

THE IMMORTAL CELLS
OF HENRIETTA LACKS
AND THE
UNEASY RELATIONSHIP OF
AFRICAN AMERICANS WITH THE
MEDICAL PROFESSION

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DEBORAH'S VOICE

- “ ‘When people ask – and seems like people always be askin to where I can’t never get away from it- I say Yeah, that’s right , my mother name was Henerietta Lacks, she died in 1951. John Hopkins took her cells and them cells are still livin today, still multiplyin, still growin and spreadin if you don’t keep em frozen. Science calls her HeLa and she’s all over the world in medical facilities , on all the computers and the Internet everywhere.
- When I go to the doctor for my checkups I always say my mother was HeLa.They get excited , tell me stuff like how her cells make blood pressure medicine and antidepresson pills and how this important stuff in science happen cause of her. But they don’t never explain more then just sayin, Yeah, your mother was on the moon, she been in nuclear bombs and made the polio vaccine. I really don’t know how she did all that, but I guess I’m glad she did, cause that mean she helpin lots of people. I think she would like that.

- But I always have thought it was strange , if our mother cells done so much for medicine, how come her family can't afford to see no doctors? Don't make no sense . People got rich off my mother without us even knowin about them takin her cells., now we don't get a dime. I used to get mad about that to where it made me sick and I had to take pills. But I don't got it in me no more to fight. I just want to know who my mother was.' “

Topics

- POVERTY
- RACISM
- CANCER
- AFRICAN AMERICAN DISTRUST OF MEDICAL PROFESSION
- MEDICAL/SCIENTIFIC ETHICS

- Henrietta was born Loretta Pleasants on August 1, 1920 in Roanoke, Virginia. Her name was later changed to Henrietta .
- In 1924 , her mother died giving birth to her tenth child. Their father took them back to Clover, Virginia.



- Mr. Lacks had farmed the tobacco fields and his family had worked as slaves. The ten children were divided among relatives and Henrietta was placed with her grandfather. He lived in the home-house- a four room cabin that once served as slave quarters. It had plank floors and gas lanterns.



- Henrietta's grandfather was also taking care of her male cousin Day. He stopped school in the fourth grade to work in the fields and she finished the 6th grade. During the school year, she would work in the livestock and garden each morning and then walked 2 miles past the white school where the children threw stones and haunted her as she went to the colored school, a three-room wooden farmhouse. After school she was in the fields with her cousins and father.
- One evening each month during harvest season, they rode into the town of South Boston, nation's second –largest tobacco market auctioning. parades, Miss Tobacco pageant and a port where boats collected dried leaves from around the world to smoke.

- She and her cousin Day ,married when she was twenty and he was twenty five. In 1941, they, like many blacks went to work at Bethlehem Steel Sparrows Point steel mill about 20 miles from Baltimore. The blacks lived in Turner Station. The men breathed in toxic coal dust and asbestos which they brought home to wives and children.
- After her fourth child, for one year she had been telling her friend that something did not feel right- stating “I got a knot inside of me” and that “it hurt something awful when that man want to get with me”. –Thought it was due to recent birth of daughter ,Deborah or bad blood husband brought after nights with other women- treated with penicillin. She did not go to the doctor -afraid he would tell her to stop having children.
- At age of 29, she was pregnant with 5th child. Several months later, she was bleeding and felt a large lump deep inside. Tested negative for syphilis and sent to Johns Hopkins.

- Hopkins built in 1889-charity hospital for sick and poor. Mostly blacks and people unable to pay medical bills. Era of Jim Crow- when blacks were sent away from white- only hospitals, even if died in parking lot. Hopkins segregated blacks in colored wards and had colored-only fountains.
- Parts of Henrietta's doctor record read –" 6th of 7th grade education. Mother of five. Only anxiety is oldest daughter is epileptic and cannot talk. Unexplained vaginal bleeding during last two pregnancies.-doctor recommended sickle cell test which she refused. She had asymptomatic neurosyphilis but cancelled treatments since she felt fine. After delivery of 5th child , test showed increased cellular activity in the cervix. Physician recommended referral to Johns Hopkins to rule out infection or cancer. She had cancelled. "

- Patient felt that walking into Hopkins was like entering a foreign country where she did not speak the language. She knew about harvesting tobacco and butchering pigs. She like most blacks only went to Hopkins when they thought they had no other choice.
- Cervical examination revealed a lump that was so delicate it bled at the slightest touch. Three months earlier after delivering her 5th child, no mention was made of an abnormality .Either the doctors missed it during her exam or it had grown at a terrifying rate.
- Biopsy results showed ” epidermoid carcinoma of the cervix Stage 1

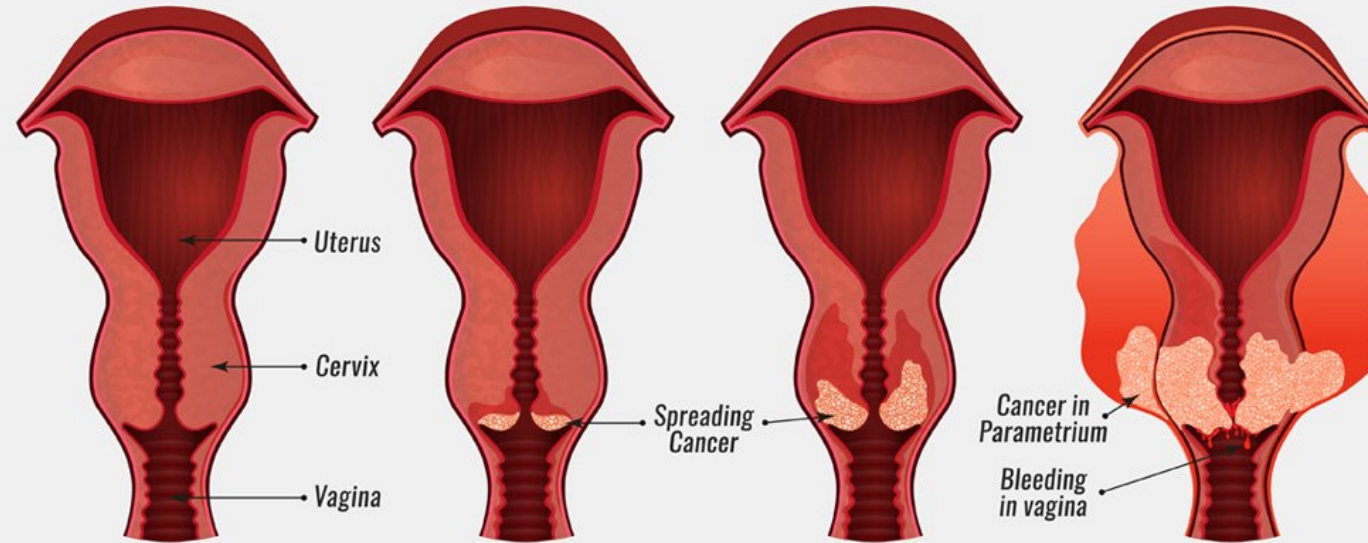
Normal Cervix

**Early stage IB
Cervical cancer**

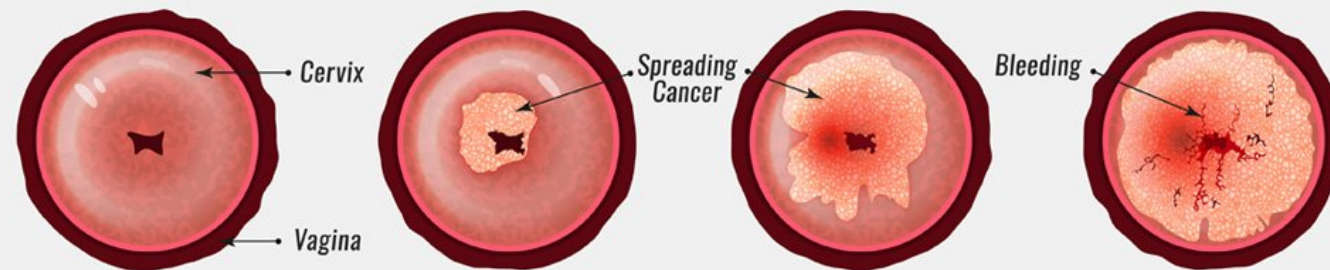
**Late stage IB
Cervical cancer**

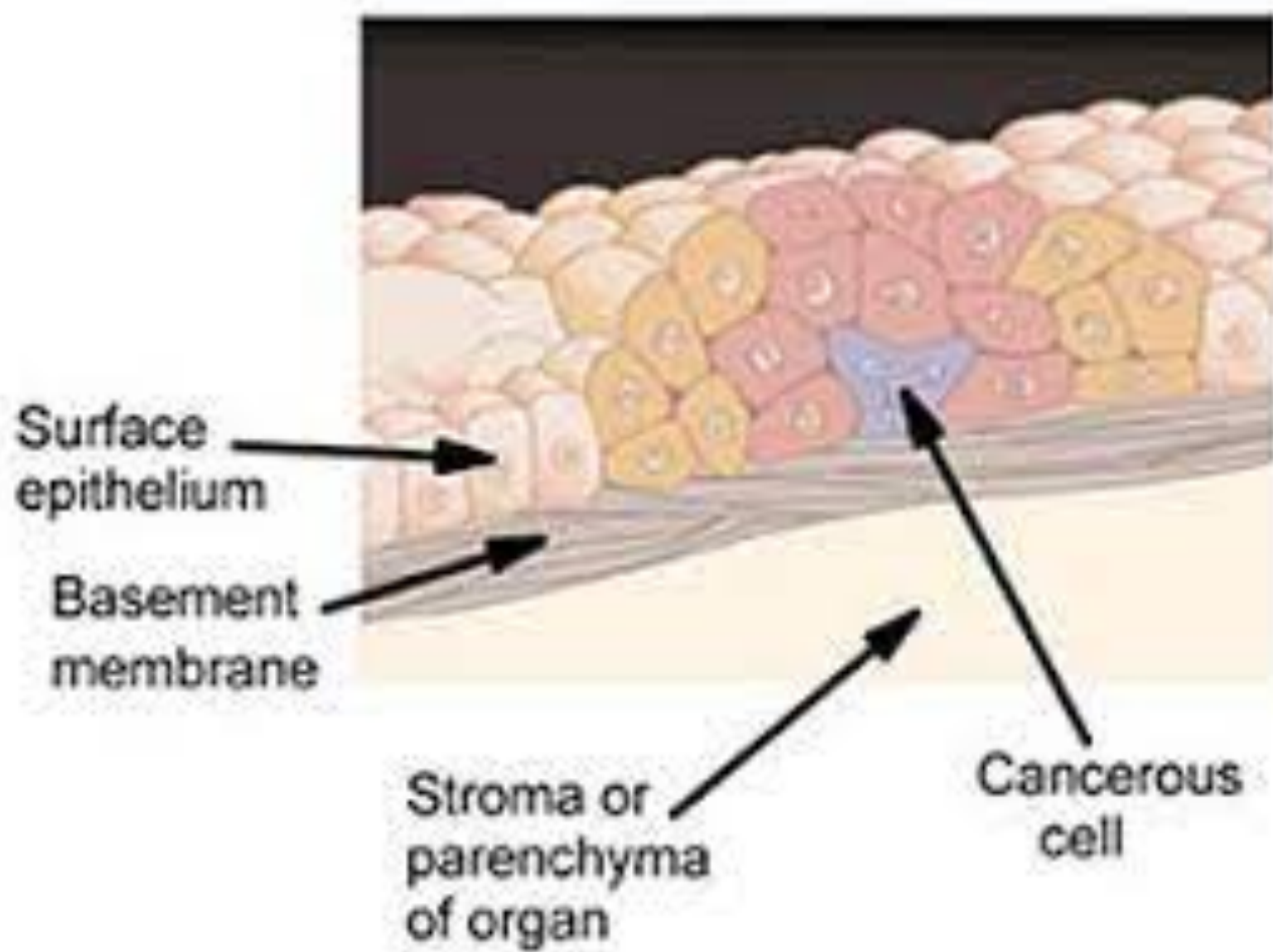
**Stage IIB
The cancer is outside cervix**

CUT-AWAY VIEW



SPECULUM VIEW





- Cervical carcinomas are divided into two types- invasive - penetrate surface of cervix and noninvasive or in situ. In 1951, most doctors thought that invasive carcinoma as deadly and in situ was not. Invasive was treated aggressively but not in situ.
- Pap smear available after 1941-detected precancerous changes under microscope. Tremendous advance because those precancerous cells were not detectable otherwise.

- First-many women like Henrietta , simply did not get the PAP and second-many doctors did not know how to interpret results because they did not know what the various stages of cancer looked like under a microscope. Some mistook cervical infections for cancer and unnecessarily removed entire reproductive tract when she only needed antibiotics. Others mistook cancerous changes for infection, sent her home with antibiotics only to have them return later and die from metastatic disease.

- Henrietta did not tell her husband that it was malignant. She signed the operation permit:

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

”

- Henrietta followed a nurse down a long hallway into the ward for colored women where several white doctors ran more tests.
- Since she had invasive cervical cancer ,like all hospitals nationwide, she was treated with radium, a white radioactive metal that glows a blue color. It causes mutations that can turn into cancer and at high doses , it can burn the skin off the body. However, it can also kill cancer cells.
- Her surgeon prepared her cervix for treatment. He also took a sharp knife and shaved two dime-sized pieces of tissue : one healthy tissue and one from the tumor. Henrietta was unaware that samples were given away and she was also not asked permission to be a donor.

- The surgeon placed a tube filled with radium inside Henrietta's cervix and sewed it into place. Another plaque filled with radium was sown to the outer surface of the cervix and packed another plaque against it. Several rolls of gauze were slid into the vagina to keep the tubes in place and a urinary catheter was placed. She was discharged two days later. Her chart said. " 30 year -old colored female lying quietly in no evident distress", and "Patient feels quite well tonight. Morale is good and she is ready to go home."

- For about two months , no one in Turners Station, knew Henrietta was sick. She went to Hopkins for a checkup and her second radium treatment. She started radiation therapy daily for one month and eventually told her cousins she had cancer.
- About two weeks after her second radium treatment, she had a very heavy period which stopped with radiation.
- Henrietta asked her doctor about having another child. Until then , she was unaware that the treatment left her infertile.
- Warning patients about fertility loss before cancer treatment was standard practice at Hopkins.

- However, something went wrong with her medical records. One doctor wrote - "Told she could not have any more children. Says if she had been told so before, she would not have gone through with treatment". It was too late when she found out.
- Also treated for gonorrhea superimposed on radiation reaction due to husband's indiscretions.
- Radiation had charred her skin a deep black from her breast to her pelvis. Henrietta said-" Lord, it just feels like that blackness be spreadin all inside me".

- In June 1951, Henrietta told her doctors several times that she thought the cancer was spreading , however notes indicated that she did not question the doctor.

“Like most patients in the 1950’s, she deferred to anything her doctors said. There was a time when ‘benevolent deception’ was a common practice- doctors often withheld even the most fundamental information from their patients, sometimes not giving them any diagnosis at all. They believed it was best not to confuse or upset patients with frightening terms they might not understand like, cancer. Doctors knew best, and most patients didn’t question that”.

- In 1951, segregation was law and it was understood that black people did not question white people's professional judgement.

- QUESTION

- Would Henrietta's treatment have differed if she were white?
- When the author of the book questioned Henrietta's physician – he stated that she got the same care any white patient would have received.-biopsy, radium and radiation.
- However, studies show that blacks were often treated and hospitalized at later stages of their illness, got fewer pain meds when hospitalized and had higher mortality rates.

- Many blacks, including Henrietta, were reluctant to seek care earlier because they were told that Hopkins and other hospitals abducted black people. There were tales of night doctors who kidnapped black people for research, with some disturbing truths behind these stories.
- White plantation owners took advantage of the belief among Africans that ghosts caused disease and death. To discourage slaves from escaping, the white owners told tales of gruesome research done on black bodies, then the owners covered themselves in white sheets, posing as spirits in the night coming to infect blacks with disease or steal them for research. Thus eventually giving rise to white hooded cloaks of KKK.

.Henrietta continued to decline-abdominal pain and she could not urinate. Xray showed that tumor was attached to her pelvic wall, nearly blocking her urethra. " Inoperable". Doctors had increased the dose of radiation in order to shrink tumor and ease pain until death.

.Tried to ease pain with Demerol, Morphine, and injecting pure alcohol into her spine.

- When Henrietta died, her husband agreed to an autopsy because he was told it might help his children someday.
- The morning of the funeral, Day and hour of their five children walked through the mud-Deborah, Joe, Sonny and Lawrence. Elsie , who had epilepsy and cerebral palsy was at the Hospital for the Negro Insane.

- Henrietta's surgeon had given the normal and cancerous cells he had shaved off to Dr. Telinde and Dr Gey.
- Dr. Telinde, top cervical expert at Hopkins, felt that non-invasive cancer was an early form of invasive. He wanted to minimize " unjustifiable hysterectomies " and felt the need to verify smear results with biopsies before operating. He, like many doctors used patients from public wards for research, usually without their knowledge.
- Dr. Gey, head of tissue research at Hopkins, for three decades was working on growing malignant cells outside of the body hoping to use them to find a cause and cure for cancer

- Many researchers , including Gey, had been working for years to develop the perfect culture medium- liquid used to feed cells.
- HeLa was written in the top of the tube with her cells for Henrietta Lacks. After several days, the cells started to grow with “mythological intensity”. Dr. Gey told his closest colleagues that he might have grown the first human immortal cells.

There is no record that George Gey who was growing her cells, ever saw her but Aurelian, another microbiologist at Hopkins said:

”I ‘ll never forget it,”. “George told me he leaned over Henrietta’s bed and said “ ‘Your cells will make you immortal’. He told Henrietta her cells would help save the lives of countless people, and she smiled. She told him she was glad her pain would come to some good for someone.”

- Immortal cells proliferate i.e increase rapidly in number. Other cancer cells can do this but HeLa increased more rapidly than others and were the first . Cells have an infinite number of times to divide but HeLa cells produce an enzyme telomerase and probably other factors which allow the cells to continue to multiple in the right environment. Stem cells from embryos are also immortal.

- By the end of 1951, the world was in the biggest polio epidemic in history. Shortly after Henrietta's death, a massive operation was started for a HeLa factory to help stop polio. In February 1952, Jonas Salk announced he developed the world's first polio vaccine but needed to test it on a large scale to prove it was safe for children.

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- President Franklin Roosevelt created the National Foundation for Infantile Paralysis (NFIP) to test the vaccine. They contacted Gey who had discovered that the HeLa cells would divide until they ran out of medium. HeLa was susceptible to polio and could be used instead of monkey cells.
- NFIP chose the Tuskegee Institute because Charles Byrum, director of Negro Activities, was a science teacher and civil rights activist who was the first foundation executive in the country. Gey wanted it at Tuskegee because it would provide hundreds of thousands of dollars in funding, many jobs and training opportunities for young black scientists.
- Within a few months, they built a factory like no other. The team mixed thousands of liters of Gey culture medium, salts, and serum collected from many students, soldiers, and cotton farmers who responded to ads seeking blood in exchange for money. A single vial of HeLa from Gey allowed Tuskegee to eventually produce twenty thousand tubes of HeLa – about 6 trillion cells weekly.

NEW YORK TIMES

Unit at Tuskegee helps polio fight
Corps of Negro Scientists Has Key Role in
Evaluating Dr Salk's Vaccine
HeLa Cells are Grown

- Tuskegee initially supplied HeLa cells only to polio testing labs but then began sending them to any scientist interested in buying them for \$10 plus Air Express fees. Although they were cancerous, they shared basic characteristics with normal cells therefore good for studying any things in culture- bacteria, hormones, proteins and especially viruses.
- Viruses inject bits of their genetic material into the cells thereby reprogramming the cell to produce the virus instead of itself. This allowed herpes, measles, mumps, equine encephalitis, covid-19 and other viruses to be studied. HeLa cells were instrumental in the development of the human papillomavirus vaccine which can eliminate the cervical cancer that took Henrietta's life.
- HeLa cells also allowed the discovery of freezing cells which stops cells division which resumes after thawing. The mass production at Tuskegee and the development of the first standardized culture medium allowed the standardization of materials.
- Cloning of her cells- sliver of her tumor is a clusters of cells. Some behave differently therefore they harness unique traits. This contributed to the advancement of the field of genetics.

- In 1953 a geneticist accidentally mixed the wrong liquid with HeLa cells which allowed for the discovery of 46 chromosomes in the normal cell. This allowed for research into Downs, Klinefelter ,Turner syndrome and other chromosomal disorders.
- Tuskegee was unable to keep up with all the demand so Microbiological Associates used the HeLa cells to launch the first industrial-scale, for profit distribution center. Their biggest customer were labs like NIH. Labs worldwide paid less than \$50 to have vials sent overnight.
- Demands for cells from Tuskegee plummeted so NFIP closed its HeLa production center.

- Some scientists exposed the cells to massive doses of radiation to study how nuclear bombs destroyed cells and to find ways to reverse damage.
- Cosmetic and pharmaceutical companies throughout the world used the cells instead of laboratory animals to test whether new products and drugs caused cellular damage.
- Gey became annoyed at the worldwide fixation on HeLa and did not like the fact it was completely out of his control. His friend said that he should have finished his own research before “releasing to the general public since once released it becomes general scientific property”.

- Concern about the person behind the cells led to a newspaper saying her name was Henrietta Lakes versus Lacks. TeLinde at Hopkins felt “that keeping patient information confidential was emerging as a standard practice , but it wasn’t law, so releasing it wasn’t out of the question.”
- Gey created the pseudonym Helen Lane to throw journalist off her real identity. From an article published in 1954 until the seventies, the woman behind the HeLa cells was know as Helen Lane or Helen Larson but never Henrietta Lacks , so her family never knew her cells were alive, bought, sold and used in research without her knowledge or theirs.

- In 1966, a geneticist announced while looking for new genetic markers, most of the cultures contained a rare genetic marker called G6PD-A which is present almost exclusively in black Americans. He was informed by Gey that HeLa were from a colored woman.
- The geneticist then announced that the HeLa cells had come from a colored woman and said it was a contaminant because Henrietta's could float through the air on dust particles, could travel from one culture to the next on pipettes or unwashed hands and could stay on researcher's clothing. If one HeLa cell landed on a culture dish, it took over, filling the whole space.
- Many scientists refused to believe HeLa contamination was real and most continued to work with the cells. Some scientists tested to see if their experiments were contaminated with G6PD-A. Others worked on developing genetic tests to specifically identify HeLa cells which lead them to identify Henrietta's family.

- It was felt that HeLa contamination could be solved if they found the genetic markers, identifiable material, usually DNA, specific to Henrietta and used them to identify which cells were hers and which were not. This required DNA samples from her immediate family.
- Scientists contacted Day, Henrietta's husband who told the author of book " 'They said they got my wife and she is part alive .They said the are doin experiments on her and they wanted to come test my children see if they got that cancer killed their mother ' ". They were actually getting markers to identify her cells.

- Dr McKusick and his postdoctoral fellow Dr. Hsu called Day to collect the blood.
- When Dr McKusick, was later asked about informed consent to get the blood , he said
- “ ‘ I suspect there was no effort to explain anything in detail. But I don’t believe anyone would have told them we were testing for cancer because that wasn’t the case.’ ”.
- When the postdoctoral fellow, Dr.Hsu, was asked the same question, she said, “ ‘No. We never gave consent form because you just go to draw blood. We are not doing some kind of medical research, you know, no long term.’ ”
- Although this attitude was not uncommon at that time, NIH guidelines stated that all human subject research funded by NIH, as McKusick’s was,-required both informed consent and approval from a Hopkins review board. Implemented 1966 and expanded to include a detailed definition of informed consent in 1971. It was in the process of being codified into law when Susan Hsu called Day .

- After blood samples were taken , about 11 years after mother's death, , Deborah called Hopkins many times to get her cancer results but the operators could not help her. She was terrified that she might have cancer and worried that researchers did and were still doing horrible things to her mother. She had heard stories about Hopkins snatching black people for research and had read an article in Jet about the Tuskegee study that suggested doctors might have actually injected men with syphilis in order to study them.

- The article explained , “ ‘The injection of disease-causing organisms into unaware human subjects has occurred before in America medical science. It was done eight years ago in New York City by Dr Chester Southam, a cancer specialist who injected live cancer into chronically ill elderly patients ‘ ”. Unbeknownst to Deborah this had been done to see if Henrietta’s cancer cells could infect the scientist working on them . Southam was chief of virology at Sloan- Kettering , when in 1954, he had injected a lady with a history of leukemia with Hela cells and noticed in two weeks , she was growing nodules about the size of Henrietta’s tumor when she went for radium treatments. He did this on about a dozen other cancer patients. He told them he was testing their immune system and said nothing about injecting with someone’s malignant cells.
- He later injected a total of 600 people, half healthy prisoners and half cancer patients. Because of “phobia and ignorance” he did not tell people he was injecting cancerous cells. “ ‘To withhold such emotionally disturbing but medically non pertinent details is in the best tradition of responsible clinical practice’ “.State Attorney General took away his medical license but he later became president of the American Association of Cancer Research

- Deborah had wondered if Dr. McKusick and Dr. Hsu had injected her family with the same bad blood that killed their mother. She asked her father many questions but he only told her that her mother had not appeared sick. He took her to Hopkins, they did treatments , her stomach turned black as coal and she died.

- When Deborah went to Hopkins, She asked Dr McKusick many questions but he only told her that Henrietta's cells were being used for the polio vaccine ,genetic research, had gone on space missions and atomic bomb testing.
- She could not stop wondering if the parts of her mother they were using in research could actually feel the things scientists were doing. McKusick only gave her a copy of the book he edited on Medical Genetics.
- When the author spoke with Susan Hsu and told her that the family thought they were testing for cancer and they were upset about scientists using the cells without their knowledge, Susan was shocked. She did not realize that they did not understand.

In 1976, Michael Rogers, reporter with Rolling Stones stating:

“ ‘Cell lines are swapped, traded, forwarded, begged and borrowed among research institutions around the world---The institutional sources of the cells range from government-supported facilities like Nelson-Rees’s to commercial outfits with toll-free 800 numbers, from whom one can order, for about \$25, a tiny glass vial of HeLa cells ‘ ”

With that article, 25 years after their mother’s death, the Lacks brothers became very interested in the story of HeLa . The also felt that Gey and Hopkins had stolen their mother’s cells and made millions selling them.

- In 1996, forty-five years after Henrietta's death, a BBC producer in London began making a documentary about Henrietta.
- The BBC interviewed the family in front of the home-house in Clover and mentioned that the family never heard about the cells until researchers wanted blood.
- They followed the family to Atlanta for a conference organized by Roland Pattillo, a black scientist at Morehouse.
- Oct 11, 1996-first annual HeLa Cancer Control Symposium at Morehouse School of Medicine. That day is called Henrietta Lacks Day.
- September 11, 2001-scheduled talk at National Foundation for Cancer Research in honor of Henrietta.
- Deborah suffered from anxiety, had a stroke and died 2009, one year before the book was published.

Scientific and Medical Ethics/ Laws

1996- HIPPA- Illegal for healthcare providers or health insurers to make personal medical information public. Use a code instead of initials . This law helps to prevent privacy violation that happened to the Lacks.

1999-RAND corp-states more than 307 million tissue samples from more than 178 million people stored in US. Majority without consent.

2005-Native American tribe Havasupai sues Arizona State Univ scientist after taking tissue samples the tribe donated for diabetes research and used them without consent to study schizophrenia and inbreeding

2005- 6,000 patients sue Washington Univ demanding that the university remove their tissue samples from its prostate-cancer bank-two courts ruled against patients

Current Laws

“It is lawful to store and use tissue from the living for audit, quality control and education without their consent and then use these tissues after death without permission. However, if the tissue is taken and stored after death then appropriate consent must be sought .”

“Currently scientists are allowed to use leftover tissues from blood tests, surgeries and biopsies for research without patients’ permission if the patient’s identity is removed. “ However with genetic testing possible now, it is possible to link tissue back to donors, the US government wants to change that.”

CONCLUSION

- WHO chief- Tedros stated at a special ceremony in Geneva that “What happened to Henrietta was wrong ” . He handed the Director-General ‘s Award for Henrietta Lacks to her 87 year old son ,Lawrence . ”Many people have benefited from those cells. Fortunes have been made. Science has advanced. Nobel Prizes have been won, and most importantly ,many lives have been saved. No doubt Henrietta would have been pleased that her suffering has saved others. But the end doesn’t justify the means.”
- WHO said that more than 55 million tons of HeLa cells have been distributed around the world and used in more than 75,000 studies.

- Earlier this month, the family sued a US biotechnology company, Thermo Fisher Scientific, accusing it of selling cells that Johns Hopkins took from her without her knowledge or consent as part of “ a racially unjust medical system”.
- Tedros said “Henrietta Lacks was exploited. She is one of many women of color whose bodies have been misused by science. We stand in solidarity with marginalized patients and communities all over the world who are not consulted, engaged or empowered in their own care.”
- “ Today is also an opportunity to recognize those women of color who have made incredible but unseen contributions to medical science “.

THE IMMORTAL LIFE

