henrietta's illness and death among themselves in the intervening years but with the increased curiosity about their mother and her genetics, they now began to ask questions.

SECTION

Daughter Deborah Lacks holds image of HeLa cells.

The treatment of Henrietta and her children reveals an unpleasant aspect of medicine in the US, where African Americans were routinely used – until relatively recently – as the subjects of highly unpleasant sets of experiments.



"Took me by surprise, it really did. It was really confusing. I mean, how much is that--how much of her cells is out there?"

- Deborah Lacks
Henrietta's daughter

Quotes from family

- “I want scientists to acknowledge that HeLa cells came from an African American woman who was flesh and blood, who had a family and who had a story,” her granddaughter Jeri Lacks-Whye told *Nature*.
- To her grandson Alfred Lacks Carter, the most important thing about HeLa cells is how they have advanced cancer research — a fitting tribute, given that Lacks died of the disease.
- The issue is summed up by Henrietta's daughter Deborah, with whom Skloot struck up a close friendship during her research on the book. "Truth be told, I cannot get mad at science, because it helps people live, and I'd be a mess without it. But I won't lie. I would like some health insurance so I don't got to pay all that money every month for drugs my mother's cells probably helped make."

The family members have not received profits gained from the research of the cells, nor have they received adequate compensation from the book, “The Immortal Life of Henrietta Lacks,” or from the HBO movie, Lawrence Lacks said.

The book was written by Rebecca Skloot with the help of Deborah Lacks, a daughter of Henrietta Lacks.

-The Lily News

During a panel discussion, Lawrence Lacks said he is still distraught over what happened to his mother at the hospital. For many years, he said, the pain was so heavy he could not talk about it. He broke into tears on stage.

“I want to go back and put everything on paper,” he said, “so I can remember it.”

Ron Lacks, 59, said in an interview: “My father just wants to have some control over what has happened in the past. Even on our family story, we have been shortchanged. . . . The family story, we don’t even own that.”

“It’s not all about the money. My family has had no control of the family story, no control of Henrietta’s body, no control of Henrietta’s cells, which are still living and will make some more tomorrow.”

-The Lily News

John Hopkins

<https://www.hopkinsmedicine.org/henriettalacks/immortal-life-of-henrietta-lacks.html>

The publication of Skloot’s book led Johns Hopkins to review our interactions with Henrietta Lacks and with the Lacks family over more than 50 years. At several points across those decades, we found that Johns Hopkins could have — and should have — done more to inform and work with members of Henrietta Lacks’ family out of respect for them, their privacy and their personal interests.

We are deeply committed to the ongoing efforts at our institutions and elsewhere to honor the contributions of Henrietta Lacks and to ensure the appropriate protection and care of the Lacks family’s medical information.

According to Skloot, during that time in history, it was common for physicians to use patient samples from public wards without their knowledge or consent.

Recognition

On October 1, 2011, the Johns Hopkins Institute for Clinical and Translational Research sponsored and produced the second annual Henrietta Lacks Memorial Lecture in Turner Auditorium on the Johns Hopkins East Baltimore (Medical) campus.

Several hundred attendees, including numerous members of the Lacks family, came together to mark the occasion and to honor the 60th anniversary of HeLa cells



Click this image to learn more about the Oct. 1 Lacks Lecture.

Improving research practices

In 2010, the Johns Hopkins Institute for Clinical and Translational Research established the annual Henrietta Lacks Memorial Lecture Series to honor Henrietta Lacks and the global impact of HeLa cells on medicine and research

In 2013, Johns Hopkins worked with members of the family and the National Institutes of Health (NIH) to help broker an agreement that requires scientists to receive permission to use Henrietta Lacks' genetic blueprint, or to use HeLa cells in NIH funded research

The committee tasked with deciding who can use HeLa cells now includes two members of the Lacks family. The medical research community has also made significant strides in improving research practices, in part thanks to the lessons learned from Henrietta Lacks' story

In 2017, Johns Hopkins University released a statement denying it had profited from the cells.

"Johns Hopkins never patented HeLa cells, and therefore does not own the rights to the HeLa cell line," the statement said

Hopkins explained that when the cells were taken from Lacks in 1951, there was no established protocol for informing patients or getting consent for research of cell or tissue specimens.

We must do better

We should ask ourselves how we would want a research study presented to us.

Would we choose to participate with the approach and information given during a visit or hospitalization?

Take everything into consideration when presenting a study, or informed consent discussion. Have they done research? Do they look overwhelmed?

While in the study (during a visit or phone call) ask them if they have any questions? Informed consent doesn't stop at screening or Day 1 visit.

Ask them questions to be sure they understand what it is they are agreeing to

Get to know them!

Who are they outside of the study?

Thank them for their contribution to research

Remind them how important their participation is to us and the future

'Those who do not learn history are doomed to repeat it.' -George Santayana

SECTION

Honorary achievements

In 2011, Morgan State University in Baltimore granted Lacks a posthumous honorary doctorate in public service

Also in 2011, the Evergreen School District in Vancouver, Washington, named their new high school focused on medical careers the Henrietta Lacks Health and Bioscience High School, becoming the first organization to memorialize her publicly by naming a school in her honor

Now, the extraordinary events of 2020 — the #BlackLivesMatter movement for racial justice, and the unequal toll of COVID-19 on communities of color — are compelling scientists to reckon with past injustices.

In 2020, Lacks was inducted into the National Women's Hall of Fame.
<https://www.womenofthehall.org/inductee/henrietta-lacks/>



In 2021, the Henrietta Lacks Enhancing Cancer Research Act of 2019 became law; it states the Government Accountability Office must complete a study about barriers to participation that exist in cancer clinical trials that are federally funded for populations that have been underrepresented in such trials.



U 53
HENRIETTA LACKS
(1920-1951)

Born in Roanoke on 1 Aug. 1920, Henrietta Pleasant lived here with relatives after her mother's 1924 death. She married David Lacks in 1941 and, like many other African Americans, moved to Baltimore, Md. for wartime employment. She died of cervical cancer on 4 Oct. 1951. Cell tissue was removed without permission (as usual then) for medical research. Her cells multiplied and survived at an extraordinarily high rate, and are renowned worldwide as the "HeLa line," the "gold standard" of cell lines. Jonas Salk developed his polio vaccine with them. Henrietta Lacks, who in death saved countless lives, is buried nearby.

DEPARTMENT OF HISTORIC RESOURCES, 2010

Exact burial location is unknown, but the family believes that it is within a few feet of her mother's grave site, which for decades was the only one in the family to have been marked with a tombstone.

In 2010, Roland Pattillo, a faculty member of the Morehouse School of Medicine who had worked with George Gey and knew the Lacks family, donated a headstone for Lacks.

The book-shaped headstone of Henrietta Lacks contains an epitaph written by her grandchildren that reads:

Henrietta Lacks
August 1, 1920 - October 4, 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

