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Trajectory of Events

(Visual Timelines also available from Media and Infographics)

Learning Activity 3: HeLa Cells & HPV Genes: Immortality & Cancer

by Katayoun Chamany Updated July 2017

1. In 1951, the first human cell line, HeLa is established using cervical cancer tissue obtained during clinical diagnosis of Henrietta Lacks, an African American women infected with HPV and seeking care in the “colored” ward of John Hopkins Hospital. [Radio Link](#)
2. In 1980, the Bayh-Dole Act is passed allowing small businesses, non-profits and research universities to own the intellectual property and products of biomedical research funded by the federal government (NIH, NSF, etc). This law led to the commercialization of products derived from genetic and cell technologies developed in academic institutions. [Link](#) or [Link](#)
3. In 1987, Ambros and Karlic publish a research study in the journal *Human Genetics* that demonstrates that the immortality phenotype of the HeLa cell line is due to multiple insertions of HPV 18 viral DNA. These viral DNA insertions reprogram the nuclear DNA of the cervical cell to activate the enzyme telomerase, thereby maintaining the length of telomeres and establishing immortality. [Link](#) Nearly 25 years later a new diagnostic screening tool for susceptibility to cervical cancer is based on this original study (OncoFish). [Link](#)
4. In 1996, the documentary film “The Way of All Flesh” directed by Adam Curtis, produced and distributed by the BBC, and winner of the San Francisco Golden Gate Film Award in 1997, exposes the story of Henrietta Lacks and the role her cells played in biomedical research. [Video Link](#)
5. In 1997, Robert Ehrlich, Congressional Representative of Maryland, asks Congress to recognize the contributions that Henrietta Lacks made to biomedical research. [Link](#)
6. In 2010, Rebecca Skloot publishes *The Immortal Life of Henrietta Lacks*, which becomes a *New York Times* Best Seller and Oprah Book Club pick, with plans for HBO and Harpo Films to co- produce a film based on the book. [Link](#)
7. In 2010, Representative Perriello of Virginia asks Congress to honor Ronald Pattillo at Morehouse School of Medicine for the tombstone dedication service on the unmarked grave of Henrietta Lacks in the name of all those who were subjected to medical injustice in the name of biomedical research. [Link](#)
8. In 2010, the lawsuit between the Native American Havasupai and Arizona State University was settled out of court, and tribe members received \$700K for compensation, funds for a clinic and school, and return of their DNA samples. The tribe had filed a lawsuit against Arizona Board of Regents and ASU researchers for misuse of their DNA samples due to lack of informed consent, unapproved use of data, and violation of medical confidentiality. [Link](#)
9. In 2011, the U.S. 9th District Court of Appeals decided in favor of Flynn in *Flynn vs. Holder*, permitting payment for the sale of bone marrow stem cells procured via the peripheral blood system, and an appeal by the U.S. Attorney General, Eric Holder, based on the intent of NOTA was rejected on March 27, 2012. [Link](#)

10. In 2011, the US Presidential Commission for the Study of Bioethical Issues (the Bioethics Commission) issued *“Ethically Impossible” STD Research in Guatemala from 1946 to 1948*. This ethical analysis revealed the specifics of the US Public Health Service’s (USPHS) studies conducted in Guatemala involving the intentional exposure of vulnerable populations to sexually transmitted diseases without their consent. [Link](#). Additionally, the USPHS also conducted studies on African American men living with syphilis (Tuskegee) around the same time, and prohibited them from receiving antibiotics once they became available, in an effort to study late stage effects of syphilis. In 1997, President Clinton issued a formal apology and reparations to the participants in the Tuskegee study. [Link](#)
11. In 2012, Rebecca Kumar, a South-Asian American adjunct instructor at Brown University writes an open letter to faculty urging them to consider the intersection of race, class, and gender in the retelling of the Lacks family history in Skloot’s book. Kumar, Rebecca. An Open Letter to Those Colleges and Universities that have Assigned Rebecca Skloot’s *The Immortal Life of Henrietta Lacks* as the “Common” Freshmen Reading for the Class of 2016. Brown Town Magazine. [Link](#)
12. In 2013, a German company released the genome sequence of the HeLa cell line, and came under fire when it was determined that it could reveal the identity of Henrietta and her family members. In response, the sequence was taken down, and the National Institutes of Health (NIH) created the Henrietta Lacks Genome Access Working Group, inviting two Lacks family members to participate in the Group’s deliberations when deciding which research projects will receive public funding using Henrietta Lacks’ genomic data. [Link](#)
13. In 2015, the United States (US) Notice of Proposed Rule Making (NPRM) for 45 CFR46, the Common Rule, for the protection of human subjects was published for public comment and proposes major changes in protocols involving human subjects, including those studies supported by the private sector and those using de-identified specimens. [Link](#)
14. In 2015, several initiatives for large-scale biobanks are put forth from the private and public sector, including Apple’s ResearchKit and the US Precision Medicine Initiative, while the [UK public Biobank](#) reaches its goal of 500,000 volunteers. [Link](#)
15. In 2015, Wales becomes the first country in the UK to adopt a soft opt-out option for organ donation to biomedical research or clinical treatment using cadavers. [Link](#)
16. In 2015, the European Union made a reversal in its legislative process regarding genetic data sharing, which would grant researchers access to data for which patients or research subjects had provided broad consent. This shift in proposed policy was influenced by the European Data in Health Research Alliance using a social media campaign that includes the URL “[datasaveslives.com](#).” More on this story and initiative can be found [at this Link](#)
17. In 2017, the United States (US) updated and finalized 45 CFR46, the Common Rule, for the protection of human subjects used in federally funded research. [Link](#)