

Henrietta Lacks and The HeLa Cell: Rights of Patients and Responsibilities of Medical Researchers

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ON THE DAY THAT HENRIETTA LACKS DIED, researcher Dr. George Gey excitedly appeared on national television. He held a vial of her cells in his hand for the entire world to see and stated, “It is possible that, from a fundamental study such as this, we will be able to learn a way by which cancer can be completely wiped out.”¹ His prediction about cancer proved premature, but Dr. Gey knew immediately the scientific importance of his discovery, and opened the floodgates to an exploration of medical science presenting questions about the importance of balancing rights and responsibilities. Individual rights of privacy and consent would clash as never before with the rapid advancement of medical research and the creation of the modern biomedical industry. Henrietta, on the other hand, did not survive to understand her contributions, and it would take more than thirty years in a process ongoing even today for her family to finally realize their rights. Rebecca Skloot, author of *The Immortal Life of Henrietta Lacks*, writes, “Since the era when Henrietta walked through the doors of Hopkins, the field of biomedical ethics was born, and with it came regulations about informed consent.”² In 1951 the cells of Henrietta Lacks were taken without her consent. Her rights were violated, but there were few laws in place to protect her and other patients from unauthorized tissue research performed for the common good. Henrietta’s harvested cells brought to the forefront the responsibilities medical researchers owed society, transforming forever, the way researchers gather information and collect samples from human subjects, and more importantly how modern tissue research is regulated.

October 4, 1951 marked the death of Henrietta Lacks. As announced by Dr. Gey, it also marked the dramatic birth of a human cell line eventually named, using the first two letters of Henrietta’s names, “HeLa.” Henrietta died a very personal, painful and private death at Johns Hopkins Hospital in Baltimore, Maryland; then, the only real choice for free but segregated medical care for impoverished African American patients in the area.³ Treatment at Hopkins for Henrietta and other indigent patients was free, but silently conditioned upon the

assumption that treatment and research would occur simultaneously. While in treatment at Hopkins, Henrietta was available for--some would say vulnerable to--the medical team of Dr. Gey who was then focused not on patient rights and his responsibilities to them, but on the goal of curing cancer. As Henrietta's dead body lay in the Autopsy Department at Hopkins, still-living HeLa cells were harvested from the tumors that killed her.⁴

Dr. Ruth Faden, the Executive Director of the Johns Hopkins Berman Institute of Bioethics, points out, "[in the 1950s] it was not at all uncommon for physicians to conduct research on patients without their knowledge or consent."⁵ No laws were broken because protections developed since did not exist. However, looking back, the right to privacy and what we now recognize as informed consent were clearly violated. By today's standards the research scientists at Hopkins arguably did not honor patients, such as Henrietta, as individuals with inviolate rights of privacy and dignity. Dr. Gey at first attempted to disguise Henrietta's identity by associating "HeLa" with a fictional person named "Helen Lane." Eventually, her identity was accidentally revealed, and she was re-identified in a November 2, 1953 article in the *Minneapolis Star*.⁶ In the 1970s, HeLa was correctly renamed after Henrietta. Even then, no effort was made to inform and obtain consent from her family. Her great-grandson, David Lacks, Jr., confirms, "It would have been nice if Hopkins could have called us when they discovered her cells were so special."⁷

That phone call never came, and HeLa, not Henrietta, took center stage for science. The cells were freely distributed to other cancer researchers in what those observing Dr. Gey at the time characterized as an altruistic manner.⁸ The overlay of race and poverty drowned out concern for Henrietta and allowed this to take place unnoticed. Rather than focusing on Henrietta Lacks as an individual with rights, the attention turned to Dr. Gey and the remarkable nature of HeLa cell line.

Once separated from Henrietta, the HeLa cell line revolutionized medical science. The HeLa cells were the first line of human cells to survive outside of the human body, and because of that, a breakthrough discovery for medical science. John R. Masters, a researcher with the Prostate Cancer Research Centre, Institute of Urology, University College London, described HeLa as "the equivalent of the goose that laid the golden egg – a constant supply of precious and essential resource."⁹ The incredible ability for the cells to regenerate every 24 hours made them the workhorse of labs around the world. When Dr. Gey came upon the HeLa cell, he found what medical science lacked, the ability to mimic the functions of the human body outside the body, combining for the first time medical practice with biological research.

HeLa cells were similar enough to normal human cells that scientists were able to use them in tests involving human diseases, and in unusual experimental circumstances, such as the effect on human cells in zero gravity, or the impact of the intense heat and radiation of nuclear fission. HeLa became essential in the search for a polio vaccine, and a staple for the study of virology. Roland Pattillo, a former colleague of Dr. Gey, stated that Henrietta's cancer cells "made it possible to grow the [polio] virus so the vaccine could be developed."¹⁰

An industry arose around HeLa. Tons of cells, nearly weightless on an individual basis, were mass-produced for science. Scientists working with The

National Foundation for Infantile Paralysis (NFIP) set up the HeLa factory. Ironically, that factory was located at the Tuskegee Institute, infamous for unethical experiments with syphilis.¹¹ Robert J. Ursano, M.D., Professor of Psychiatry and Neuroscience confirms, "It is estimated that scientists have grown 20 tons of her cells. There are almost 11,000 patents involving HeLa cells....HeLa cells currently live by the trillions in laboratories and biological companies all over the world. They are still robust after more than 60 years."¹² Journalist Roblu McKle agrees that HeLa cells "have become a medical workhorse, benefiting hundreds of millions of patients thanks to their role in the development of polio vaccines, in vitro fertilization techniques, genetics research, the understanding of cancers, and the manufacture of drugs for herpes, influenza and many other illnesses."¹³

More recently, HeLa's interface with the Human Genome Project indicates that research disconnected from privacy and consent presents a challenge to balancing rights and responsibilities. Phoebe Haddon, Dean of the University Maryland School of Law, emphasizes just how difficult this balancing act is today. She points out, "What is required is an ongoing conversation between patients, doctors, nurses and bioethicists."¹⁴ Approximately fifteen years ago when the Human Genome Project began to take shape, HeLa was at its foundation, once again center stage for biomedical science. Evolution of HeLa came full circle when geneticists tracked down the Lacks family asking for blood samples. In 1973, when a scientist approached them for blood samples needed to study their genetics, Henrietta's family learned that the HeLa cells were spread worldwide.

Study of the genetic makeup of HeLa thrust Henrietta and her descendants to the forefront of the clash of science, ethics, and privacy. Exponential growth in the field of genomics enabled scientists to map the exact genetic code of HeLa. Suddenly, the essence of Henrietta and her descendants, her entire genetic code, was published for everyone to see on the Internet.¹⁵ Just as Dr. Gey arguably overlooked Henrietta the individual in 1951, with the mapping and publication of the HeLa's genetic code, geneticists were again infringing on the privacy rights of the Lacks family. HeLa embodied standardization of human material for research on human biology and genetics, but in the process Henrietta and her family had again been overlooked.

Publication of the genetic makeup of HeLa on the Internet drew attention to the dangers of ignoring the principles of privacy, consent and medical ethics. The focus has been on the responsibilities of science and scientific research for the advancement of medicine and this has enriched researchers and industry, yet paid nothing to the people contributing tissue. To protect themselves, Henrietta's descendants had to learn about their rights. To start the process, the Lacks family asked questions about scientific interest in their tissue samples. Resulting scrutiny focused attention back to the individual rights of donors, especially unwitting donors like Henrietta.

Lessons learned from the story of HeLa in medical research have begun to serve us all in ways not contemplated when Henrietta was first treated for cancer. The Lacks family felt their rights had been violated when German scientists posted Henrietta's genetic code on the Internet. Dr. Lars Steinmetz, one of the German geneticists, said that the team never intended to create controversy or any

harm to the Lacks family.¹⁶ The Lacks family did feel violated and disrespected. Indeed, Veronica Spencer declares, “No matter what field you are in, you have to treat people with respect.”¹⁷ Fortunately, a system of checks and balances has developed that permit science to fulfill responsibilities of advancement, while also protecting the rights of donors.

Publication of Henrietta’s genetic code on the internet resulted in a historic agreement between the U.S. National Institutes of Health (“NIH”) and the Lacks family. NIH Executive Director Francis Collins placed two of the Lacks family members, David Lacks, Jr. and Veronica Spencer, on a board to oversee the HeLa in research.¹⁸ That unprecedented board must now approve all federally funded studies involving HeLa. In this way, HeLa has revolutionized the concept of rights and responsibilities in research. Unfortunately, that agreement does not constrain private industry.¹⁹ Nevertheless, the NIH has called upon researchers everywhere to seek board permission before conducting research on the HeLa.

Today there are even more complicated questions presented regarding who can profit from the use of our bodies and tissues. Advent of genomics and the ubiquity of tissue specimen that are a byproduct of modern medicine mean that we are all confronted with these issues. NIH Director, Dr. Francis Collins, speaking about the agreement with the Lacks family said, “[t]his has wrapped in it science, scientific history, ethical concerns, the bringing together of people of very different cultures, a family with all the complications that families have.”²⁰ Veronica Spencer, Henrietta’s great-granddaughter, stated, “The strange thing is that for a long time we were the last to know about HeLa, but now we are the first people to be asked since we sit on the board that grants rights to use HeLa in research.”²¹

Since the mishandling of Henrietta’s rights, government has acted comprehensively to protect research subjects. *The Belmont Report*, written in 1979 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, spurred the creation of the so-called Common Rule, which is applicable to federally funded research. The Common Rule is shorthand for The Federal Policy for the Protection of Human Subjects that was first published in 1991 to protect vulnerable categories of test subjects. The Department of Health and Human Services enacted regulations implementing the Common Rule.²² These regulations gave rise to the Institutional Review Board (IRB) process, a process that strives to permit robust medical research and advancement while also protecting the rights of individual patients, especially those deemed vulnerable, such as pregnant women, fetuses, prisoners, children and the indigent. The IRBs are overseen by the Office for Human Research Protections (OHRP) that, according to its mission statement, “provides leadership in the protection of the rights, welfare, and wellbeing of subjects involved in research conducted or supported by the U.S. Department of Health and Human Services. OHRP helps ensure this by providing clarification and guidance, developing educational programs and materials, maintaining regulatory oversight, and providing advice on ethical and regulatory issues in biomedical and behavioral research.”²³

In 1996, Congress passed the Health Insurance Portability and Accountability Act of 1996 (HIPAA), in part to protect patient privacy. However, as illustrated

by the experience of the Lacks family, genetic information is not protected by HIPAA. To fill the gap concerning genetic information, in 2008 Congress passed the Genetic Information Nondiscrimination Act (GINA). In 2009, the Presidential Commission for the Study of Bioethical Issues was created by President Obama and is comprised of experts in fields, such as medicine, genetics, political science, engineering, advocacy, and ethics.

In part because of Henrietta, basic tenants of medical ethics have evolved. Ethical requirements now include non-maleficence (not harming), as the basis for medical decisions; beneficence (benefiting or doing good); autonomy, the patient has the right to choose or refuse medical treatment; and, justice, patients are treated impartially, without bias on account of gender, race, sexuality, wealth, etc.²⁴ Despite that progress, the life and legacy of Henrietta Lacks and HeLa serve as a cautionary note for the future of human tissue research and technical advancement that will continue to challenge our collective commitment to the rights of individuals. We live in an age in which organs can be regrown. We are increasingly confronted with questions about who owns human tissue and who should benefit, both medically and economically, from advancements and achievements derived from it. We must keep the story of Henrietta Lacks in the forefront of our minds as society continues to push the boundaries of science and medicine.

NIH Deputy Director for Science, Outreach, and Policy, Kathy L. Hudson, Ph.D. agrees, “[b]esides their priceless contributions to biomedical research over the past 60 years, Mrs. Lacks and her family are now serving as a catalyst for policies that advance science, build trust, and protect research participants.”²⁵ Henrietta Lacks, the HeLa cell, and the Lacks family have, in combination, advanced medicine by 60 years and revolutionized the way we must embrace the responsibility to protect the rights of tissue donors. By protecting Henrietta’s rights we safeguard the rights of everyone. Laws need to be put in place to advance patients’ rights without also stifling medical research. In a report, the Presidential Commission observes that, “Due to the rapid development of technology, we need to craft policies that are flexible and agile enough to ensure that we do not constrain our ability to adapt to evolving technology and social norms related to privacy and access.”²⁶ Lisa M. Lee, Ph.D., M.S., Executive Director of the Presidential Commission, agrees, “The benefits of research have to outweigh the risks to the individuals involved.”²⁷ The cells of Henrietta Lacks were taken without her consent. Her rights, and later the rights of her family, were violated because few laws existed to protect her and others from unauthorized medical research, even if performed for the common good. Lacks’ harvested cells brought to the forefront the responsibilities medical researchers owe society, transforming forever the way researchers gather information and collect samples from human subjects and more importantly, how modern research is regulated. Henrietta, the source of our ability to study the living human body in the laboratory, has reintroduced the human being to modern biomedical research.

Notes

1. Jamie Manfuso and Stephanie Desmon, "WEB EXTRA: Honoring the Henrietta Lacks Legacy at Hopkins," *Hopkins Medicine Magazine*, May 20, 2011 (http://www.hopkinsmedicine.org/news/publications/hopkins_medicine_magazine/hopkins_medicine_magazine_spring_summer_2011/web_extra_honoring_the_henrietta_lacks_legacy_at_hopkins).
2. Rebecca Skloot, "Henrietta's Dance," *Johns Hopkins Magazine*, April 2000, <http://www.jhu.edu/~jhumag/0400web/01.html>, p. 7.
3. Brian D. Smedley, Ph.D., "The Lived Experience of Race and its Health Consequences," *American Journal of Public Health*, 102 (2012): No. 5.
4. Howard W. Jones, Jr., M.D., "Record of the First Physician to See Henrietta Lacks at the Johns Hopkins Hospital: History of the Beginning of the HeLa Cell Line," *American Journal of Obstetrics and Gynecology*, 1997; 176: S227-8.
5. Telephone interview with Dr. Ruth Faden, Executive Director of the Johns Hopkins Berman Institute of Bioethics. April 23, 2014.
6. "U-Polio Detection Methods to Aid in Prevention Plans," *Minneapolis Star*, November 2, 1953.
7. Personal interview with David Lacks, Jr., great-grandson of Henrietta Lacks, 24 March 2014.
8. The Johns Hopkins Hospital, Office of Public Relations, "Memo to City Desk" press release dated April 7, 1954 [Dr. Gey was given an award for the discovery of HeLa and his contribution to cancer research. See, Appendix IV].
9. John R. Masters, "HeLa Cells 50 Years On; the Good, the Bad and the Ugly," *Nature Reviews Cancer* 2, 315-319 (April 2002) | doi:10.1038/nrc775.
10. Skloot, "Henrietta's Dance," p. 3.
11. Harriet A. Washington, *Deadly Monopolies, the Shocking Corporate Takeover of Life Itself – and the Consequences for Your Health and Our Medical Future*, (2011) Anchor Books, pp. 318-319.
12. Robert J. Ursano, M.D., "Science Calls Her HeLa," *Psychiatry: Interpersonal & Biological Processes* 2012 Summer; 75(2):101-2. doi: 10.1521/psyc.2012.75.2.101.
13. Roblu McKle, "Henrietta Lack's Cells Were Priceless, But Her Family Can't Afford a Hospital," *The Observer* (April 3, 2010) <http://www.theguardian.com/world/2010/apr/04/henrietta-lacks-cancer-cells>.
14. Telephone interview with Phoebe Haddon, Dean of the University of Maryland, School of Law. April 7, 2014.
15. Andy Coghlan, "Storm Erupts Over Publishing of HeLa Genome," March 28, 2013 *New Scientist*, <http://www.newscientists.com/article/dn23330-storm...>
16. Telephone interview with Lars Steinmetz, Ph.D. May 5, 2014.
17. Personal interview with Veronica Spencer (great-granddaughter of Henrietta Lacks who sits on the NIH committee) conducted at the *2014 Henrietta Lacks Baltimore City Youth Symposium*. March 24, 2014.
18. Ibid.
19. Claire Devine, "Tissue Rights and Ownership: Is a Cell Line a Research Tool or a Person?" *Columbia Science and Technology Law Review* (March 9, 2010), <http://www.stlr.org/2010/03/tissue-rights-and-ownership-is-a-cell-line-a-research-tool-or-a-...>
20. Ewen Callaway, "NIH Director Explains HeLa Agreement." *Nature*, August 7, 2013 doi:10.1038/nature.2013.13521.
21. Personal interview with Veronica Spencer. April 16, 2014.

22. Code of Federal Regulations, Title 45 Public Welfare, Department of Health and Human Services, Part 46, Protection of Human Subjects.

23. Office for Human Research Protection (OHRP) <http://www.hhs.gov/ohrp/about/index.html.hhs.gov>.

24. Graham, Ernie, M.D., "Medical Ethics," [PowerPoint Presentation] Johns Hopkins University School of Medicine, http://www.hopkinsmedicine.org/gynecology_obstetrics/pdfs/medstudent/ethics_class_9.pdf.

25. "NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells," National Institutes of Health, <http://www.nih.gov/news/health/aug2013/nih-07.html>.

26. "Privacy and Progress in Whole Genome Sequencing," Presidential Commission for the Study of Bioethical Issues (2012), <http://bioethics.gov/node/764>.

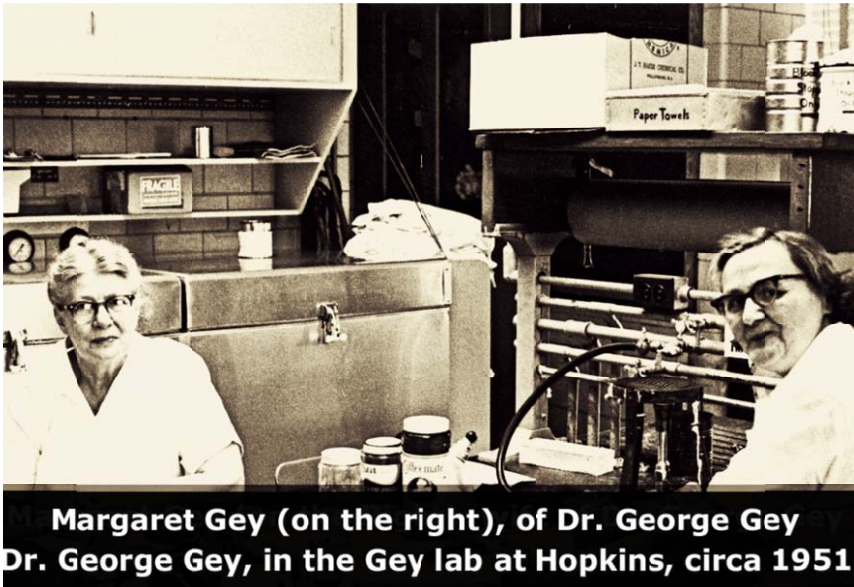
27. Interview with Lisa M. Lee, Ph.D., M.S., Executive Director of the Presidential Commission for the Study of Bioethical Issues, May 14, 2014.

Appendix I

CERTIFICATE OF DEATH		Registered No.	
DECEASED HENRIETTA LACKS		DATE OF DEATH Oct 4, 1951	
Maryland A-2		RESIDENCE STATE MARYLAND	
PLACE OF DEATH JOHNS HOPKINS HOSPITAL		CITY OR TOWN BALTIMORE	
In Baltimore		STREET ADDRESS 713 NEW PITTSBURG AVE.	
COLOR OR RACE White		DATE OF BIRTH 8-18-20	
SINGLE, MARRIED, WIDOWED, DIVORCED MARRIED		AGE IN YEARS 31	
PLACE OF BIRTH Roanoke, Va		PLACE OF BIRTH Roanoke, Va	
MARRIAGE Home		MARRIAGE Lisa Lacks	
MARRIAGE Home		MARRIAGE JOHNS HOPKINS HOSPITAL	
CAUSE OF DEATH			
IMMEDIATE CAUSE OF DEATH UREMIA			
PRECEDENT CAUSE CARCINOMA OF CERVIX			

The Certificate of Death for Henrietta Lacks dated October 4, 1951.

Appendix II



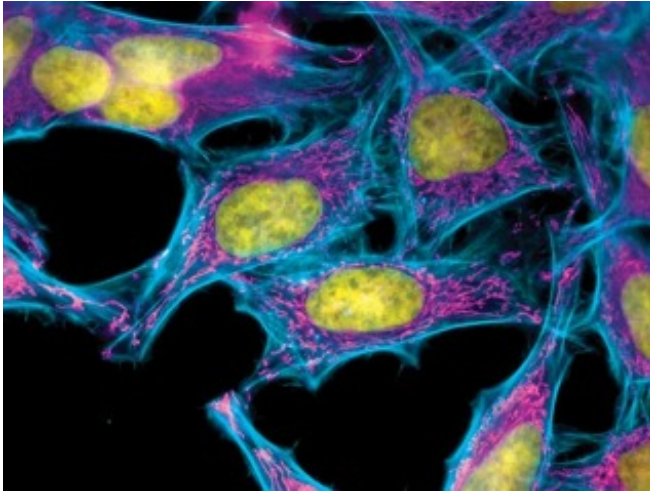
A photograph of the wife of Dr. George Gey, Margaret Gey, in their lab located within the Johns Hopkins Hospital in 1951.

Appendix III



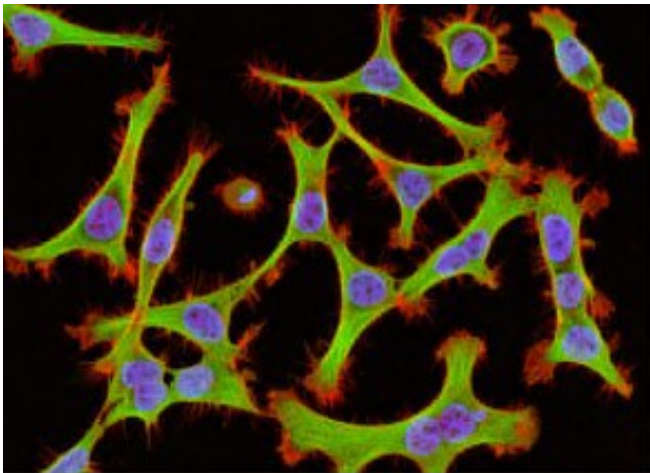
A cartoon drawn to illustrate and put emphasis on the incredible contribution to medical science that was the HeLa cell.

Appendix IV



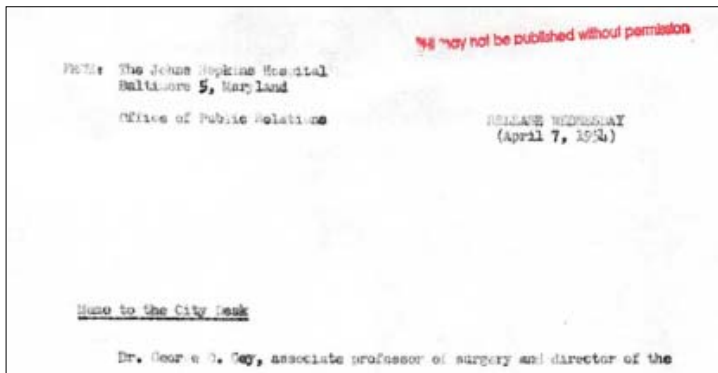
Photograph of the HeLa cell in a microscope slide.

Appendix V



Photograph of the HeLa cell in a microscope slide.

Appendix VI



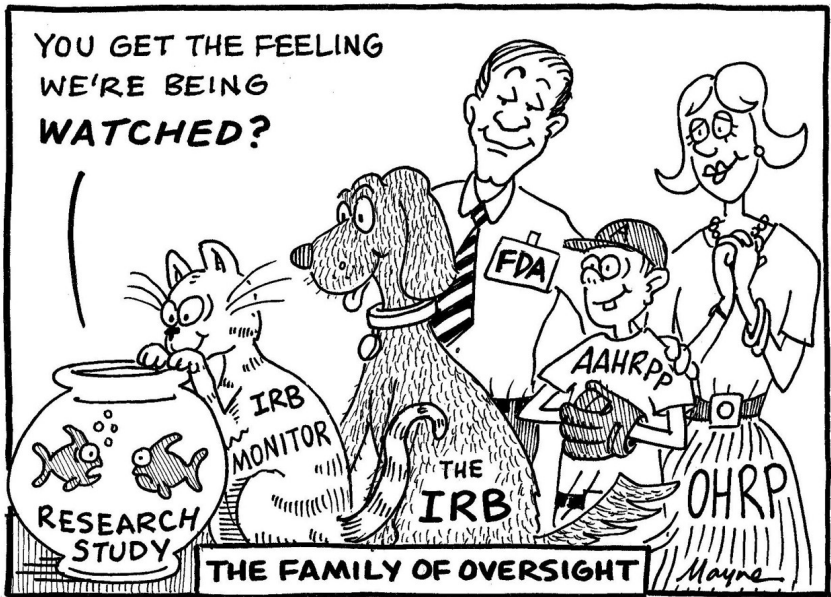
Johns Hopkins Hospital April 7, 1954 press release.

Appendix VII



Photograph of Lacks family members, Johns Hopkins staff, and symposium participants taken at the “Henrietta Lacks Symposium,” held at Johns Hopkins Medical Center. 24 March 2014. [Pictured, from left to right: (1) *Liz Martinez*, Research Participant Advocate with the Johns Hopkins Institute for Clinical and Translational Research; (2) *Jim Potter*, Research Consultant to the Lacks Family, and a Johns Hopkins University School of Medicine Assistant Professor of Medicine, Director-Translational Research; (3) *Dr. Hogan Tang*, Post-Doctoral Research Fellow with the Johns Hopkins Department of Molecular Microbiology and Immunology; (4) unnamed Baltimore high school student symposium participant; (5) *Dr. Dan Ford*, Director Johns Hopkins Institute for Clinical and Translational Research; (6) *Veronica Spencer*, great granddaughter of Henrietta Lacks; (7) unnamed Baltimore high school student symposium participant, and, (8) *David Lacks, Jr.*, great-grandson of Henrietta Lacks.]

Appendix VIII



“The Family of Oversight” cartoon that I obtained from Liz Martinez RN, BSN, CCRC, Research Participant Advocate Johns Hopkins University School of Medicine Institute for Clinical and Translational Research.

Appendix IX



Photograph taken during site visit to the National Institute of Child Health and Human Development, Brain and Tissue Bank for Developmental Disorders, located at the University of Maryland School of Medicine - Department of Pediatrics in Baltimore, Maryland. April 17, 2014.

Annotated Bibliography

Primary Sources

INTERVIEWS

Lacks, Lawrence. Telephone interview. April 7, 2014.

When my mother and I went to Baltimore, Maryland, we had no idea that we would be eating lunch with the two members of the Lacks family, Veronica Spencer and David Lacks, Jr., that sit on the NIH board. I also had no idea that Veronica would become one of my close friends and would end up calling me again a month after the day we first met her. She asked if we would like to interview her grandfather, Lawrence Lacks, son of Henrietta and the only surviving member of the Lacks family that remembers Henrietta. After asking some generic questions (If you could tell the world anything about Henrietta, what would it be, etc.), Veronica informed me that Lawrence could describe Henrietta if I wanted him to. He was the only child of Henrietta that was old enough to remember her. So, Lawrence Lacks told me about his mother. He explained that she never raised her voice, but got her point across by using a stern tone. He also explained that she was very strict, but after she gave him a whooping, she would always bake him a cake to make him feel better. Veronica also told me that I was the first person the Lacks family had ever allowed to interview Lawrence. It is amazing for me to think that I have spoken with someone who knew Henrietta Lacks so intimately, and talking with him brings to life all of the theoretical discussion of rights and responsibilities in the medical research setting.

Lacks, Lawrence. Personal interview. April 16, 2014.

Lawrence has been very helpful in providing me with a personal view of Henrietta's life and her amazing family. He is Veronica Spencer's grandfather and the oldest child of Henrietta's with memories of his mother. It has been challenging for Lawrence with all the media coverage of his mother because her death was a very emotional experience for him as her son. He is very kind and supportive of my research. I feel that we have created a special bond together because he agreed to interview with me, and he has never agreed to interview with anyone before my request.

ARCHIVAL SOURCES

Collection of newspaper obituary articles dated November 9, 1970 addressed to the death of Dr. George O. Gey (*The Sun*; *The Evening Star*, Washington, D.C.; *The Blade*, Toledo, Ohio; *The Evening Sun*.)

I found this collection of newspaper obituary articles in the George O. Gey collection at the Alan Mason Chesney Medical Archives, the archives associated with Johns Hopkins Hospital. These were interesting to me because they show how prominent Dr. Gey was and mention that he was known because he "began the culture of the HeLa strain, human cancer cells used by researchers all over the world." Even though that is what made Dr. Gey famous as a cell biologist, I found it interesting that there is no mention of the patient from whom the cells were taken.

Loche, Timothy. Handwritten letter dated May 25, 1964 written on stationary of the Lord Baltimore Hotel, Baltimore Maryland, by Timothy Loche.

I found this letter in the George O. Gey collection at the Alan Mason Chesney Medical Archives, the archives associated with Johns Hopkins Hospital. Even though I do not know who Timothy Loche is, I assume he was a colleague from the content and tone of his writing. I found this statement especially informative, "You have given something to

all of us by the spirit of ‘vocation,’ of calling, which you bring to observation of living cells.” This letter reinforces for me the heavy emphasis on scientific advancement that motivated Dr. Gey’s career. He obviously felt his responsibility was to the advancement of science. This also reminds me that there was then very little thought given to the rights of the tissue donors such as Henrietta Lacks.

Letter to Dr. George Gey from Dr. Al Lehnilger at the Università Di Padova Istituto Di Chimica Biologica Via F. Marzolo, 3.

This personal, handwritten letter to Dr. George Gey from the Director of the University of Padova is a congratulatory letter for his many medical accomplishments. The letter comments that Dr. Gey has many admirers for the time and dedication he has given to his medical research. The letter gave me a sense that Dr. Gey had many friends and was well liked. It made me realize that the sharing of the HeLa cell line was international in nature because of Dr. Gey’s many medical contacts around the world.

Western Union Telegram dated May 25-27, 1964 (Dr. Harry Eagle, Mr. Merle Tuve, Zolff Gaillard Fell, and Russell A. Nelson, M.D. President of the Johns Hopkins Hospital).

I found these documents in the George O. Gey collection at the Alan Mason Chesney Medical Archives, the archives associated with Johns Hopkins Hospital. These congratulatory messages from colleagues of Dr. George O. Gey sent to Dr. Gey in connection with an award he received for his work in cell biology, including the discovery and development of the HeLa cell line, show me just how prominent he was as a cell culture biologist and that he received all the credit for the HeLa cell line while Henrietta Lacks remained at first misidentified (named “Helen Lane”) and then largely unrecognized for her contribution until approximately 2010.

The Johns Hopkins Hospital, Office of Public Relations, “Memo to City Desk” press release dated April 7, 1954.

I obtained this document from the Alan Mason Chesney Medical Archives in Baltimore, Maryland. This press release was issued by Johns Hopkins Hospital in connection with the award to Dr. George D. Gey of the Katherine Berkan Judd Award for Cancer Research. That award was established by the Katherine Berkan Judd Estate in 1936 and was intended to be presented to “those individuals who have made the greatest advances toward the discovery of a cure for cancer.” The press release gives a description of the biography of Dr. Gey and lists his accomplishments including the following statement: “His most prominent discovery in cancer research was that of the ‘HeLa strain’ a cellular culture that has become one of the standards of studies the world over.” [See, Appendix VI to the paper.]

ARTICLES

Blakeslee, Alton L. “Scientists Grow Polio Virus On Cancer Cells for Early Test.” *The News and Courier*, April 10, 1953, morning edition. <http://news.google.com/news-wspapers?nid=2506&dat=19530410&id=b19SAAAIAIBAJ&sjid=KTcNAAAIAIBA-J&pg=3626,2371228>.

This was an interesting article to read after I had read about the HeLa Factory at the Tuskegee Institute from my other sources. I realized how exciting it must have been for doctors and researchers to be involved in this work at that time in history.

Brown, Russell Henderson, James. “The Mass Production and Distribution of HeLa Cells at Tuskegee Institute, 1953-55.” *Journal of the History of Medicine and Allied Sciences, Inc.*, 38 (1983): 415-431.

This article details how the HeLa was mass produced at the Tuskegee Institute. It came to be known as the HeLa Factory. This article gave me more background information on the production of HeLa cells on a large scale than I learned about from other sources such as the Radiolab documentary about the HeLa.

Davidson, Bill. "Probing the Secret of Life." *Collier's Weekly*, May 14, 1954, 78-83.

This article chronicles Dr. George Gey's demonstration of the immortal HeLa cell line in his laboratory on film. His article, written in 1954, refers to Henrietta Lacks as "Mrs. L." I also found a draft of this article in the George O. Gey collection at the Alan Mason Chesney Medical Archives.

Daytona Beach Morning Journal. "Simple New Test To Determine Whether Salk Vaccine Works." April 14, 1954 <http://news.google.com/newspapers?nid=1873&dat=19540414&id=zloeAAAAIBAJ&sjid=IcgEAAAAIBAJ&pg=5820,2823806>.

This article helped me to better understand the extensive collaborative efforts that were going on with the HeLa in different labs for different purposes. People are always referring to how the HeLa cell line was used to create a polio vaccine and this article taught me about the other medical researchers and doctors involved in the effort.

Eagle, Harry, "Nutrition Needs Of Mammalian Cells in Tissue Culture," *Science*, Volume 122, Number 3168, September 16, 1955.

Eagle's article explains the nutritional needs of mammalian cells in tissue culture in great detail. These findings were revolutionary because it helped scientists to understand the mixture of amino acids, vitamins, cofactors, carbohydrates, and salts made for the required nutrients for the cell cultures to remain alive. The HeLa cell line was instrumental in helping the scientists and researchers to determine this mixture.

Gey, George Otto, Coffman, W.D., and Kubick, M.T. "Tissue Culture Studies on the Proliferation Capacity of Cervical Carcinoma and Normal Epithelium." *Cancer Research*, 12 1952: 264-265.

This fascinating study published by Dr. George Gey and his colleagues describes how the cell strain HeLa was isolated at the Johns Hopkins University Hospital on February 8, 1951 by Dr. Gey and his co-workers from epithelial tissue taken from a patient with cervical adenocarcinoma. I found this article at the Alan Mason Chesney Medical Archives in Baltimore, Maryland.

The Maryland Cancer Bulletin. "Devoted Lives To Cancer Research." April 1955.

Dr. and Mrs. George O. Gey are highlighted in this medical bulletin as a couple who worked together for more than thirty years side by side in a cancer research laboratory. Together they have dedicated their professional lives to cancer research. The writer emphasized Dr. Gey's most prominent discovery in cancer research as that of the HeLa strain, a cell culture that had become one of the standards of study the world over. I found this article at the Alan Mason Chesney Medical Archives in Baltimore, Maryland.

New York Herald Tribune. "Hunt For A Cold Cure Getting Hot As Virus Trail Leads to Test Tube." Sunday, September 26, 1954.

This article from the early 1950s explains how scientists and researchers used test tubes in roller wheels to study viruses. The tubes contained blood plasma, salt solution, penicillin, and bits of monkey flesh. The photograph of the female scientist using the roller wheel was very interesting to look at and it helped me to understand what the tool actually looked like and how it worked.

Puck, Theodore T. and Fisher, H.W. "Genetics of Somatic Mammalian Cells: Demonstration of the Existence of Mutants With Different Growth Requirements in a Human Cancer Cell Strain (HeLa)." *Journal of Experimental Medicine* 104 (1956): 427-434.

This paper describes the application of the single cell plating procedure to the isolation of mutants in the population constituting in the HeLa strain. The characterization of two stable mutants with different growth requirements is described. The summary highlighted that the HeLa cell population is morphologically uniform with two mutants. I was interested in how the HeLa was referred to as the reliable stock cultures, and I thought about all the scientists and researchers who knew they could count on the cell line for their research.

Puck, Theodore T., and Marcus, Philip. "A Rapid Method For Viable Cell Titration and Clone Production With HeLa Cells In Tissue Culture: The Use of X-Irradiated Cells To Supply Conditioning Factors." *Proceeding of the National Academies of Sciences USA* 41 (1955): 432-437.

This study was complex, but an interesting description of the requirements for a medium in order to insure growth of a cell culture. This investigation emphasized the need for "conditioning" of the living cells of the nutrient media in the tissue culture before the multiplication can be supported. As I read it I thought about how amazed Dr. Gey and his colleagues must have been when they witnessed the replication and heartiness of Henrietta's amazing cells right before their eyes.

Puck, Theodore T., Marcus, Phillip L., and Cieciora, Steven J. "Clonal Growth Of Mammalian Cells In Vitro Growth Characteristics of Colonies From Single HeLa Cells With and Without a "Feeder" Layer." *The Journal of Experimental Medicine*, February 1, 1954, 103 (2) 273.

This article described two methods for simple and rapid plating of single HeLa cells, human, carcinomatous cells. It explains how using these two methods, it is possible to isolate mutant colonies and grow pure clonal stocks of animal cells.

Scherer, William F., and Hoogasian, Alicia C. "Perseveration at Subzero Temperatures of Mouse Fibroblasts (Strain L) and Human Epithelial Cells (Strain HeLa)." *Experimental Biology and Medicine* (Maywood), 1954, 87:480.

This article describes how scientists and researchers preserved cell samples from mouse fibroblasts (Strain L) and the human epithelial cells (Strain HeLa) at subzero temperatures. This is a landmark study because it highlights their ability to freeze the samples that revolutionized scientific advancement while creating new rights and responsibilities involved in these practices. This article demonstrated that with all HeLa advancements new bioethical questions regarding rights and responsibilities were presented.

Syverson, Jerome T., and McLauren, Leroy C. "Human Cells In Continuous Culture." *Cancer Research* (1957): 923-26.

This was an interesting article to read about how the HeLa cell line was used in cancer research even as early as the 1950s. I thought about Dr. Hogan Tang, the Johns Hopkins cancer researcher I met at the Lacks' Symposium in Baltimore and how he is still using the HeLa in cancer research today. This article also made me think about the fact that Dr. Hogan Tang, a cancer researcher, introduced me to the Lacks family and Dr. Gey, a cancer researcher, introduced the world to the HeLa cell, and eventually the Lacks family.

WEBSITES

Radiolab. "HeLa Cells," 1956. Online Video Clip. *Vimeo*. Accessed 21 March 2012. "HeLa Cells," *Vimeo*, 2010. Web. 3 December 2012, <http://www.vimeo.com/9581140>.

This video was about the HeLa cells looking at them through a microscope to see how they divide themselves to create more. It was an interesting video that fascinated me because of all the mystery surrounding the HeLa cells. As I watched the video, I thought about how many scientists and researchers had watched this take place over the years. I also thought of how many lives have been saved after Henrietta Lacks lost her own life.

IMAGES

Appendix I. Death Certificate of Henrietta Lacks, October 4, 1951 (<http://www.issues4life.org>) Google Images.

This certificate is the official document that Henrietta's death was recorded on. Henrietta died on October 4, 1951. This document reminds me that Mrs. Lacks lost her life because of the amazing cancer cells that have since, ironically, saved so many.

Appendix II. Photograph of Margaret Gey, wife of Dr. George Gey in Dr. Gey's laboratory at Johns Hopkins Hospital.

(<http://www.google.com/url?sa=i&rect=j&q=&esrc=s&source=images&cd=&docid=gg3D8xy4OkNmBM&tbnid=Lft2EPGbNaie2M:&ved=0CAQjB0&url=http%3A%2F%2Fthehauntologicalsociety.blogspot.com%2F2013%2F12%2Fhenrietta-lacks-life-afterdeath.html&ei=rdsCU9SrMtH-moATfs4DwBQ&bvm=bv.61535280,d.cGU&psig=AFQjCNEqAxzsE-8TvS-Sollps-8TjD6uVnA&ust=1392782310175768>) Google Images.

This image depicts Margaret Gey, wife of Dr. Gey, and lab assistant Mary Kubicek, the assistant who first cultured the cells. It is amazing to see the lab that the HeLa was born in. It is also fascinating to look at the women who nurtured the cell line into perpetual existence.

Appendix IV. Photograph of the HeLa cell on a microscope slide.

(<http://moralcompass.blog.sbc.edu/files/2010/09/HeLa-cells-DNA-2.jpg>).

This is an image of the HeLa cell in a microscope slide. Seeing this really helped me to connect what I learned about the cells to the living organism that was and still is helping to advance medical science.

Appendix V. Photograph of the HeLa cell on a microscope slide.

(<http://idiopathicmedicine.files.wordpress.com/2010/09/cancer-cell-helamicrograph.jpg?w=630>).

This is another photograph of the HeLa. Over the course of my research I have seen many different images of the HeLa cell. It never ceases to amaze me that scientists can dye the cells and that in almost every picture the cells always appear both different and strangely beautiful.

Secondary Sources

INTERVIEWS

Bechtel, Pamela, Community Relations Representative at Johns Hopkins Hospital in Baltimore, Maryland. Personal interview. March 24, 2014.

Ms. Bechtel talked with me about the importance of community partnerships between Johns Hopkins and the surrounding Baltimore, Maryland community. She works on organizing special events, attending community meetings and other programs to strengthen the relationship between Johns Hopkins and the people they serve locally. I attended a Henrietta Lacks Symposium for Baltimore High School students that featured amazing speakers and presenters. The special event seemed like it was organized as a perfect fit for my History Day research on Henrietta Lacks and the HeLa cell line.

Civin, Curt I, MD, Professor and Director of the Center for Stem Cell Biology & Regenerative Medicine and Associate Dean for Research, University of Maryland. Telephone interview. April 7, 2014.

I first learned of Dr. Civin because he was a speaker in a panel discussion I found on the Internet. In that discussion, Dr. Civin explained how stem cells can form every type of cell in the human body. He explained how the HeLa is now a more complex situation with the rights and responsibilities with the ability to make any cell in the body. This brings into question tissue ownership with competing interests and stories. It highlights the rights and responsibilities between tissue cell usage in research and human lives. One very interesting thing Dr. Civin said was that “you can’t regulate what you can’t predict. So, for example, back in 1951 the scientists had no idea that in 2013 the HeLa genetic information would be published on the Internet.”

Cottrell, John R., MS, PA, ASCP, Tissue Coordinator and Clinical Instructor for the National Institute of Child Health and Human Development, Brain and Tissue Bank for Developmental Disorders, located at the University Maryland School of Medicine - Department of Pediatrics in Baltimore, Maryland. Personal interview. April 17, 2014.

John Cottrell is a pathologist who works in the highly specialized brain bank in Baltimore located at the University of Maryland. It is one of only six brain banks in the United States. We were provided an interview and tour of his lab that was arranged by Joe Giffels (previously with the University of Maryland) who introduced us to Dr. Asaf Keller (a neurosurgeon for the pediatric center at the University of Maryland). Dr. Keller serves on the Steering Committee of the NICHD Brain Bank making it possible for us to include this visit in our Baltimore trip on very short notice. I learned that today all bio specimens are de-identified from their human donors. Patients and their families sign full consent forms in advance. The Internal Review Board (IRB) at the University of Maryland must preapprove the consent forms. It was interesting to learn about how the bio specimens are stored in freezers kept at a constant -83 degrees Celsius. Mr. Cottrell explained how researchers who want to study autism, genetic disorders and other genomic studies use the brain tissue samples maintained at this facility. [See, Appendix IV to the paper.]

Faden, Ruth R., Ph.D., MPH, Philip Franklin Wagley Professor of Biomedical Ethics and founding Director of the Johns Hopkins Berman Institute of Bioethics. Telephone interview. April 23, 2014.

I asked Dr. Faden about the rights and responsibilities involved in the HeLa cell story and similar issues faced in medical research today. Dr. Faden told me that the concept of rights and responsibilities in this context changes all the time because the medical and scientific communities have a huge responsibility to acknowledge when there is a breakthrough in science and to recognize the associated advantages. She said that this concept clashes with the rights of patients and research subjects and our understanding of those rights has evolved over time. For example, she said that in 1951 there was,

compared to today, very little discussion about ethics and concepts of consent. She told me that is wrong and that a medical breakthrough does not justify violating the rights of individuals. According to Dr. Faden the major lesson to take away from the story of Henrietta Lacks is that the consent by or permission of the patient/research subject must always be obtained and we need to recognize that consent is complicated because of the inability to predict today how biological samples will be used in the future.

Ford, Dan, M.D., Director Johns Hopkins Institute for Clinical and Translational Research. Personal Interview. March 24, 2014.

Dr. Ford gave a very insightful presentation on the bioethics involved in the ethical questions raised by the HeLa cell line. He spoke about the rights and responsibilities involved with examples from a variety of fields. I found his depth of knowledge about the HeLa to be impressive. I took so many notes during the presentation because he gave me so many new ideas to research and follow up on.

Giffels, Joe, Associate Vice Provost for Research Compliance, University of Washington. Telephone interview. April 15, 2014.

Joe Giffels was very kind to grant me a phone interview and proved to be a very valuable resource. He explained to me that we have to look at this problem through the lens of the time period it happened in. This means that back in 1951 the racial side of the story played a major part. He also mentioned that it's easy to look back on events of the past and say, "Oh, that was so unethical!" or, "How immoral!" However, the truth of the matter, Giffels says, is that in 1951 the doctors and scientists who cared for Henrietta were not thinking about obtaining consent or even about how what they were doing might hurt Henrietta's family. They were simply thinking about how they could advance science by using what they had discovered. "We have to remember," Giffels told me, "The standards were different."

Haddon, Phoebe A. Dean, University of Maryland School of Law. Telephone interview. April 7, 2014.

I first learned of Ms. Haddon because she was a member of a panel presentation by the University of Maryland that I watched on the Internet. In that presentation, she explained the importance of the protocols that must be allowed in this process. Ms. Haddon described the following of the letter of the law versus the "spirit of the law" with signatures on forms that represent a handshake, an agreement of sorts to continue the conversations regarding the rights and responsibilities throughout the research process. Ms. Haddon pointed out that these discussions need to take place at all levels between patients, doctors, nurses, and bioethicists. I also had the good fortune of interviewing Dean Haddon by telephone. She was very helpful and provided an interesting perspective. One thing she said seemed especially important in the Henrietta Lacks story. She said, "Law and medicine always interact but they have different goals and values. The medical world wants to find the cure, but the legal world is focused on patient rights and wants to obtain consent."

Hudson, Kathy, Ph.D., Deputy Director, second to the Director Francis Collins, of the National Institutes of Health. Email interview. April 7, 2014.

I was able to interview Dr. Hudson by email. She informed me that the new agreement regarding the HeLa cell line's genome was going well, and that the scientific community was very supportive of and compliant with the newly reached agreement. I was also shocked to hear that a Google search for "HeLa cell" generates 2.5 million results with 74,000 publications citing HeLa. Dr. Hudson explained to me that in the last ten years,

the majority of Nobel Prizes in medicine have been awarded for projects involving the HeLa cell in one way or another. I was also interested in the fact that young scientists have used HeLa to win competitions. I was thinking that next year for Science Fair I will do something with the HeLa cell as well.

Lacks, David Jr., great-grandson of Henrietta Lacks. Personal interview. March 24, 2014.

I had the honor and privilege of interviewing David Lacks, Jr. when I attended the Henrietta Lacks Symposium at Johns Hopkins Medical Center in March 2014. It was so exciting to be able to ask him how he feels as a direct descendant of a woman who has done so much for medical advancements and to gain his perspective about the rights and responsibilities involved in these issues. He was very kind and supportive of my research providing me with his opinion of the past and where they are headed as a family into the future helping to navigate these complicated issues. I have a great deal of respect for David and his entire family.

Lacks-Whye, Jerrie. Personal interview. April 16, 2014.

Jerrie Lacks-Whye is a cousin of Henrietta Lacks' great-granddaughter, Veronica Spencer. She told me that she wants the world to know that Henrietta unknowingly saved millions of lives and that her legacy continues. Jerrie said that Henrietta is a piece of everyone because of all of the contributions she has made over time. She also stated that the National Institutes of Health (NIH) agreement is a very positive thing because it gives the family an opportunity to be involved with research decisions concerning the HeLa cell. She emphasized that instead of her family being in the background, they are now in the forefront of these important issues. Jerrie said that she would like to see more people acknowledge Henrietta's contributions.

Lacks, Kim. Telephone interview. April 16, 2014.

Kim Lacks is a great-granddaughter. She talked with me on the cell phone after our dinner with the Lacks family. Veronica Spencer was very helpful in calling additional family members for me to talk with following our dinner in Baltimore. Kim said she is very excited about the movie about Henrietta Lacks that Oprah Winfrey is creating. She shared with me information on the casting of actors and other details about the film project.

Lee, Lisa M., Ph.D, M.S., Executive Director of the Presidential Commission for the Study of Bioethical Issues. Telephone interview. May 14, 2014.

I was so excited to obtain a telephone interview with the help of my local Congressman, Kevin McCarthy, with Executive Director, Dr. Lisa Lee. She is a top advisor to President Barack Obama for bioethical issues. I was so amazed at her willingness to help me with my research and her in-depth knowledge regarding Henrietta Lacks and the HeLa cell line. She stressed the importance of balancing the rights and responsibilities. She explained in detail providing examples of how the benefits of research have to outweigh the risks involved. She was also very encouraging about my interest in pursuing bioethics and my mother's interest in helping their initiative by creating curriculum for Henrietta Lacks and the HeLa cell line for others to have access to in the future.

Martinez, Liz, Research Participant Advocate with the Johns Hopkins Institute for Clinical and Translational Research in Baltimore, Maryland. Personal interview. March 24, 2014.

Ms. Martinez gave a presentation on "Clinical Research Basics and Career Paths" that explained all of the rules and regulations that govern a research study and its

subjects. I learned how complicated the process is and how many agencies are involved to insure that the research study's subjects rights are protected. It is her responsibility to oversee these rights and be sure they are not violated at any point in the studies. I especially liked the visuals that she used to teach about the various regulatory groups that oversee research studies (see for example, Appendix VIII). I was also inspired by her information on career paths that got me thinking about my own future and how my research will influence my studies and possibly my decision about my vocation. I am now considering studying bioethics.

Mathews, Debra, Ph.D, MA, is the Assistant Director for Science Programs for the Johns Hopkins Berman Institute of Bioethics. Personal interview. April 16, 2014.

Dr. Debra Mathews was very informative in our interview. She research is extensive focusing on the intersection of science, public policy and society. She told me a great deal about the history of bioethics and its regulations have evolved over time. She provided me with many helpful articles, interview possibilities and website recommendations. I am proud to say that I followed up on all the things she suggested to broaden my research. I am looking forward to seeing her at future Johns Hopkins Henrietta Lacks symposiums.

Potter, Jim, Research Consultant to the Lacks Family, and a Johns Hopkins University School of Medicine Assistant Professor of Medicine, Director-Transitional Research. Personal interview. March 24, 2014.

Mr. Potter gave an informative presentation on the scientific history of the HeLa cell line. It was very helpful to take notes on because it provided me many leads for my research regarding other doctors and researchers who achieved medical advancements regarding the HeLa cell line. It was also interesting to hear about all the things he has done to help the Lacks family with learning about their family history. He was so helpful to me when I visited Johns Hopkins for the symposium. He even welcomed me and my mother to his office to see his collection of Lacks' family memorabilia and books that he has collected over the years.

Rodriguez, Laura Lyman, Ph.D., Director Division of Policy, Communications, and Education, National Institutes of Health, National Human Genome Research Institute, Washington, D.C. Personal interview. April 9, 2014.

Dr. Laura Rodriguez graciously met with me at the Smithsonian Natural History Museum on the day she was chaperoning her son's school field trip. She met with me at the Human Genome exhibit and explained in great detail the type of work she does at the National Institutes of Health in the area of bioethics. I was thankful for her insight and willingness to share her expertise with me. I was also surprised at how accessible she was to me in my request for an interview during her busy schedule. Without her suggestion for me to visit the museum to interview her, I may not have learned about the special exhibit on genetics that taught me a great deal.

Skinner, Elizabeth, Bioethicist from Johns Hopkins Medical Center and a Mason Chesney Archives Volunteer in Baltimore, Maryland. Personal interview. March 26, 2014.

Ms. Skinner was extremely helpful providing me with information on the complex ethical issues involved with the HeLa cell line. She also helped me to better understand all of the regulatory agencies that Liz Martinez had also discussed. Ms. Skinner also directed me to a colleague of hers at the Human Genome Project to interview, Laura Rodriguez.

Spencer, Antonetta. Personal interview. April 16, 2014.

Antonetta Spencer is Veronica Spencer's mother and the granddaughter of Henrietta

Lacks. She is a very kind woman who offered to make dinner for my family when we met with her in Baltimore. She believes that Henrietta would have consented to sharing her special cells had Johns Hopkins doctors asked her before she passed away. She said that Henrietta was a very caring woman that would have wanted to help others. She also feels strongly that Johns Hopkins should dedicate a hospital wing in honor of Henrietta Lacks for her countless contributions to medicine. I am looking forward to visiting her again and having her cook dinner for my family. Her husband provided my family a ride back to our hotel after our dinner with the Lacks, and that gave me the chance to also interview him about Henrietta Lacks and his family.

Spencer, John. Personal interview. April 16, 2014.

John Spencer is Veronica Spencer's father and the grandson-in-law of Henrietta Lacks. He was very kind in offering my family a ride home from the restaurant after I interviewed the Lacks family members. He provided an inside look regarding how a family is affected by all of the media attention concerning Henrietta's life and her amazing cell line. He shared with us that he is a cancer survivor and understands fully the complexities of the rights and responsibilities involved in receiving medical care, and also the importance of medical research. He expressed his thoughts and feelings very clearly giving me a more in-depth understanding of the experiences and challenges that his family has faced over the years.

Spencer, Veronica. Personal interviews. March 24, 2014 and April 16, 2014.

I had the honor and privilege of interviewing Henrietta Lacks' great granddaughter, Veronica Spencer, at the Henrietta Lacks Symposium at Johns Hopkins Medical Center in Baltimore, Maryland in March 2014. She was so strong and intelligent. I admire her for her boldness and confidence as a speaker on her family's behalf. She shared with me that it was unfortunate that they did not know about her grandmother's amazing cells until 30 years later, but she focused on the importance of moving forward and helping to educate people about the rights and responsibilities involved in their family's situation. She was encouraging and enthusiastic about my research. She provided us with other contacts and information to include in my research paper, including an introduction to Lawrence Lacks and other members of the Lacks family. I will feel forever grateful for her assistance and the openness she brought to our interviews.

Steinmetz, Larz, Ph.D., Associate Head of Unit and Senior Scientist with the European Molecular Biology Laboratory located in Heidelberg, Germany. Telephone interview. May 5, 2014.

Dr. Steinmetz is also a professor of genetics at Stanford University where I was able to reach him by phone for an interview for my project to discuss his study, "The Genomic Transcriptomic Landscape of a HeLa Cell Line," that he had to remove from the Internet after a barrage of objections. He explained that they had never intended to create that level of chaos, and that they aiming to show the degree to which the genomes of the HeLa cells diverged from those of healthy cells, so that other researchers could take this into consideration when creating their own studies using the HeLa cell line. Having the HeLa genome may also assist other researchers in checking new lines of cells for contamination of the HeLa cells. Steinmetz informed me that they were able to repost their study once they apologized to the Lacks family members and after the NIH had formed a special committee to approve and oversee all studies involving the HeLa genome. That committee is comprised of six members: Dr. Francis Collins, Dr. Kathy Hudson, Dr. Ruth Faden, David Lacks, Jr., Veronica Spencer and one other official.

Tang, Hogan, M.D., Post-Doctoral Research Fellow with the Johns Hopkins Department of Molecular Microbiology and Immunology, Bloomberg School of Public Health. Personal interview. March 24, 2014.

Dr. Tang was so kind to me when I visited Johns Hopkins for the Henrietta Lacks Symposium. He introduced himself before his presentation on “Anastasis: Lesson From HeLa Cells in Survival After A Cell Suicide Attempt” presentation. He gave a PowerPoint that explained how he uses the HeLa for his cancer research at Johns Hopkins. He is a Fulbright Scholar who does amazing work in science, and there I was talking with him about my research on the HeLa. He was so excited about my efforts to document her contributions for History Day. He was instrumental in introducing my mother and me to the Lacks family members at the symposium. The Lacks family members then invited us to join them for lunch and an interview. I will be forever grateful for Hogan Tang and his help and to the Lacks family for being so supportive of my research efforts.

GOVERNMENT DOCUMENTS

Code of Federal Regulations, Title 45 Public Welfare, Department of Health and Human Services, Part 46, Protection of Human Subjects.

These are the regulations enacted by the Department of Health and Human Services in an effort to protect human subjects in medical research.

Congressional Record 105th Congress (199701998) In Memory of Henrietta Lacks. Honorable Robert L. Ehrlich, Jr., In the House of Representatives, June 4, 1997.

This is a record of Hon. Robert L. Ehrlich, Jr. paying official tribute to Henrietta Lacks, for her contributions to medical research and science unnoticed for the past 46 years. He gave information on her background and family members. He said she has gone without recognition for far too long, and that it was time to extend his deepest thanks for her and her family. He hoped that she would be immortalized as a person of great courage, hope and strength.

Gutmann, Amy, Ph.D. Commission Chair, Presidential Commission for the Study of Bioethical Issues. “Privacy and Progress in Whole Genome Sequencing.” Executive Summary. (October 2012) <http://bioethics.gov/>.

This is the a summary of the ongoing work by the Presidential Commission for Study of Bioethical Issues formed by President Obama in 2009. It is interesting because there is an obvious attempt by the commission to try to balance rights of patients and tissue donors with the responsibility of working to ensure continued advancement of medical science, especially in the area of genomics. I had no idea when I first read this report that I would later have the privilege of interviewing the Commission’s Executive Director, Dr. Lisa Lee.

Office for Human Research Protection (OHRP) <http://www.hhs.gov/ohrp/about/index.html.hhs.gov>.

The Office for Human Research Protection (OHRP), implements the “Common Rule,” which is shorthand for The Federal Policy for the Protection of Human Subjects first published in 1991 to protect vulnerable categories of test subjects. The Department of Health and Human Services enacted regulations implementing the “Common Rule”. These regulations gave rise to the Institutional Review Board (IRB) process designed protect the rights of vulnerable individual patients.

Presidential Commission for the Study of Bioethical Issues Webinar, “Implementing Education Across Disciplines.” April 24, 2014, 12:00 – 1:00 pm ET.

The webinar was helpful because it gave me information from the Presidential Commission for the Study of Bioethical Issues regarding their new initiative to teach bioethics at the undergraduate, graduate and postgraduate levels in the near future. It also described the plan to begin a public campaign to teach people of all ages about these important bioethical issues. I was excited to hear this news the day before I traveled to my California History Day state competition in Riverside, California. I knew that my topic was an important one on a national level, and now I had high-level evidence of our President's cabinet members stressing the timeliness of these crucial issues involving rights and responsibilities. It was helpful that they provided educational materials for free download at www.bioethics.gov/education.

BOOKS

Bynum, William. *The History of Medicine: A Very Short Introduction*. Oxford: University Press, 2008.

This book is a short, easy to read tour through the history of medicine from classical times to today. It provides information on key turning points in Western medicine such as the establishment of hospitals, an increase in experimentation with humans, and others. Bynum weaves in past histories with modern day concerns, rights and responsibilities.

Chafe, William. *Remembering Jim Crow: African Americans Tell About Life in the Segregated South*. New York: The New Press, 2001.

This book contains stories of African American southerners as part of the Behind the Veil Project at Duke University's Center for Documentary Studies. It contains audio transcripts of recordings of African Americans who tell their life stories of segregation and persecution. The stories shed light on the different facets of racism that people from a variety of different backgrounds experienced. The readings and illustrations helped me to gain a deeper understanding of how racial segregation affected all aspects of African American people's lives both on a public and institutionalized level from their homes, work, and school environments. I learned a great deal from the oral histories that were shared in the book. It helped me to gain a better understanding of the manual labor Henrietta Lacks did as a tobacco farmer, the way medical care was segregated during her lifetime and some of the challenges African Americans faced when dealing with poverty and racism.

Farley, Margaret A. *Compassionate Respect: A Feminist's Approach to Medical Ethics and Other Questions*. New York: Paulist Press, 2002.

This book covered the rights every human person deserves in terms of respect and compassion. It describes how medical ethics has focused primarily on the autonomy of patients while not giving fair consideration to the social contexts and responsibilities involved when dealing with human subjects. The author outlines an ethic of caring that comes from her female experience that acknowledges the idea as a patient who is a physical body, a person and a spiritual being. Her traditional approach includes the acceptance that there is a God that has created all humans. She writes that this God is a merciful God that also requires humans to be merciful, as well. This source brought in an interesting added perspective that is often omitted or overlooked in other sources. It also reflects how many people feel this perspective is important and must be represented on peer review boards as well with pastors, reverends or religious officials alongside doctors, nurses and others. Her book discusses important concepts such as individual autonomy, non-maleficence (restraining from harming a patient), beneficence (the positive promotion of patient welfare), and distributive justice (fair allocation of limited medical resources). Her list also includes truth telling, confidentiality, fidelity,

and rights of privacy all important ingredients in strong relationships in medicine and life in general. Her examination of the covenant or promise between medical providers and their patients is central to the theme of this year's History Day with its focus of rights and responsibilities.

Friedman, David. M. *The Immoralists: Charles Lindbergh, Dr. Alexis Carrel, and Their Daring Quest To Live Forever*. New York: Harper Collins, 2007.

This book describes the collaboration between Charles Lindbergh, the hero of flight, and Dr. Alexis Carrel, a Nobel laureate surgeon. It provides history on cell research while telling the story of bioengineering, medical research and their quest to accomplish immortality. The story sheds light on how in Carrel's medical laboratory, in 1930 at the Rockefeller Institute for Medical Research in New York, funded by John D. Rockefeller, the medical investigators could pursue their medical endeavors and dreams without the usual checks and balances of medical practice. The events described in the book helped me to understand how medical research can take on "a life of its own" when conducted unchecked by outside sources. It helped me to see the important role the peer review process has come to play in modern medicine and research.

Gold, Michael. *A Conspiracy of Cells: One Woman's Immortal Legacy and the Medical Scandal It Caused*. Albany: State University of New York Press, 1985.

Gold's book gave a detailed behind the scenes account to the HeLa cell line contamination scandal. It helped me to understand the difficulty some scientists and researchers had informing the medical industry of these difficult circumstances. With the "War on Cancer" raging and grant money flowing for cancer research, the fact that cell lines were contaminated by the HeLa was very problematic both financially and scientifically.

Ham, R.G. *Survival and Growth Requirements of Nontransformed Cells: Handbook of Experimental Pharmacology*, Volume 57, 1981, pp 13-88.

Ham describes the environmental requirements for survival and growth of nontransformed cells and the important considerations of studying those requirements. I thought about how the HeLa was so amazing in its survival and growth causing it to become the "workhorse" in labs around the world.

Kiessling, Ann A. and Anderson, Scott. *Human Embryonic Stem Cells: An Introduction to the Science and Therapeutic Potential*. Sudbury, MA: Jones and Bartless, 2003.

This single reference provided basic information on the variety of disciplines of science as they pertain to the science of stem cell research and experimentation. I learned that this is a controversial area of science that ignites debate worldwide.

Mukherjee, Siddhartha. *Emperor of All Maladies*. New York: Scribner, 2010.

This book was an interesting biography of the history of cancer research and cancer biology researched by physician, researcher, and award-winning science writer Siddhartha Mukherjee. It was written in a similar style as Rebecca Skloot's *The Immortal Life of Henrietta Lacks* by giving personal information about the people involved in the extensive research of cancer. It also helped provide broader historical context for the history of cancer. It was awarded Ten Best Books by the New York Times Book Review in 2010. The statistics in the book regarding cancer telling how about 600,000 Americans and more than 7 million humans around the world will die each year from cancer were amazing. I learned that one in three women will develop cancer and one in two men during their lifetime. Fifteen percent of all deaths are connected to cancer. It was also told that cancer will cause more deaths than heart disease in some

nations becoming the most common cause of death. It made me realize how cancer is so pervasive around the world and how important the HeLa cell line has been and continues to be in cancer research.

Oshinsky, David, M. *Polio An American Story: The Crusade That Mobilized the Nation Against the 20th Century's Most Feared Disease*. Oxford University Press, 2005.

This book is a 2006 Pulitzer Prize winner in History. It is science writing that tells the story of the polio epidemic and the intense quest to find a cure from the March of Dimes to the discovery of the Salk and Sabin vaccines and beyond.

Puck, Theodore T. *The Mammalian Cell As A Microorganism: Genetic and Biochemical Studies In Vitro*. Holden-Day, Inc., 1972.

This book was helpful as a source that provided me with additional information on genetics and microbiology and the ideas that guide the research in those fields. I was impressed that he shows a serious concern about the ethical and social implications of the rights and responsibilities of biological research, and he dedicates entire sections to discussing these important topics in great detail.

Rader, Karen. *Making Mice: Standardizing Animals for American Biomedical Research, 1900-1955*. Princeton University Press, 2004.

Making Mice is a scientific biography, history of institutions and cultural study to highlight how genetically standardized mice were the central subjects in biomedical research across the country. This book was interesting to me because the author refers to the breeders of the mice as “scientific entrepreneurs” striving to create different characteristics. It helped me to recognize the emergence of the modern biomedical research industry and the tension between “natural” and “man-made” in scientific research and experimentation.

Sandel, Michael J. *Justice What's the Right Thing to Do?* New York: Farrar, Straus, and Giroux, 2009.

This *New York Times* best seller is written by the Harvard political philosopher who writes about public and social issues. He addresses issues that are woven into our everyday lives such as stem cell research among others. His writing helps to point out how these issues affect all of us that are human living with other humans here on Earth. It was interesting to see many different chapters on different rights and responsibilities that arise from different situations in society.

Skloot, Rebecca. *The Immortal Life and Henrietta Lacks*. New York: Random House, 2010.

This book was extremely helpful by Rebecca Skloot because it tells the story of Henrietta Lacks as a person and describes the way she is known by scientists as the HeLa. It weaves the story of how Henrietta was a poor black tobacco farmer in 1951 who become a key tool in medicine, instrumental in developing the polio vaccine, gene studies, cloning and many other studies and research. Skloot shows the stark contrast between the billions of HeLa cells that have been sold and how Henrietta remained virtually nameless while her own family could not afford basic health care. Skloot spent over 15 years tirelessly researching the Lacks family and the HeLa's many contributions. I also had the honor of attending Skloot's book discussion at California State University, Bakersfield hosted by *One Book, One Bakersfield, One Kern* (a countywide reading program) gaining more information and insight on her writing and research. Her talk was inspiring to me as I continued my own research on this fascinating subject. I was also able to ask her specific questions for my research project.

Talbot, Marianne. *Bioethics: An Introduction*. Cambridge University Press, 2012.

This was a helpful introduction to bioethics for my research. It gave general background on ethics in general, and then it gave more detailed information on bioethics. I found it interesting to think about how these principles apply to all areas of our life. I would like to take courses in bioethics now that I have conducted this research project.

Wailoo, Keith, Nelson, Alondro, and Lee, Catherine. *Genetics and the Unsettled Past: The Collision of DNA, Race and History*. Rutgers University Press, March 15, 2012.

This unique book united scholars from a variety of disciplines: biology, history, cultural studies, law, medicine, anthropology, ethnic studies, and sociology to investigate the connections between DNA, race and history. It has interesting stories from history that feature different situations. There is an interesting section on the HeLa cell line that helped add to my research. I was very happy to find this book on the Internet while looking for other articles. I stumbled onto it, and it was a great find.

Washington, Harriet A. *Deadly Monopolies, the Shocking Corporate Takeover of Life Itself – and the Consequences for Your Health and Our Medical Future*. New York: Anchor Books, 2011.

This book highlights the tension between profit motives and medical ethics. Harriet Washington is one of my favorite authors from my project. I hope to meet her some day and possibly hear her speak or take a class from her to learn more about bioethics. She is a research fellow and professor. That would be an amazing career, and I am hoping she will become a mentor to help guide my future academic and professional choices. Veronica Spencer, Henrietta's great-granddaughter, told me that Harriet was a speaker at one of their past Henrietta Lacks' symposiums at Johns Hopkins in Baltimore.

Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to the Present*. New York: Anchor Books, 2006.

This book is the first complete history of black America's appalling abuse as experimental subjects for medical research. The book chronicles how for centuries African Americans have served as unknowing and unwilling research subjects. The book includes medical journals, reports, and interviews that reflect the scientific world's mistreatment of these people. I found the information in the book on the Tuskegee syphilis study and the section of Race, Technology and Medicine helpful in providing historical context for the Henrietta Lacks story. Washington's book helped to give me an understanding of the "bigger picture" involved in how Henrietta's race and socioeconomic background played a huge role in how she was treated and how the HeLa came to be used.

Welsome, Eileen. *The Plutonium Files: America's Secret Medical Experiments in the Cold War*. New York: Random House, 1999.

This book told the stories of the Manhattan Project in the 1940s and how human experimentation was conducted using radioactive plutonium. *The Plutonium Files* tracks the behind the scenes story of the massive cover up that took place for more than fifty years in our country. The author's writing style combining science with character's lives reminds me of Rebecca Skloot's *The Immortal Life of Henrietta Lacks*. This science writing helps me to understand the untold stories behind the research reports and medical journals.

ARTICLES

Acker, Amelia. "How Cells Became Records: Standardization and Infrastructure in Tissue Culture." *Archival Science*, September 2013.

This article follows the history of tissue cultures through its standardization as a technology, instrument and ubiquitous object of reference for scientists working with cells. It chronicles how human cells such as the HeLa are established as cell lines and become records. This introduced new terms to me that I had not read before such as "bio record."

Baker, Stacy. "Life After Death: An Activity to Investigate the Scientific, Legal, and Racial Issues of the Henrietta Lacks Story." *American Biology Teacher* 73, no. 6 (2011): 337-340, doi: <http://dx.doi.org/10.1525/abt.2011.73.6.6>.

This article and two part educational activities show how students examine cervical cancer cells and chromosomes from Henrietta Lacks. Following the science activity, the instructor leads the students in a debate over the bioethical and legal issues surrounding the usage of her cells. It shows how Henrietta's cells are used to teach key concepts such as mitosis, cancer research and rights and responsibility issues at the same time.

Ball, Madeline Price. "HeLa's Genome: Help Us Create Well-Consented Cell Lines," *Personal Genome Project Blog*. http://personalgenomes.files.wordpress.com/2013/03/hela_cells_stained_with_hoechst_33258.jpg.

This news and update about the Personal Genome Project (PCP) refers to the scientists in Europe sequencing the most famous cell line in science without the Lacks family's permission. Ball describes this problem as the elephant in the living room: cell lines collected from individuals before the modern era of whole genome sequencing. She states that specimens can no longer be treated as anonymous; they come from people especially with the advent of personal direct-to-consumer genotyping services that are now available. She points out that we must do much better in addressing the questions about the rights and responsibilities involved. The PCP does not have any government funding, and Ball is encouraging people to voluntarily donate their information to their project.

Baulig, Laurie T. "Are There Property Rights in Human Tissue? The Law "Lacks" Definitive Answers." *The Journal of Lancaster General Hospital* 5, no. 3 (Fall 2010).

Laurie Baulig is an attorney and Director of the Center for Liberal Arts and Society at the Franklin and Marshall College in Pennsylvania. She detailed information on the Common Rule, Health Insurance Portability Accountability Act (HIPAA), Genetic Information Nondiscrimination Act (GINA), and other regulations and protections. At first I was overwhelmed by all these different things, but as I learned more about them in my research from different articles it became easier to keep them all straight in my mind.

Beecher, Henry K. "Ethics and Clinical Research." *The New England Journal of Medicine* 274 (June 16, 1966): 367-373.

This special article was very interesting because it stated that human experimentation since World War II has created some difficult problems with the increasing use of patients as experimental subjects who are not truly aware of all the risks involved in their participation. Beecher's historic study gives specific examples of why this is such an urgent discussion. He cites examples with problems of consent, unethical studies and the need for the presence of an intelligent, informed conscientious, compassionate and responsible investigator. This article is key to my research, and I am impressed with his insight and courage in publishing this important work in 1966.

Brooks-Staub, Kelly. "Ward by Ward." *Johns Hopkins Nursing Magazine*. (November 9, 2011) <http://magazine.nursing.jhu.edu/2011/11/ward-by-ward/>.

In this article excerpts are taken from, "A History of Segregation and Desegregation at the Johns Hopkins Medical Institutions," by Louise Cavagnaro. It describes how the wards in the Johns Hopkins Research Hospital used to be segregated according to race. It wasn't until the 1950s that the desegregation of the wards began to take place.

Brown, Russell W. and Henderson, James, H.M. "The Mass Production and Distribution of HeLa Cells at Tuskegee Institute, 1953-55." *The Journal of the History of Medicine and Allied Sciences, Inc.*, 415-431.

This article describes the mass production of the HeLa cell line and the historical role it played in the evaluation of the field trial of the Salk vaccine against polio. I learned that the HeLa cell strain was selected as an alternative source host cells with specific doctors and researchers named as supervisors to the project.

Buchanan, Charles. "Immortal Balance Weighing Rights and Responsibilities in Medical Research." *UAB Magazine*. (November 2010) <http://www.edu/uabmagazine/2010/november/immortalbalance>.

This is an interesting article in which the author interviews specialists at the University of Alabama at Birmingham including philosophy professor Gregory Pence, Ph.D. Dr. Pence listed the key ethical issues with the Henrietta Lacks case as "confidentiality, informed consent, and the right to control the products of your body." Dr. Pence also observed, consistent with my research on Henrietta and the HeLa cell line that the kinds of protections for patients that have developed since did not exist for the protection of Henrietta in 1951.

Callaway, Ewen. "Deal Done Over HeLa Cell Line." *Nature*. (August 8, 2013): 132-133 doi: <http://dx.doi.org/10.1038/500132a>.

This online article tells of how Henrietta Lacks' family agrees to the release of genomic data. Details of the four months of meetings between NIH Director Francis S. Collins and the family to make up for decades of slights are detailed in the article. Henrietta's grandson David Lacks, Jr. is quoted as saying, "We wanted to get a better understanding of what information was going to be out there about Henrietta, and what information was going to be out there about us."

Callaway, Ewen. "Deal Reached With NIH Over Henrietta Lacks Cell Line." *Scientific American*. (August 7, 2013) <http://www.scientificamerican.com/article/deal-reached-with-nih-over-henrietta-lacks-cell-line/>.

This is another article that highlights the deal reached between the NIH and the Lacks family points out the wide audience of readers interested in this topic. It compares and contrasts the differences in research practices of 1951 that lacked consent to today's approach where consent receives so much focus. It also points out that the publication of genomic information will also be controlled.

Callaway, Ewen. "NIH Director Explains HeLa Agreement." *Nature*. (August 7, 2013) doi: 10.1038/nature.2013.13521.

The article explains how the Henrietta Lacks family will endorse controlled access to the cell line genome after they had collaboration meetings with the head of the National Institutes of Health, Dr. Francis Collins. It chronicled how the German researchers had released the HeLa genome without the family's knowledge. The NIH Director

discussed his meetings with the Lacks family with the *Nature* writer. The question and answer format of the interview provided insight into the talks and possible future implications of the talks.

Canguilhem, Georges and Savage, John. "The Living and Its Milieu." *Grey Room*, No. 3 (Spring, 2001 [1952]): 6-31, The MIT Press.

The notes from a lecture that Georges Canguilhem gave in 1952 were interesting to me because he referred to the situation of the living thing when the laboratory, biotechnology, and contemporary life science are its milieu. The story of Henrietta Lacks and the HeLa cell line is a perfect example of this combination. He gave his lecture one year before the discovery of DNA that would launch the HeLa into an entirely new realm of research and experimentation.

Clements, John D., Connell, Nancy, Dirks, Clarissa, El-Faham, Mohamed, Hay, Alastair, Heitman, Elizabeth, Stith, James A., Bond, Enriqueta C., Colwell, Rita R., Anestidou, Lida, Husbands, Jo L. and Laboy, Jay B. "Engaging Actively With Issues in the Responsible Conduct of Science: Lessons From International Efforts Are Relevant For Undergraduate Education in the United States." *CBE Life Science Education* 12(4) (2013 Winter): 596-603. doi: 10.1187/cbe.13-09-0184.

The authors are a team of professors from top universities and medical institutions that are united in expressing the importance of engaging actively in the responsible conduct of science. It highlighted training in responsible conduct of research and ethics, developing professionalism in science, conducting research responsibility, being part of a responsible scientific community, and making these discussions a top priority at all levels.

Coughlin, Andy. "German Lab Apologizes For Publishing the Genome of 'Immortal' Woman's Cell Line." *New Scientist*, April 1, 2013.

The article provided background on the HeLa story and how the German team was asked to remove their study from the Internet on the HeLa genome. It included quotes from Lacks family members expressing their disagreement with the information being published without their permission. It also included how the European Molecular Biology Laboratory (EMBL) officials apologized to the relatives and how they were in talks with them to attempt to resolve the situation.

Coughlin, Andy. "Storm Erupts Over Publishing of HeLa Genome." *New Scientist* 17:15 (March 28, 2013) <http://www.newscientist.com/article/dn23330-storm-erupts-overpublishing-of-hela-genome.html#.U3bgcfdV4k>.

The article details how one of the world's most prestigious laboratories was frantically trying to resolve a dispute over the decision to publish the genome of the HeLa cells. It tells how the research group first published their findings online with the journal *G3: Genes, Genomes and Genetics*. The scientists withdrew the article in the midst of many complaints and protests. The objectors felt that the information should not have been published without the consent of the Lacks family.

Collins, Francis, M.D., Ph.D. "The HeLa Genome: An Agreement of Privacy and Access." U.S. Department of Health and Human Services (August 7, 2013) <http://www.nih.gov/about/director/statement-hela-08072013.htm>.

This statement from the Director of the National Institute of Health describes the unique concerns posed by the HeLa genome data. Dr. Collins describes the

responsibilities of researchers seeking access to this valuable resource and the dangers to privacy presented because it is genetic information. He stressed how he wants to work with the Lacks family to develop a solution that allows researchers access while respecting the wishes of the family.

Collins, Francis, M.D., Ph.D. Hudson, Kathy L. “Biospecimen Policy: Family Matters.” *Nature* 500 (August 7, 2013): 141-142. doi:10.1038/500141a.

The Director of the NIH, Dr. Francis Collins and Dr. Kathy Hudson describe the recent agreement between the NIH and the Lacks family regarding the consent of future use of bio specimens, with the goal of strengthening the partnerships between researchers and research participants. It explains why they agreed to meet with the Lacks family to craft an agreement for access to the HeLa genome data. It highlights how patients are partners not subjects. It stresses the need for broad consent for the future use of specimens, and asks for the public to please comment on possible revisions to the current regulations.

Connelly, Tracey DePellegrin. “Access to HeLa Cell Genome Data Restored Following Agreement.” *Genetics Society of America*, August 7, 2013.

This article informed me that the article by Dr. Lars Steinmetz and his research team in Germany were able to repost their study on the Internet after they apologized to the Lacks family and the NIH officials formed the special committee including two Lacks family members that would approve and oversee all HeLa genome research from that point on in the United States.

Culliton, Barbara, J. “HeLa Cells: Contaminating Cultures Around the World.” *Science*, vol. 184, (June 7, 1974): 1059.

This article gave more details about the HeLa contamination of other cell lines. It also highlighted the work done between the United States and Russia during this time period. This contamination eventually led to an overhaul of the protocols and procedures applied to tissue sample storage and verification.

Columbia Journalism Review. “HeLa-cious Coverage.” (March 28, 2013) http://www.cjr.org/the_observatory/henrietta_lacks_hela_genome_pr.php?page=all.

The author examines how the media overlooked many angles of Henrietta Lacks story. It tracks the dark history of experimentation on African Americans, the birth of bioethics and the legal battles that continue today. The writers point out it is due to Rebecca Skloot’s book *The Immortal Life of Henrietta Lacks* that these questions of consent, right to privacy and cell/tissue ownership are now being raised and discussed across the country in newsrooms, classrooms and research centers.

DeMaria, Anthony N., M.D. “Problems With Immortality,” *Journal of the American College of Cardiology*, November 8, 2010; 56(25):2140-2142. doi: 10.1016/j.jacc.2010.11.008.

Dr. DeMaria points out that while the HeLa cells were cause for celebration with the many discoveries and medical advancements they helped to make, they have also raised a number of complicated issues in medicine, many which are still unresolved. He also points out that many of these issues are even of greater concern today because of stem cells and tissue regeneration.

Devine, Claire. “Tissue Rights and Ownership: Is a Cell Line A Research Tool or a Person?” *The Columbia Science and Technology Law Review*, March 9, 2010. <http://www.stlr.org/2010/03/tissue-rights-and-ownership-is-a-cell-line-a-research-tool-ora-person/>.

The article explores the tissue rights and ownership questions, consent and the fair distribution of profit. Raising questions such as “Do patients still own tissue cells once they have been removed from their bodies? Do doctors have the duty to ensure their patients understand that these cells may be cultured and preserved, and to share any profit from selling the cells?” It also profiled the personal side of the story and the legal complications.

Faden, Ruth. “Immortal Cells, Moral Issues.” *Baltimore Sun*. February 12, 2010.

The newspaper article is written by bioethicist Dr. Ruth Faden that reports on the case of Henrietta Lacks and the need for an ethical component to be included in health care reform. The writer points out the sharp contrast between the wealthy world of biomedical research and the socioeconomic background of the Lacks family. The writer points out the social inequalities in our society. It points out the complications and competing interests involved with biomedical research and medicine. I later learned when I was visiting Baltimore for the Lacks Symposium that Ruth Faden is the Director of the Bioethics School at Johns Hopkins. It was exciting to know that she is one of the authors I have also read in my research. Many of the symposium presenters encouraged me to consider their bioethics school for my college studies.

Fost, Norman. “A Cell’s Life.” *Issues in Science and Technology*, Volume 26: Issue 4, July 1, 2010.

This article helped me to understand the importance of Institutional Review Boards (IRBs) and other regulatory agencies. Fost stressed the importance of making the HeLa cell line a required read for all those involved in policies and practices in these areas. He also said we need to reexamine the current policies in place.

Gamble, VN. “*The Immortal Life of Henrietta Lacks* Reconsidered.” *Hastings Center Report*, January 2014, Vol. 44, Issue 1.

This review of Rebecca Skloot’s book, *The Immortal Life of Henrietta Lacks*, is not favorable. The author states that she is not a fan of the book because she feels “it views the history of African Americans in medicine and bioethics exclusively through the lens of exploitation, powerlessness and victimization.”

Gartler, S. “Apparent HeLa Cell Contamination of Human Heteroploid Cell Lines.” *Nature*, 1968: 217:750-1.

Gartler points out in the late 1960s the HeLa contamination in particular human heteroploid cell lines. He would go on to publish many more articles about the HeLa helping to inform scientists and researchers of this problem.

Gartler, S. “Genetic Markers As Tracers in Cell Culture.” *NCI Monograph 26*: Second Decennial Review Conference on Cell, Tissue and Organ Culture. NCI: 1967.

This article came up repeatedly in my research from many different authors referencing it. It explains the importance of the HeLa’s genetic information of Henrietta Lacks helping them to realize the other cell lines were contaminated when she surfaced in the genetic materials of the other lines.

Gelling, Cristy. “Five Reasons Henrietta Lacks Is the Most Important Woman in Medical History.” *Popular Science*, February 2010, Volume 276, Issue 2, page 81.

The five reasons given in the article to thank Henrietta Lacks were interesting and informative. It pointed out that, before HeLa cells, scientists were struggling to keep cells alive. The endless supply of the HeLa allowed scientists to spend more time on research and discovery. It was also used to test the polio vaccine that protected millions

of people. The HeLa also helped scientists to isolate one particular cell, multiply it and start a cell line according to the article. This led the way for in-vitro fertilization and cloning. It was also used in genetic research and to create anti-cancer drugs.

Gibson, Greg and Copenhaver, Gregory P. "Consent and Internet-Enabled Human Genomics." *PLOS Genetics, Peer-Reviewed, Open Access Journal*, June 2010.

This article helped me to understand the peer review process that involves people from the institution, the community and others who are required to apply standardized procedures to the oversight process. It also promoted consent and transparency in all partnerships between subjects, researchers and society. This article reminded me of the cartoon depicting research oversight that I obtained from Johns Hopkins Patient Advocate, Liz Martinez. [See, Appendix VIII to the paper.]

Gold, Michael, "The Cells That Would Not Die," *Science*, April 1981, 29-35.

Staff writer for *Science*, Michael Gold, describes how Henrietta Lacks' cells were stored in labs worldwide, and how they contaminated other cell lines. It described how Dr. Walter Nelson Rees was considered the Ralph Nader (advocate for the public) of tissue cultures by some and an opportunistic publicity hound by others.

Harris, Paul. "Final Twist to the Tale of Henrietta Lacks, the Woman Whose Cells Helped to Fight Against Cancer." *The Observer*, March 30, 2013, <http://www.theguardian.com>.

This is an excellent article that discusses the incident where Henrietta Lacks' genetic code was published by scientists on the Internet. It chronicles the reaction by the Lacks family and the media support they received in that response. The article conveys the outrage of the family and those supporting them. For example, the following excerpt captures that time well, "David Kroll, a science writer and board member of the Henrietta Lacks Foundation, was furious that Lacks and her family had again apparently fallen into a scientific ethics blind spot."

Hawkins, Alice K. O'Doherty, Kierna C. "Who Owns Your Poop? Insights Regarding the Intersection of Human Microbiome Research and the ELSI Aspects of Biobanking and Related Studies." *BMC Medical Genomics*, October 7, 2011, doi: 10.1186/1755-8794-4-72.

The article describes the social, ethical and legal implications of biobanking and largescale data sharing that are already complicated enough, and how they may be further compounded by research on human microbiome. This article was fascinating and inspired me to seek out a biobank that I could visit to learn more about this aspect of my topic and the rights and responsibilities involved. Before this History Day project, I had never heard of a biobank before. I was fortunate to get the opportunity to visit the National Institute of Child Health and Human Development, Brain and Tissue Bank for Developmental Disorders, located at the University of Maryland, School of Medicine - Department of Pediatrics in Baltimore, Maryland. (See, Appendix IX.)

Health, Science and Technology. "Family of Henrietta Lacks Will Have Say in How Her Genetic Materials Is Used." August 8, 2013, <https://hub.jhu.edu/2013/08/08/henrietalacks-hela-cells-agreement>.

Cells collected from Henrietta Lacks will now be controlled by the Lacks family in terms of which scientists will be given access to Lacks' genetic blueprint. The article points out how Rebecca Skloot's book helped the family receive national attention regarding the story of their mother's cells.

Hepworth, Jeri, Ph.D. "Advocacy for Henrietta Lacks and for Family Medicine." *Family Medicine*, Vol. 43, No.8, September 2011.

This article in the President's column highlights the HeLa story from the perspective of the general practice of family medicine. It points out the public's fascination with the merging of science and human life. It shows how the human condition and science are intertwined on a daily basis in family medicine. It discusses the complex richness of life biographies, exciting advances in science, and unending ethical decisions that are at the always the backdrop of each and every interaction between patients, doctors, researchers and the public.

Holliday, Deborah Speirs, Valerie. "Choosing the Right Cell Line For Breast Cancer Research." *Breast Cancer Research*, August 2011, 13:215 doi: 10.1186/bcr2889.

This was a complicated article to read with many medical terms I did not understand. It gave me a sense of how the researchers use the HeLa in breast cancer research, but it also made me realize how much I do not know about medical terminology. I began to get a feeling for how Henrietta's daughter, Deborah, must have felt when she was traveling around the country to medical centers, with author and researcher Rebecca Skloot, learning about the HeLa cell line. I enjoyed learning how she carried a medical dictionary with her to help her understand the terms and information she was given by the doctors and researchers about her mother.

Hudson, Kathy, Ph.D. "A New Chapter for the Lacks Family." Deputy Director for Science, Outreach, and Policy at the National Institute of Health, <http://acd.od.nih.gov/agendas/ANew-Chapter-for-the-Lacks-Family.pdf>.

This informed me about the Lacks' family background with amazing visuals and statistics. It was shocking to learn that a Google search for "HeLa cell" generates 2.5 million results with more than 74,000 publications citing HeLa cells. It also pointed out that within the last ten years; the majority of Nobel Prizes in medicine have used HeLa cells. I thought it was also interesting that our young student scientists have also used the HeLa to win science competitions. I was thinking next year for Science Fair I will do something on the HeLa as well. I was honored to participate in an email interview with Dr. Hudson. Her PowerPoint presentation slides helped me prepare to ask her specific, in depth questions about rights and responsibilities.

Hudson, Kathy L., Collins, Francis. "Biospecimen Policy: Family Matters." *Nature* 500, August 2013.

The National Institute of Health (NIH) officials met with the Lacks family members to create an agreement to restrict the use of the HeLa cell line for federally funded research. This article emphasizes how patients are partners not subjects and should be respected as such. It helped me to understand issues such as broad consent that means a patient providing researchers the right to use their samples or information for future use that has not yet been defined. This article reminded me of a quote by Dr. Civin, Director of the University of Maryland's Stem Cell Research Center. He told me that, "It is difficult to regulate how tissues will be used in the future because we don't know what advancements in science will be made in the future."

Ikemoto, Lisa C. "The Racialization of Genomic Knowledge." 27 *Seton Hall Law Review*, 937, 1997.

This article details the Human Genome Project. It describes how the Human Genome Project is huge made up of an estimated 100,000 to 300,000 genes that are being

used together to make approximately three billion base pairs. The US government's plan to spend \$200 million per year for fifteen years to map the genome. The author questions what is it we are seeking to gain from this information? She examines the goals, expected results and the plans on how they will be used once they are gathered. Since some refer to the Human Genome Project as one of the greatest adventures ever undertaken in our time it is important we examine the questions surrounding it. Ms. Ikemoto's informative article prepared me for a later personal interview with Dr. Laura Rodriguez, an NIH official from the Human Genome Project with whom I spoke while visiting Washington, D.C. for my research.

Josefson, Deborah. "Human Tissues For Sale; What Are The Costs?" *Western Journal of Medicine*, November 2000; 173(5) 302-303.

The need for centralized, data-linked tissue banks and surplus tumor tissue is routinely thrown away anyway; however, this practice does create a variety of ethical, legal and financial issues. The issues of privacy, commodification of body parts and whether there is any monetary or moral obligation to pay back the donor of the tissue for contributing the biomaterial for medical research and advancement. The article pointed out that according to the American Association of Tissue Banks, tissue donation has increased by 172% in the past five years.

Jones, Howard W., Jr., Harper, Peter S., and Wu, Kuang Dong. "George Otto Gey (1899-1970): After Office Hours; The HeLa Cell and a Reappraisal of Its Origin." *Obstetrics and Gynecology*, 38.6, (1971): 945-49. Web. 16 March 2014.

This short article about the HeLa was a memorial tribute to George Gey. The authors were taking another look at the origin of the famous HeLa cell. One of the authors, Dr. Howard W. Jones, is one of the first doctors to see Henrietta Lacks when she came to Johns Hopkins. It was amazing to read details of her tumor and how the doctors thought of it as a research opportunity.

Jones, Howard W., M.D. "Record of the First Physician to See Henrietta Lacks at the Johns Hopkins Hospital: History of the Beginning of the HeLa Cell Line." *American Journal of Obstetrics and Gynecology* 176 (1997): S227-8.

In this journal article, Dr. Howard Jones, the first gynecologist to see Henrietta, explains his education and his relation to Hopkins as well as the work he was then doing for victims of cervical cancer. He gives a first-hand account of the very first examination he performed on Henrietta Lacks: "Her general examination was completely negative. Inspection of the cervix, however, revealed a lesion about as big as a 25-cent piece at the 4 o'clock position." He also included background information about Dr. Richard TeLinde, M.D., and the disagreement on invasive and noninvasive carcinomas that doctors were facing when Henrietta walked into Johns Hopkins for the first time. This source helped me to better understand why Henrietta's samples were taken in the first place, and why the doctors at Hopkins were so interested in carcinomas at the time.

Kabacoff, Cathryn, Srivastava, Vasudha, and Robinson, Douglas. "A Summer Academic Research Experience for Disadvantaged Youth." *The American Society For Cell Biology*, Fall 2013.

The internships provided by Johns Hopkins connected high school students to the sciences in meaningful ways. The Summer Academic Research Experience (SARE) program provides enrichment for underrepresented youth. The partnership is between the local schools and the Johns Hopkins Nanotechnology Center where they also learn about

the HeLa cell line. I was fortunate to be able to attend a Henrietta Lacks Symposium in March 2014 with Baltimore High School students similar to this program.

Karp, Laurence E. "The Immortality of a Cancer Victim Dead Since 1951." *Smithsonian Magazine*, May 1976, 51-56.

I found a copy of this article in the George O. Gey collection at the Alan Mason Chesney Medical Archives, the archives associated with Johns Hopkins Hospital. The article itself is interesting, but the fact that a copy of it is in the collection regarding Dr. Gey is more interesting to me because it was written around the time that Henrietta Lacks, not "Helen Lane" or "Helen Larson" was identified as the source of the HeLa cell. Even though it makes note of the misidentification of Henrietta, I am surprised that most of the article is a discussion of the good work of Dr. Gey and uses of the HeLa cell. There is no discussion of the rights of Henrietta Lacks, and no mention of her family.

Keiger, Dale. "Immortal Cells, Enduring Issues." *Johns Hopkins Magazine*, June 2, 2010.

Keiger's article was interesting because it was published in the Johns Hopkins Magazine from the institution that Henrietta visited for treatment. It addresses the deep mistrust that is felt in some situations between the public and medical researchers. It pointed out the complexities of these issues and ongoing discussion. I thought of how the Lacks family is now working with Johns Hopkins to educate the public about important bioethical issues to help increase the level of trust between researchers and the public in Baltimore.

Kelly, Jacques. "Her Cells Made Her Immortal Research: A Turners Station Woman Donated Cells That Revolutionized Medical Science." *Baltimore Sun*, March 18, 1997.

This article also chronicled the Henrietta Lacks story. It provided interesting quotes by her daughter Deborah Lacks stating, "Our family was kept completely in the dark." The article also had insightful quotes from officials at John Hopkins Hospital stating that Henrietta made a remarkable contribution to medical advancements of our time. It also contained quotes from her husband that were interesting telling more about their private lives such as when they moved to a new house in Baltimore, and how Mr. Lacks had earned 85 cents per hour when he worked for a local steel company.

Knoppers, Bartha Maria. "Consent to 'Personal' Genomics and Privacy." *EMBO Reports*, May 7, 2010.

The Director of the Centre of Genomics and Policy from McGill University, Montreal, Quebec, Canada provided information on the importance of consent and privacy. The bibliography from this article was very helpful because it gave me many additional sources from other countries. It helped me to understand that these are international issues that concern people from all over the world.

La Guardia Community College. "Science, Medical Research, Experimentation and Litigation." February 2013.

This is an article that supplements Rebecca Skloot's book, *The Immortal Life of Henrietta Lacks*. It provides additional resources and legal cases that go with each chapter's events. It was helpful in providing additional articles to review for my research. I also began to see all the legal cases and details behind each chapter. Each bibliography led to another bibliography that helped me to continue my research with books, articles and other possible people to interview.

Lacey, Brendan P., M.D., Nelson-Rees, Walter A., Ph.D, Hutchins, Grover M., M.D. "Henrietta Lacks, HeLa Cells, and Cell Culture Contamination." *MD Archives of Pathology and Laboratory Medicine*, Volume 133, September 2009.

This source helped me to understand the cell culture contamination that took place with the HeLa cell line. This medical information was very technical and challenging to read, but it helped me better understand the nature of Henrietta's cervical cancer.

Landecker, Hannah. "Culturing Cells: How Cells Became Technologies." *Isis*, Volume 102, No. 1, March 2011, p. 149-150.

The article chronicles how cells in the 1960s had become tools with wide accessibility, availability and manipulability. Cells have evolved over time into technologies to be used in science for vaccines such as with Salk and others turning it into large-scale production centers. Now with the cell's plasticity it is suggested that cells are becoming as technologies of living substances. This article helps to show the complications of the rights and responsibilities as we continue to move forward with scientific advancements and research. This article led me to her award winning book entitled *Culturing Life How Cells Become Technologies*.

Landry, Jonathan. "Genes and Cells: Famed Cancer's DNA Sorted Out: Analysis Sheds Light on Virulence of HeLa Cell line." *Science News*, September 7, 2013, Vol. 184 Issue 5, p.8, doi: 10.1002/scin.5591840504.

The article provides more information about how researchers found the gene is activated in chromosomes upon contact with human papillomavirus DNA, leading scientists to conclude that it might be the reason for the extreme cancer virulence in HeLa cells. It also raises concerns about the rights and responsibilities involved in the story because Henrietta Lacks was not asked for her consent.

Landry, J.M. "Editorial: HeLa Cell Sequela." *G3-Genes-Genomes-Genetics* (Bethesda), June 2013; 3(6): 927. Published online June 1, 2013, doi: 10.1534/g3.113.006304.

This article published on the National Institute of Health website stresses how free and informed consent of participants in research studies, in the cornerstone to all biomedical research. It describes how the editors of G3: Genes/Genomes/Genetics – a peer-reviewed, peeredited, open-access journal of the Genetics Society of America – published early online an article in which the authors described the genome sequence of the HeLa cell line that promises to increase its utility and reveal its limitations for research. It describes how soon after the release of that article, the authors withdrew access to the sequence data in response to the Lacks' family and Rebecca Skloot's concern about genetic privacy. It tells of the importance of having thoughtful conversation on the issues raised by this case, with the goal of developing common standards for the acquisition and distribution of personal genomic information. It tells of the desire to engage the entire community in seeking solutions because everyone – scientists, clinicians, ethicists, and the public—has a stake in the outcome.

Landry, Jonathan, Pyl, Paul Thoeodore, Rausch, Tobias, Zechner, Thomas, Tikkedil, Manu M., Stutz, Adrian, Jauch, Anna, Aijar, Raeka S., Pau, Gregoire, Delhomme, Nicolas, Gagneur, Julien, Korbel, Jan O., Huber, Wolfgang, and Steinmetz, Lars M. "The Genomic and Transcriptomic Landscape of a HeLa Cell Line." August 1, 2013. Volume 3, No. 8, page 1213-1224.

The article explains how the HeLa cell line is the most widely used cell line for studying human and molecular biology. The article gave complex scientific information about how scientists began using different techniques to analyze genetic information the

HeLa. These techniques gave the scientists a broader view of the genomic landscape of the analyzed cell line.

Lohdahl, Michael Mohammed, Khaleel and Tsomo, Karma Lekshe. "Is Henrietta Lacks Immortal?" *The Center for Ethics in Science and Technology*, (April 4, 2012) <http://www.ethicscenter.net/files/u576/lacks.immortal.pdf>.

Three men from three different religions, Islam, Buddhism, and Christianity, fielded questions about HeLa cells and the religious side of the story. Each man had different ideas embedded in their religious beliefs and tried to explain to a live audience why they were correct in their beliefs. Although the panelists each had different beliefs, they all agreed that the main problem in the Henrietta Lacks story was how Henrietta and her family's rights were not upheld when they did not get to decide what happened to Henrietta's tissues once they were removed from her body.

Mandal, Jharma, Halder, Ajay, and Parija, Subhash Chandra. "Ethics and Clinical Research." *Tropical Parasitology*, July 2011, Volume 1, Issue 2.

The article maps out ethical principles involved in conducting research on human subjects with reverence for life needing to be the foundation for all ethics. It provided explanations of key ethical terms such as non-maleficence when one should do good and avoid doing harm. It was helpful because it also discussed the rights and responsibilities of the NIH and WHO including their responsibilities of funding and monitoring research. This is a very timely issue with the recent collaborations between the NIH Director and the Lacks family.

Manfuso, Jamie and Desmon, Stephanie. "WEB EXTRA: Honoring the Henrietta Lacks Legacy at Hopkins." *Hopkins Medicine magazine*, May 20, 2011 (http://www.hopkinsmedicine.org/news/publications/Hopkins_medicine_magazine/hopkins_medicine_magazine_spring_summer_2011/web_extra_honoring_the_henrietta_lacks_legacy_at_hopkins).

This was an interesting article highlighting many of the events that have taken place at Johns Hopkins since 1951 when Henrietta Lacks' cells were taken for research. It pointed out the irony of Johns Hopkins spending approximately \$100,000 annually to purchase HeLa cells for its own research use. It also reported on the differences involving consent today. It concluded with highlighting the new era and new questions that are raised today. It discussed the concerns over legal and moral obligations to compensate a person if something of eventual commercial value comes from their cells or genes. It also pointed out the biotech revolution, with thousands of new patents being filed. Dr. Ford pointed out in the article that none of these issues were raised in 1951, and that important discoveries, such as the HeLa cells, were offered freely to the scientific and medical world to advance science and to improve and save lives.

Masters, J.R. "HeLa Cells 50 Years On: The Good, the Bad and the Ugly." *Nature*, April 2002, 2.

This article details the history, the research and the future implications of the HeLa cells. It provides a description of the cell sample and how the research fellow George Gey took her sample back to his lab for further investigation. It also highlights the historical context of the case. It then follows up with how the HeLa cell has been perceived as a positive breakthrough, even possibly as a cure for cancer. It states how her cell lines have been used extensively in medical research. The article concludes with pointing out the pitfalls and consequences of the HeLa cells.

McKie, Robin. "Henrietta Lacks' Cells Were Priceless, But Her Family Can't Afford a Hospital." *The Guardian*, April 3, 2010.

The article points out how the tissues taken from cancer victim Henrietta Lacks in 1951 have accumulated enormous profits for private and commercial companies, but today her surviving family members can't pay for health insurance. It has strong data about the many people who have benefitted from the HeLa cells. It has an excellent quote from her son, "If our own mother is so important to science why can't we get health insurance?" It was helpful to hear directly from her descendants about the injustices and inequalities they have experienced all of these years.

McLaughlin, Tom. "An Epitaph At Last." *South Boston News and Record* (Boston) 31 May 2010:1.

McLaughlin describes how Henrietta Lacks' gravesite has a grave marker because of a generous donor who was a colleague of Dr. Otto Gey. It seems fitting that this amazing woman would be recognized and memorialized by a medical professional for all of the contributions she has made to science and research.

McManus, Rich. "NIH Restricts Access to Henrietta Lacks' Genomic Data: Respect For Privacy." *NIH Record*, August 30, 2013, http://nihrecord.od.nih.gov/newsletters/2013/08_30_2013/story2.htm.

The document produced for the National Institute of Health (NIH) publication, *NIH Record* tells about how the Lacks' gift to science was exploited without either her consent or that of her surviving family members. It details how NIH Director Dr. Francis Collins and Dr. Kathy Hudson were able to persuade the authors of the scientific study to remove the sequence from an open-access database. They asked for time to create a plan to honor the Lacks' family privacy and allow the scientific community to move forward with medical and research studies of the first-even human cell line.

Minneapolis Star. "U-Polio Detection Methods to Aid in Prevention Plans." November 2, 1953.

This newspaper article is one where Henrietta Lacks is identified as the source of the HeLa cell line. Before this, because of the way Dr. George Gey identified the sample taken, HeLa was associated with "Helen Lane." Interestingly, even though Henrietta Lacks was identified in 1953, it is interesting that even as late as the 1970s the HeLa was still identified in publications as originating from "Helen Lane."

The Milwaukee Journal. "Cell Contamination Perils Research." September 5, 1974, <http://news.google.com/newspapers?nid=1499&dat=19740905&id=bB8qAAAAIBAJ&s-jid=ASkEAAAIBAJ&pg=7136,2667946>.

This article details the HeLa cell line contamination of other cell lines in research labs. It was interesting to learn how hardy the HeLa cells are and how they can easily contaminate other cell samples. I later learned that many people thought of Henrietta Lacks as a strong woman who also could persevere despite so many difficult conditions in her life. It was interesting to think about Henrietta and the HeLa cell line as both a person and a scientific marvel.

Nardone, Roland M., "Eradication of Cross-Contaminated Cell Lines: A Call For Action." *Cell Biology and Toxicology*, November 2007, Volume 23, Issue 6, pp 367-372.

This white paper was prepared by Nardone in an attempt to shoot up a flare regarding the long term problem of the misuse of misidentified and cross-contaminated cell cultures

in biomedical research. He called for a bold response to bring about a profession-wide change in practice that he hoped would prevent further erosion of the cultures being utilized. His article made me realize how difficult this process must have been and how many scientists' careers and investments into research were being brought into question. Nardone was brave to publish his concerns and to push for scientists to act responsibly in dealing with this pervasive, complicated scientific and ethical problem.

Naomi, Rogers. "Race and the Politics of Polio." *American Journal Public Health*, May 2007, 97 2007 May; 97(5): 784–795 doi: 10.2105/AJPH.2006.095406.

The article highlights the Tuskegee Institute's opening of a polio center in 1941 funded by the March of Dimes. The center was opened with this funding in response to the embarrassment of President Roosevelt having a "Whites only" polio center at the time. This type of admission policy showed the nature of race-segregated health facilities of that time. The article stated that after 10 years of civil rights activism a more integrated approach was taken with health care being provided regardless of race, color or creed.

The Nation. "Whose Body Is It Anyway?" June 25, 2012.

This article examines the question of who owns our bodies? It refers to different cases that have brought this question into the forefront. It also discusses how research and development involved in genetic research and testing may be customized to tell about a person's genetic lifestyle, family history and commercial exploitation. The author feels that part of the profits made from medical discoveries should be channeled back into nonprofits to help people receive low cost treatment at least for the people who volunteered to be subjects for the research.

Nelson-Rees, W. "Responsibility For Truth in Research." *Phil. Trans. R. Soc. Lond. B* 29 June 2001 vol. 356 no. 1410, pp. 849-851.

Nelson-Rees refers to how for over half a century, cell cultures derived from humans and animals have aided scientists across all fields of study. He highlights how cross contamination of cell line cultures have plagued research for researchers for years, often leading to attempted cover-ups and falsification of data and results because of the incorrect use of cells. He stresses the importance of being responsible and promoting truth in research.

New Scientist. "Cell Disputes Settled." August 10, 2013.

This article highlights how the HeLa cell, one of the most commonly used cell lines in history and taken from Henrietta Lacks without permission, would now be handled differently. It reported how the new committee was formed with some of the Lacks family members on it to provide permission for researchers wanting to use the HeLa genome.

Nisbet, Matthew Fahy, Declan. "Bioethics in Popular Science: Evaluating the Media Impact of The Immortal Life of Henrietta Lacks on the Biobank Debate." *BMC Medical Ethics*, February 28, 2013.

This is a fantastic article that provided invaluable data on the biomedical industry. I was amazed to learn that more than \$1 billion has been spent on the establishment of biobanks worldwide. This article also quoted some of the top bioethicists in the world leading me to other useful research. The study had hard data on the number of public discussions and debates that have resulted about the rights and responsibilities involved with the HeLa because of Rebecca Skloot's book, *The Immortal Life of Henrietta Lacks*.

The Observer. "Henrietta Lacks' Cells Were Priceless, But Her Family Can't Afford A Hospital." Sunday, April 3, 2010.

The article discusses how the tissue taken from Henrietta Lacks in 1951 has made huge profits for drug companies, but today her descendants are unable to afford basic health care coverage. The article points out the social inequities of different racial groups of people. It also pointed out how many people have benefitted from the cells, but how her family struggles for access to quality medical care. Her son is quoted as saying, "If our mother is so important to science why can't we get health insurance?" This question was raised repeatedly in the research.

Ohio Northern University Consumer Health Complete. "Henrietta Lacks' Descendants To Speak at ONU." January 20, 2014.

This article highlights how every incoming freshman at Ohio Northern University is required to read *The Immortal Life of Henrietta Lacks* by Rebecca Skloot, and how the university will bring Skloot and two of the family's members to present their thoughts to the student body. This article reflects how many universities are incorporating the book into their course of study across different disciplines because of its relevance that delves into so many different issues from bioethics, history, science and research.

Psychiatry. "Science Calls Her HeLa." Summer 2012, 75.

This is a fascinating article that tells about the huge gap between the medical world benefitting from her cells to her family not knowing anything about the cells, research or advancements. It highlights the trillions of HeLa alive today in scientific labs across the country.

Pressman, Barbara. "Two Wrongs Don't Make A Right, But 40,000 Do: How Henrietta Lacks' Stolen Genes Painted SCOTUS Into A Jurisprudence Corner." December 2011, http://www.academia.edu/3172009/Two_Wrongs_Dont_Make_a_Right_but_40_000_Do-How_Henrietta_Lacks_Stolen_Genes_Painted_SCOTUS_into_a_Jurisprudence_Corner.

Barbara Pressman outlined the ethical considerations of the HeLa cell line in her article with different examples of patents that have been established using the HeLa cell line that have been overturned. In 2010, there was a case that called into question all 40,000 patents issued on which the entire biomedical and agricultural industries are based. She stated that all researchers all over the world had to investigate their motives and methods and that it was an intense questioning period for all involved.

Pattillo, Roland, A. "Morehouse School of Medicine First Annual Women's Health Conference: The HeLa Cancer Control Symposium." *American Journal of Obstetrics and Gynecology*, June 1997, pp. 2258-2268.

The first annual Henrietta Lacks Symposium held at the Martin Luther King, Jr. Chapel was described along with a list of keynote speakers and symposium articles published. I read over the articles and descriptions of the event and thought of the Henrietta Lacks Symposium that I was fortunate enough to attend at the Johns Hopkins Turner Auditorium along with many Baltimore High School students in March 2014. The recent symposium featured Lacks family members (Veronica Spencer and David Lacks, Jr.) along with other bioethicists, medical researchers and historians. I plan on attending the symposiums annually to continue adding to my knowledge of this fascinating topic and to visit the Lacks family members and other Johns Hopkins officials I have interviewed.

Randal, Judith. "Cancer Patient's Tumor Cells May Invalidate Past Research." *The Day*, June 12, 1974, <http://news.google.com/newspapers?nid=1915&dat=19740612&id=X-0gAAAAIBAJ&sjid=EHIFAAAAIBAJ&pg=1650,2083523>.

This article talked about the HeLa cell line contaminating other cell samples in research labs. It also stated that this contamination process may invalidate past research that had been conducted using these contaminated cells. This must have been a major concern for researchers everywhere that had used the HeLa for their work.

Ritter, Malcolm. "The Big Story: Feds, Family Reach Deal on Use of DNA Information." *Associated Press*, New York. August 7, 2013.

The article included information on the meetings between the National Institute of Health officials, the Lacks family and Rebecca Skloot. It details the HeLa cells support in launching a broad spectrum of medical advancements and helping to lay the foundation for the multi-billion dollar biotech industry today. The federal government announced the agreement, and it states that the Lacks family would have a say in how such research now proceeds. Photos of Henrietta Lacks were also included that were provided by her family via the Henrietta Lacks Foundation.

Ritter, Malcolm. "Henrietta Lacks' Family, Feds Reach Settlement of Use of DNA Information." *Huffington Post*, August 7, 2013.

This article gave additional information about opinions different bioethicists had on the NIH, Lacks' family agreement last August. The article pointed out that the Lacks' family situation is unique and that they do not expect this kind of agreement to be repeated in other cases. The author did feel that it will promote the idea of controlling access to genome information, or at least obtaining explicit and informed consent from donor before putting such information in publicly accessible databases.

Rivard, Laura. "HeLa: Immortal Cells, Enduring Questions." *The Center for Ethics in Science and Technology*, (September 7, 2011) <http://www.ethicscenter.net/files/u573/lacks.rivard.pdf>.

In this article, HeLa expert Laura Rivard explains how policies regarding donor privacy have changed since the 1950s, and talks about how when Dr. Gey first discovered the HeLa, he was so excited he just shipped them off to anyone who wanted to use them. Today, new restrictions and policies like the Federal Policy for Protection of Human Subjects and "The Common Rule" protect donors and their rights. Rivard stated that this incident with the HeLa "shows us that science matters, and, perhaps more importantly, that *how* we do science matters."

Rivard, Laura and Hing, Margaret Ng Thow. "Immortal Cells: Complicated Rights and Responsibilities." *Voice of San Diego*, September 9, 2011.

This article brings an interesting perspective to the discussion coming from San Diego, a center for biomedicine. It delves into the existing rights and responsibilities that protect people participating in medical research. It points out that there is also protection of patient privacy but the existing laws do not cover what happens to tissue once it has been removed from the human body.

Rogers, Michael. "The Double-Edged Helix." *The Rolling Stone Magazine*, March 25, 1976.

This well researched article deftly describes the complicated arena of biomedical research that the immortal cells of Henrietta Lacks entered into that created questions and raised ethical issues. It was a detailed description of the taking of the cells, the family's

thoughts about it and the medical researchers involved. It also told how Henrietta was Catholic. I thought about her and how she loved the statue of Jesus Christ that still stands in the lobby of the Johns Hopkins Hospital. I love that statue, too, and I have a picture of it on my cell phone now as a screen saver to remind of Him and Henrietta who have both suffered so much to benefit so many.

Rogers, Michael. "The HeLa Strain: Why a Line of Cells From a Woman Long Dead Is Sending Tremors Through the World of Bio-Medical Research." *Detroit Free Press*, March 20, 1976.

This article describes the Henrietta Lacks story and how her HeLa cell line has contaminated many other cell lines. Within the article there is a conversation between the journalist and Dr. Walter Nelson-Rees that told of how the doctor helped the news reporter trace the cells back to Henrietta Lacks and not the fictitious name of Helen Lane. It was interesting to read the quotes in the article given by Henrietta's son Lawrence Lacks and then to think of the things he told me directly in our personal interviews.

Scherer, William F., Syverton, Jerome T., and Gey, George O. "Studies on the Propagation In Vitro of Poliomyelitis Viruses." *Journal of Experimental Medicine* September 30, 1952: 695-708. Web 02 March 2014.

This was an interesting article because it introduced me to some challenging medical terminology that described how the doctors and researchers used the HeLa to study different viruses. The article came to life for me when I visited Dr. Gey's lab at Johns Hopkins in March 2014. As I stood in the lab I could imagine him working with his colleagues doing research using Henrietta's cell line.

Science. "HeLa Genome Withdrawn." March 29, 2013. Vol. 339, Issue 6127, p. 1504.

The writers report that the European Molecular Biology Laboratory (EMBL) had withdrawn the genome sequence of the HeLa cancer cell line taken from Henrietta Lacks without her consent. I was later able to conduct a phone interview with the scientist who published this report, Lars Steinmetz, from Germany. I was able to question him about the rights and responsibilities he feels are involved with this story and his work as a geneticist and researcher at Stanford University and internationally at his lab in Heidelberg, Germany.

Serrano, A.R. "Pieces of Me: The Immoral and Unjust Appropriation of Genetic Information of Genetic Materials." *Michigan State University Journal of Medicine and Law*. Fall 2011.

This article highlights the history of turning blood into tissue and tissue into property. It includes the immortal, famous and exploited life of Henrietta Lacks. It raises the concern of old laws and new issues. It includes discussions on informed consent, the fight to keep control over genetic materials, and my body, my property issues. It points out how these are all social issues in need of attention as well as medical issues and research.

Silver, Lee. "Scientists Push the Boundaries of Human Life." *Newsweek*, June 3, 2007.

This *Newsweek* article was interesting because it told about engineers, computer scientists, physicists, chemists and others who are working on innovations and inventions using genetic materials. Some of the work includes converting sunlight into biofuel or creating antimalarial drugs. Others are working to create synthetic life. NIH Director Francis Collins is called a bitter opponent of some of the scientists profiled in the article for their approach to the genetic research. James Watson, the co-discoverer of DNA structure is quoted saying, "If we don't play God, they who will?" This is a controversial

statement that has drawn much criticism from religious leaders and believers in God. This article helped to remind me of the significant role that faith and religion plays in the discussion of rights and responsibilities of these issues.

Skloot, Rebecca. "Cells That Save Lives Are a Mother's Legacy." *New York Times*, November 17, 2001, <http://www.nytimes.com/2001/11/17/arts/17HELA.html?pagewanted=1>.

Skloot tracks the HeLa cell line story while telling how some bioethicists and lawyers want legislation requiring researchers to obtain consent before conducting research on any tissues, including those already in storage. But it also highlights how many research organizations--the American Society for Investigative Pathology, for example, and the College of American Pathologists--have argued that such blanket legislation could seriously damage scientific progress.

Skloot, Rebecca. "Henrietta's Dance." *Johns Hopkins Magazine*, April 2000, <http://www.jhu.edu/jhumag/0400web/01.html>.

This article chronicles the HeLa story citing to excellent sources including Lacks family members and medical staff. It also incorporates Ruth Faden, Executive Director of the Johns Hopkins Bioethics Institute. It was interesting to me that this article written by Rebecca Skloot was published almost ten years before the publication of her major work, *The Immortal Life of Henrietta Lacks*. I look back on my project now amazed at all the places I was able to visit and people that I interviewed about this topic. I am grateful to have had this experience that has changed my life forever.

Smedley, B.D. "The Lived Experience of Race and Its Health Consequences." *American Journal of Public Health*, May 2012, Volume 102, No. 5.

This article highlights the science of research on racial/ethnic discrimination and health. It shows how there is a growing body of research that shines light on the studies that have been done that reflect racism and discrimination of people of color. It shows how the studies need to include consideration of race, gender, socioeconomic status and geography of the subjects being researched. I began to see how all my research showed different aspects of these issues such as Harriet Washington's *Medical Apartheid* and *Deadly Monopolies*.

Svalastog, Anna Lydia Martinelli, Lucia. "Representing Life As Opposed to Being: the Bio-Objectification Process of the HeLa Cells and Its Relation To Personalized Medicine." *Croatian Medical Journal*, August 2013, 397-402.

The authors describe how we have moved from the HeLa "cells" to the HeLa "bioobject" over time. They detail the process of how they started as a biological phenomenon, research object, and commercial product, and how this shift is a part of a more complex interaction between biology, science, technology, and society. It described the new paradigm of science that will intertwine life sciences, social sciences, and humanities contribute to the human well-being.

Szego, Michael J. and Burchanan, Anet A., Scherer, Stephen. "Building Trust in the 21st Century Genomics." *G3, Genes, Genomes, Genetics*, doi: 10.1534/g3.113.007690 G3 August 1, 2013 vol. 3 no. 8 1209-1211.

The authors describe how science has gotten ahead of our rights, and how with data release the data sharing has yielded unanticipated findings that we hadn't planned for in the past. It describes how in the past research ethics guidelines were originally meant to protect research subjects from bodily harm rather than informational harm. It

also explains how complex these issues have become since bio samples are shipped internationally creating a prolific spreading of the HeLa cells with varied jurisdictions, protocols, oversight committees, and outcomes. We now find ourselves grappling with the attempt to make recommendations but we have no power to create world mandates.

Truog, Robert D. "Paying Patients for Their Tissue: The Legacy of Henrietta Lacks." *Science*, July 6, 2012: Vol. 337 no. 6090 pp. 37-38 doi: 10.1126/science.1216888.

The authors examine that ethical issues linked to the financial compensation of medical tissue donors from profits generated by the research. They stress that researchers much keep in mind the factors of consent, the effort or burden connected to tissue donation, and the rights to future revenue generated.

Tschopp, Jurg. "An Immortal Contribution." *Baltimore Sun*, August 8, 2013.

The article states that the Lacks family needs to be formally recognized and acknowledged for Henrietta's contribution to medical advancement throughout the world. The report details how the National Institute of Health is formally recognizing Henrietta Lacks and her family for their contributions.

"Turner's Station African American Survey District 1900-1950." *African American Historic Survey Districts*, March 2014, http://resources.baltimorecountymd.gov/Documents/Planning/historic/survey_districts/turners_station.pdf.

This was an interesting survey to review about the region Henrietta Lacks' family resided. When I visit Baltimore again with my family I am going to visit Turner Station to see it. We were so busy at the Johns Hopkins Henrietta Lacks' Symposium and visiting their archives we did not have time to go to Turner Station when we visited in March of 2014 and again in April 2014.

Ursano, Robert J. "Science calls Her HeLa." *Psychiatry: Interpersonal & Biological Processes* 2012 Summer; 75(2):101-2. doi: 10.1521/psyc.2012.75.2.101.

This article was interesting because it gives descriptions of Dr. Howard Jones, Henrietta's treating doctor at Johns Hopkins. The article gave excellent statistics on the number of cells produced since discovery and the number of patents associated with HeLa. The article also gave some interesting perspectives from the Lacks family.

Vergano, Dan. "Henrietta Lacks' Family Reaches Privacy Agreement With Scientists." *USA Today*, August 8, 2013.

The article points out the recent debate over genetic privacy in the time of gene mapping. It tells of the details of the German research team publishing the gene map, or genome of the HeLa cells in March. It created a backlash from the family and Rebecca Skloot over the invasion of genetic privacy. The German team swiftly withdrew the genome from public view. It also launched a first time ever discussion and ongoing collaboration between the Lacks family members, the head of the National Institutes of Health, Francis Collins, who was the original lead in the Human Genome Project.

Wagner, Jennifer K. "Genomic Research Ethics Special Rules for HeLa Cells." *Genomics Law Report*, Robinson, Bradshaw and Hinson, August 27, 2013, <http://www.genomicslawreport.com/index.php/2013/08/27/genomic-research-ethicsspecial-rules-for-hela-cells/>.

The article clearly charts the significant developments in ethical and legal governance of biomedical research from the Nuremberg Code in 1947 to the Human Subjects

Research Protections of 2011. It also includes special rules for HeLa genomic research that was recently added following the meetings the Lacks family had with the Director of the National Institute of Health. She incorporates Rebecca Skloot's criticism of the system not addressing the Lacks family's concerns during the peer review process.

Washington, Harriet A. "Non-Consenting Adults." *New Scientist*, January 22, 2012.

This was an interesting article by Harriet A. Washington about how the Nuremberg Code, a set of ethical guidelines for human research and experimentation, is (in her opinion) being routinely ignored. She feels that much more can be done to protect the rights of human research subjects. I have learned a great deal from this author, and I highly respect the depth and breadth of her research on bioethics. Her award winning books *Medical Apartheid* and *Deadly Monopolies: The Shocking Corporate Takeover of Life Itself and the Consequences For Your Health and Our Medical Future* have been an excellent addition to my understanding of the rights and responsibilities involved in medical research.

Watson, Denise M. "After 60 Years of Anonymity, Henrietta Lacks Has A Headstone." *The Virginian-Pilot*, May 30, 2010, <http://hamptonroads.com/2010/05/after-60-years-anonymity-henrietta-lacks-has-headstone>.

The story was from Henrietta's birthplace Clover, Virginia. It gave very personal information about how the family members felt about Henrietta receiving a donated headstone for her grave. It said that before the memorial service family, doctors, and politicians had gathered at her church, St. Matthew Baptist, to pay tribute to the science, but also to "Hennie," as she was known there. I hope to someday visit her home and gravesite there to honor her life.

Williams, Nigel, "Prize for the HeLa Cell Story." *Current Biology*, December 7, 2010. Volume 20, Issue 23, pages R10003-R1004.

This article highlights Rebecca Skloot's contribution to bringing medical and scientific research to the general public with her book, *The Immortal Life of Henrietta Lacks*. It gives information on what makes the HeLa cell unique and so helpful to medical research. It states that this is a very valuable book because it has everything--a compelling science story, an emotional personal story and intriguing ethical dilemmas--all woven together and written with great style. It is a prestigious Wellcome Trust book prize for books of both fiction and nonfiction on the theme of health and medicine.

Zielinski, Sarah. "Henrietta Lacks' 'Immortal' Cells." *Smithsonian.com*, January 22, 2010, <http://www.smithsonianmag.com/science-nature/henrietta-lacks-immortal-cells-6421299/>.

Sarah Zielinski, a writer for the *Smithsonian* magazine, combined information from different interviews with Rebecca Skloot. The articles included gave extensive information on the HeLa cells and Henrietta Lacks. It also included interviews with other key people in the medical field that have used the HeLa cells in their research.

Zimmer, Carl. "A Family Consents to a Medical Gift, 62 Years Later." *The New York Times*, August 17, 2013.

This article explains how the HeLa cell line started and how the Lacks family is now being asked by the National Institute of Health to serve on the board that oversees how the Lacks' genome is used. Dr. Francis S. Collins, the Director of the NIH is quoted, "In 20 years at the NIH, I can't remember something like this." It explains the agreement

was prompted by the two projects that sequenced the genome of HeLa cells, the second of which was published in the journal *Nature*. It says the article marks a milestone in the sage of Ms. Lacks' story, and it draws attention to the lack of policies to balance the benefits of studying genomes with the risks of the privacy of people whose genomes are studied as well as their rights.

Zuhn, Donald. "NIH Implements New Policy on HeLa Genomic Data." *Patent Docs, Biotech & Pharma Patent Law & News Blog*, August 8, 2013, <http://www.patentdocs.org/2013/08/nih-implements-new-policy-on-hela-genomicdata.html>.

This article explains the agreement between the National Institutes of Health ("NIH") and the Lacks family. It details the new policy governing the use of HeLa in genomic research. It was interesting because it noted that in addition to seeking approval for research involving the HeLa, the researchers had to promise to "include an acknowledgement and expression of gratitude to the Lacks family in their" resulting publication.

WEB SITES

CBS Sunday Morning. "The Immortal Henrietta Lacks," March 15, 2010, <http://www.cbsnews.com/news/the-immortal-henrietta-lacks/>.

This CBS Sunday Morning news coverage featured interviews with Skloot, members of the Lacks family, and a Johns Hopkins representative. The news segments helped to explain the different points of view involved in this story. It was interesting to have an official from Johns Hopkins included in the interview.

CBS News. "The Immortal Henrietta Lacks." CBS News.com CBS News, 2010, February 9, 2013, <http://www.cbsnews.com/news/the-immortal-henrietta-lacks/>.

In 2010 CBS News ran a special news report on the HeLa cells. The interview showed how the Lacks family struggles to receive health care and coverage while their mother's cells have helped countless people throughout the world. The interviews include the Lacks family, Rebecca Skloot author of *The Immortal Life of Henrietta Lacks* and Johns Hopkins faculty members. The news coverage was extremely helpful in providing many different viewpoints on the HeLa cells and the rights and responsibilities involved in the story.

Curtis, Adam. "The Way of All Flesh," 1998 Modern Times: BBC Documentary, <http://topdocumentaryfilms.com>.

This documentary by Adam Curtis and the BBC chronicles the story of Henrietta Lacks in an extraordinary way. The project holds many primary sources that helped guide my research and actual interviews with the Lacks family members. It was an amazing experience to think of this documentary as I was interviewing some of the Lacks family members in Baltimore, Maryland.

Giffels, Joe, MAS. "Henrietta Lacks Symposium, Campus Leaders' Panel Discussion," University of Maryland, February 11, 2011, <https://www.youtube.com/watch?v=ODMOKNbkCXw> (uploaded March 8, 2011).

Mr. Giffels is the Chief Research Compliance Officer with the University of Washington. He discussed the importance of having all interested parties at the table to discuss the rights and responsibilities involved with the HeLa. He also highlighted the crucial role that the Institutional Review Boards (IRBs) play in insuring transparency in the process. I was later able to interview Joe Giffels to learn more about the oversight at universities, hospitals, and other research centers. He was also instrumental later

in helping me to obtain a site tour of the University of Maryland School of Medicine NICHD Brain and Tissue Bank for Developmental Disorders which taught me a great deal about bioethical concerns in this setting.

Graham, Ernie, M.D. "Medical Ethics," [PowerPoint Presentation] Johns Hopkins University School of Medicine, http://www.hopkinsmedicine.org/gynecology_obstetrics/pdfs/medstudent/ethics_class_9.pdf.

In this PowerPoint Presentation Dr. Graham lays out the principles of ethics in medicine and research which are founded on four basic elements, including non-maleficence, (not harming) as the basis for medical decisions; beneficence, (benefiting or doing good); autonomy, the patient has the right to choose or refuse medical treatment; and, justice, patients are treated impartially, without bias on account of gender, race, sexuality, wealth, etc.

"The Lacks Family HeLa Foundation," <http://helafoundation.org/>.

The HeLa Foundation is a nonprofit organization that assists the Lacks family in raising funds and supporting research that uses the HeLa cells. I thought this was a very good organization that many people would be inspired to donate funds towards to help educate others about the HeLa cell line. I hope to help the Lacks family raise money for this foundation in the future.

"Henrietta Lacks Receives Honorary Degree." Host Robert Siegel, Michele Norris, Dr. Burney Hollis, David "Sonny" Lacks, Jr., National Public Radio broadcast, 23 May 2011.

In 2011 National Public Radio broadcasted a conversation between Robert Siegel, Michele Norris, Dr. Burney Hollis and David Lacks, Jr. (Henrietta Lacks' grandson) that provided additional information on the many different viewpoints involved with the HeLa cells. This segment also noted that Henrietta had received an honorary degree for her contributions to science and research. Her great granddaughter, Veronica Spencer, recommended that I refer to Henrietta as *Dr. Henrietta Lacks* in my interviews to show the History Day judges that I am aware of this fact that she said not many people are aware of today.

Indiana University. "David Lacks Speaks Out." [Newsinfo.iu.edu](http://newsinfo.iu.edu). Indiana University, 8 Nov. 2012. Web 02 March 2014.

This was helpful in learning about David Lack's opinion about his mother's cells being taken without permission and what his thoughts are on what should be done today. They also discussed how the family feels about the genetic ownership of the HeLa cell line. Later I was able to conduct a personal interview with David Lacks, Jr. I am so impressed with the role he plays on the NIH board as a gatekeeper approving and overseeing HeLa research in the United States.

Johns Hopkins. "Statement About HeLa Cells and Their Use." [Hopkinsmedicine.com](http://hopkinsmedicine.com) Johns Hopkins Medicine, 1 Feb. 2010. Web 09 Feb. 2013.

Johns Hopkins Hospital, the hospital where Henrietta Lacks received treatment and where the HeLa cells were taken, released a public statement to the Rebecca Skloot's book *The Immortal Life of Henrietta Lacks*. The hospital's statement explained how there was not an established system in place of gaining permission from patients, and how, at the time, the cells were legally the property of the Johns Hopkins Hospital. The statement helped me to understand the different points of view and historical contexts of the Henrietta Lacks and HeLa cell story.

Lacks, D. Jr. "Impressive Number of the HeLa Cell." *Lacks Family* (Web log post), January 26, 2013 <http://www.lacksfamily.net/index.php>.

It was interesting to read about the impressive number of HeLa cells from the Lacks family members' point of view. I had read so many sources from medical, media and bioethicists that it seemed right and appropriate that I would hear from their perspective since this is their family and matriarch. It was an honor to later meet and talk with David Lacks, Jr. and Veronica Spencer at the Henrietta Lacks Symposium at Johns Hopkins in Baltimore, Maryland in March of 2014. I was grateful that I had read his point of view before speaking with him so that I could ask thoughtful, well-prepared questions in my interview.

Manfuso, Jamie. "Web Extra: Honoring the Henrietta Lacks Legacy at Hopkins," *John Hopkins Medicine*, May 20, 2011, http://www.hopkinsmedicine.org/news/publications/hopkins_medicine_magazine/hopkins_medicine_magazine_spring_summer_2011/web_extra_honoring_the_henrietta_lacks_legacy_at_hopkins.

This website detailed the significance of Henrietta Lacks' cells to the medical community and was presented by the Johns Hopkins faculty. The writer details the HeLa cells and their many uses in the medical field and at the hospital.

Morgan State University Newsroom, Morgan State University, 21, May 2012. <<http://www.morganstatenewsroom.com/2011/05/21/congratulations-class-of-2011>>.

This was an article describing how Morgan State University had given Henrietta Lacks an honorary doctorate degree for all of her contributions to science and medical research. When I interviewed Henrietta's descendant, Veronica Spencer, she told me to be sure to refer to Henrietta as *Dr.* Henrietta Lacks since she had been awarded this outstanding degree. Veronica said it would show the History Day judges that I had done my homework on Henrietta if I referred to her in that way.

National Institutes of Health. "NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells," August 2013, <http://www.nih.gov/news/health/aug2013/nih-07.htm>.

The NIH released this article from the Office of the Director Francis S. Collins highlighting the new NIH policy that requires researchers to apply for access to the full sequence data from HeLa cells. Collins states, "Just like their matriarch, the Lacks family continues to have a significant impact on medical progress by providing access to an important scientific tool that researchers will use to study the cause and effect of many diseases with the goal of developing treatments." Other officials are noted for pointing out, besides having made priceless contributions to biomedical research over 60 years, Mrs. Lacks and her family are now serving as a catalyst for policies that advance science, build trust, and protect research participants," said Dr. Hudson.

The New Johns Hopkins. "Statement About HeLa Cells and Their Use." *Hopkinsmedicine.com*. Johns Hopkins Medicine, 1 Feb. 2010. Web. 02 March 2014.

This was an interesting statement to read produced by the Johns Hopkins Medical Center. It was helpful in preparing me for the Henrietta Lacks Symposium that I attended at Johns Hopkins Medical Center in March 2014.

National Public Radio. "'Henrietta Lacks': A Donor's Immortal Legacy, Fresh Air from WHYY February 2, 2010, <http://www.npr.org/templates/search/index.php?searchinput=Henrietta+Lacks&dateId=0&programId=13>.

National Public Radio host Terry Gross interviewed author Rebecca Skloot about her book, *The Immortal Life of Henrietta Lacks*. It was interesting to hear Skloot talk about the challenges of her work, how it changed her life, and how she became a science writer. It also included information about the journey she took with Henrietta's family members to various hospitals, labs and places of interest to learn more about Henrietta's story.

PBS, Tavis Smiley. "Science Writer Rebecca Skloot," May 14, 2010, <http://www.pbs.org/wnet/tavissmiley/interviews/science-writer-rebecca-skloot/>.

Tavis Smiley did an excellent job interviewing Skloot that provided additional information on the Henrietta Lacks story. Skloot detailed her personal journey in researching the Lacks family for fifteen years investigating the rights and responsibilities raised by this unique situation. I was inspired by her dedication and tenacity as a science writer.

Radiolab. "Henrietta's Tumor," <http://www.radiolab.org/story/91716-henriettas-tumor/>.

Radiolab provided a segment on Henrietta Lacks story and her family, including audio footage of her daughter, Deborah, talking about her mother's HeLa cells and other events in their lives. It provided a very personal side to this amazing story. I wish I would have been able to interview Deborah before she passed away.

Shorpe, Tanya. "Henrietta Lacks Symposium, Campus Leaders' Panel Discussion," University of Maryland, February 11, 2011, <https://www.youtube.com/watch?v=ODMOKNbkCXw> (uploaded March 8, 2011).

Tanya Shorpe is an Assistant Professor of Social Work, University of Maryland. Professor Shorpe reminds us that the African American church serves as an anchor in the black community to its parishioners helping to educate them about wellness, regulations, informed consent, encouraging conversation about the rights and responsibilities and the importance of representation in the discussion of these crucial issues.

Skloot, Rebecca. "About The Immortal Life of Henrietta Lacks," 2010, <http://rebeccaskloot.com/the-immortal-life/>.

This website is about Rebecca Skloot's bestselling book *The Immortal Life of Henrietta Lacks*. The website was helpful because it provided additional information about the HeLa cells. It also provided more personal information about Skloot regarding her life and her enormous research project of Henrietta Lacks. I felt a great deal of respect of Rebecca Skloot and her efforts after I read her book and viewed her informative website. She was a diligent researcher and writer helping to teach the world about this important topic and Henrietta's legacy.

Skloot, Rebecca. "*The Immortal Life of Henrietta Lacks* Trailer," YouTube.com, Rebecca Skloot, 24 Jan. 2011 Web 09 September 2013.

The book, *The Immortal Life of Henrietta Lacks*, written by Skloot, had a creative trailer that instantly got my attention when I first started my research on Henrietta Lacks. It helped me to have a visual overview of Henrietta's life.

Stohler, Christian S., DMD. "Henrietta Lacks Symposium, Campus Leaders' Panel Discussion," University of Maryland, February 11, 2011, <https://www.youtube.com/watch?v=ODMOKNbkCXw> (uploaded March 8, 2011).

Dr. Stohler explained how the HeLa has changed the course of medicine. He explained that Institutional Review Boards (IRBs) are regulatory groups that should

be driven by compassion to protect humans and help institutions to be transparent. Dr. Stohler stressed the importance of having the public more involved in the discussions of the rights and responsibilities involved in these matters.

Weems, Renita J., Reverend. “Henrietta Lacks Symposium, Campus Leaders’ Panel Discussion,” University of Maryland, February 11, 2011, <https://www.youtube.com/watch?v=ODMOkNbkCXw> (uploaded March 8, 2011).

Reverend Weems is with the American Baptist College in Nashville, Tennessee. She pointed out that the HeLa is more than cells; it is a person, a human being with a family with dreams. She has a soul. A soul that exists before and after death that refuses to be forgotten. The faith issues remind the scientists that this is an additional accountability partner in the formula, and that partner is God. The Lacks family reminds each of us of the role that they believe faith plays with Henrietta and all of humanity.

IMAGES

Appendix III. Political cartoon regarding Henrietta Lacks, 2010 Keith Knight

(<http://www.google.com/url?sa=i&rct=j&q=&esrc=s&source=images&cd=&cad=rja&docid=6ixDM4yo8ufWUM&tbnid=YhVB5ND2tMtGzM:&ved=0CAQQjB0&url=http%3A%2F%2Fserendip.brynmawr.edu%2Fexchange%2Fcourses%2Fliterarykinds%2Fs12%2Fnotes%2F18&ei=T9wCU46cHcPhoATe-64KwAw&bvm=bv.61535280,d.cGU&psig=AFQjCNGKk52CkPAHdCzG24TAK-dY8V9DRZg&ust=139278279551481>) Google Images.

This image puts emphasis on the HeLa cell’s incredible contribution to medical science. Henrietta’s cells advanced medical science 60 years, and changed the world for us all. So, in a way, Henrietta really is “Mother Science.”

Appendix VII. Photograph of Lacks family members, Johns Hopkins staff, and symposium participants taken at the “Henrietta Lacks Symposium,” held at Johns Hopkins Medical Center. 24 March 2014.

The entire panel of speakers from the annual “Henrietta Lacks Symposium,” posed for a picture after the event. I had the privilege to interview each of them personally, and this picture reminds me of how wonderful that day was and how the experience has changed me forever.

Appendix VIII. “The Family of Oversight” cartoon.

I obtained from Liz Martinez RN, BSN, CCRC, Research Participant Advocate Johns Hopkins University School of Medicine Institute for Clinical and Translational Research. She presented this as part of her presentation for the “Henrietta Lacks Symposium,” and I found it effective at conveying the fact that today, unlike when Henrietta Lacks was treated at Johns Hopkins, research studies are performed under the close eye of regulators.

Appendix IX. Photograph of frozen brain tissues. April 17, 2014.

This is a photograph taken during my site visit to the National Institute of Child Health and Human Development, Brain and Tissue Bank for Developmental Disorders, located at the University of Maryland School of Medicine - Department of Pediatrics in Baltimore, Maryland. This was a fascinating tour and discussion. In addition to learning about the tissue samples and how they are maintained, I was also able to learn how tissue donor consent is obtained and maintained over time.

SITE VISITS

Alan Mason Chesney Medical Archives at Johns Hopkins Medical Institutions, 5801 Smith Avenue, Suite 235, Baltimore, Maryland. March 26, 2014.

My visit to the medical archives was an exciting adventure where I gained many primary sources that would otherwise be unavailable to my research. Archivist Marjorie Kehoe was extremely helpful in instructing my mother and me. She helped us in searching the archives examining letters, bulletins, photographs and studies about Dr. George Gey and his research with the HeLa cell line. It was also exciting to be working side by side with other professional researchers and historians working on their projects and books. Marjorie Kehoe also introduced us to a Johns Hopkins bioethicists and archivist volunteer Elizabeth Skinner who I interviewed during my visit as well. Elizabeth Skinner then shared her contact with Dr. Laura Rodriguez with me who works at the NIH with the Human Genome Project. Looking back on my research efforts I see how beautifully one site visit led to more information and contacts that broadened my understanding of Henrietta Lacks and the rights and responsibilities involved in the HeLa. I am grateful for the collaborative support I received from all of the Johns Hopkins staff and researchers.

Dr. George O. Gey's laboratory at the Johns Hopkins Medical School, Baltimore, Maryland. April 17, 2014.

Pamela Bechtel from the Johns Hopkins Community Relations department kindly arranged for my mother and I to visit Dr. George Gey's laboratory at Johns Hopkins during our visit to Baltimore. I had seen the lab in photographs at the medical archives and in media articles, and now I found myself actually standing inside of it where Dr. Chatterly and his assistant are currently conducting cardiac research that involves the HeLa cell. I was pleased to learn that the laboratory itself may be sent to the Smithsonian to be preserved as part of our nation's history. I hope that happens because the HeLa discovery is so important to medical research and scientific advancements that it should be officially elevated to a national audience and preserved for future generations. See, Appendix II.

Johns Hopkins Berman Institute of Bioethics, 1809 Ashland Avenue, Baltimore, Maryland. April 16, 2014.

I had the privilege of visiting Johns Hopkins Berman Institute of Bioethics in Baltimore, Maryland to conduct an interview with Dr. Debra Matthews. This visit expanded my knowledge base on my topic and also inspired me to consider bioethics as a future career path. My Mother and I were warmly welcomed into the offices of the center and given the most up to date research on our complex topic. My mother, an educator, has also been inspired to consider bioethics for her future career in education. We hope to revisit the Berman Institute of Bioethics in the future for other research projects.

National Institute of Child Health and Human Development, Brain and Tissue Bank for Developmental Disorders, located at the University of Maryland School of Medicine - Department of Pediatrics, 655 West Baltimore Street, Baltimore, Maryland. April 17, 2014.

John R. Cottrell, the Tissue Coordinator and Clinical Instructor provided me a tour of the University of Maryland School of Medicine BICHD Brain and Tissue Bank for Developmental Disorders in Baltimore, Maryland. The bank was interesting place to visit unlike anyplace I had ever experienced before. So many things have changed since Henrietta Lacks' lifetime regarding the rules and regulations that govern these

sites. John Cottrell explained how they obtain consent often before the patient dies or immediately following their death from their family. The samples are also deidentified immediately by removing the individual's name from the sample and replacing it with a number to be catalogued. John Cottrell also spoke of the importance of the samples and how they help make medical and scientific advancements that help people throughout the world. See, Appendix IX.

Smithsonian Institution National Museum of Natural History, 10th Street and Constitution Avenue, Washington, D.C. April 15, 2014.

My visit to the Smithsonian Institution National Museum of Natural History took place because I was meeting Dr. Laura Rodriguez from the National Institutes of Health (NIH) for an interview who happened to be on a field trip with her son's class to the museum that day. She was extremely knowledgeable about the HeLa and she directed to a special exhibit entitled "The Human Genome: Unlocking Life's Code" that provided me with additional scientific knowledge about genetics and the HeLa genome. Another interesting aspect of the exhibit was based on the ethical concerns and the public's response to genetic studies in our country.

Turner Auditorium, Johns Hopkins Medical School, 720 Rutland Avenue, Baltimore, Maryland. March 24, 2014.

My visit to the Turner Auditorium was magical because that is the location where I met Dr. Hogan Tang, the Johns Hopkins postdoctoral researcher and Fulbright scholar who uses the HeLa cell for his cancer research. It was Dr. Tang who also introduced me to the Lacks family members, Veronica Spencer and David Lacks, Jr., during the lunch provided at the Turner Auditorium at the Henrietta Lacks Symposium day for Baltimore High School students. I also now realize how historical the Turner Auditorium is after conducting my research because it was often cited as a place for medical gatherings, symposiums, presentations and grant awards all in honor of the HeLa.