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Stakeholders Chart and Brief Biographies of Characters for Role-play
Learning Activity 3: HeLa Cells & HPV Genes: Immortality & Cancer
by Katayoun Chamany Updated July 2017

Character/Stakeholders Possible Connections Chart

Name	Experience & Practice	Affiliation	Possible Allies/Opponents	Buzzwords for Resources
1. Lawrence Lacks	Eldest son of Henrietta Lacks	Challenges other family members as head of the estate; not in agreement with no compensation	Shares values with: 5,12,18,19 Values conflict with: 2, 6, 7	COMMODIFICATION RESEARCH ETHICS RACE
2. David Lacks Jr., Kimberly Lacks or Jeri Lacks	Grandchild, and great grandchild of Henrietta Lacks,	Member of the HeLa Genome Access Working Group; Public speaker on the Lacks Case	Shares values with: 10,11,15,18,19 Values conflict with: 1,6, 14,17	COMMODIFICATION RESEARCH ETHICS RACE
3. Bob Ehrlich/John Hopkins U	Congressional Representative from Maryland and former governor	Constituency includes employees of John Hopkins University	Shares values with: 4,6,10 Values conflict with: 2,8,9,19	COMMODIFICATION CHOICE
4. Christoph Lengauer or Lori Andrews	Lengauer is a scientist who shared his expertise with the Lacks family, Andrews is a lawyer for patients and a writer	Lengauer: cancer researcher at John Hopkins School of Medicine, CSO of Blueprint Medicines; Andrews: Professor of Law at Chicago-Kent College of Law	Shares values with: 1,2,15, 17 Values conflict with: 5,8,9,18	RESEARCH ETHICS PATIENT RIGHTS GENOME BANKS
5. Larry Palmer	Health Policy Scholar, executive producer of educational documentary film "Susceptible to Kindness: Miss Evers' Boys"	Former professor, provost at Cornell University and Professor of Health Law and Policy at Williams and Mary, and ethics consultant at Weill Cornell Medical College	Shares values with: 1,15, 19, 21 Values conflict with: 1,13, 14, 17	RESEARCH ETHICS PATIENT RIGHTS HEALTH RISK RACE
6. Darrell Salk	Son of Jonas Salk (who developed the polio vaccine), experimental subject for polio vaccine, physician, and geneticist	University of Washington, Vice President of NeoRx and Targeted Genetics. Co-organizer of Polio50/50	Shares values with: 4,14,17, Values conflict with: 8, 9,10, 21	RESEARCH ETHICS GENOME BANKS

7. Jimmy Sarkett	Man whose body as a boy was used to culture live polio by Jonas Salk	Polio survivor now on disability	Shares values with: 4, 5,9,10 Values conflict with: 8,13,14	RESEARCH ETHICS PATIENT RIGHTS HEALTH RISK
8. Kara Saxby	Daughter of John Moore, man who fought to have rights over his biological material	Has spoken about the lack of transparency in developing a potential commercial product from the Mo cell line	Shares values with: 2,4, 9, 20, 21 Values conflict with:13,14, 17	COMMODIFICATION RESEARCH ETHICS PATENTS
9. Wendy Chung (ACLU)	Served as plaintiff in the gene patent lawsuit on behalf of the American Civil Liberties Union (ACLU) in the lawsuit against Myriad Genetics and the US Patent and Trademark Office	Pediatrician and Geneticist at Columbia University and Simons Foundation Director of Variations in Individuals Project	Shares values with: 8, 10, 18 Values conflict with: 3,14,	COMMODIFICATION RESEARCH ETHICS PATIENT RIGHTS PATENTS
10. Mary Claire King or Jeanne Loring	Geneticist and Social Justice Advocate, fought against Myriad Genetics gene patent Sued WARF/ WiCell for patents on embryonic stem cell lines and protocols for their derivation	American Cancer Society Research Professor in the Departments of Medicine and Genetics at the University of Washington, discovered the gene variant BRCA1 that increases susceptibility to breast and ovarian cancer and an advisor for Color Genomics Professor of Developmental Neurobiology, Director of the Center for Regenerative Medicine Department of Chemical Physiology, California Campus, The Scripps Research Institute	Shares values with: 8, 9, 18, 20, 21 Values conflict with: 3,14,	SCIENCE RESEARCH ETHICS PATIENT RIGHTS BIOBANKS PATENTS
11. Jill Peters or Nanibaa Garrison or Abigail Echo-Hawk	Policy scholars, scientists, social justice activists for Native American Communities, familiar with the lawsuit brought against U of Arizona State by the Havasupai	Peters: Director of Community Outreach and Legislative Affairs of TGen Garrison: author of Online Genetics Resource Center for tribes developed by the National Congress of Native American Indians (NCAI) Echo-Hawk: Associate Director of Partnership for Native Health and Tribal Liaison for the U of Wash Institute for Translational Medicine	Shares values with: 2, 9, 12,18, 19 Values conflict with: 3,14, 17	RESEARCH ETHICS PATIENT RIGHTS BIOBANKS PATENTS
12. Shaka Mitchell	Involved in the lawsuit of <i>Flynn v. Holder</i> challenging compensation for human tissue	MoreMarrowdonors.org requesting compensation for donations to diversify bone marrow public stem cell banks	Shares values with: 4,8, 16,19 Values conflict with: 3,13,	BIOLABOR COMPENSATION RACE

13. Eric Holder	In disagreement with the 9th Circuit decision on payment for bone marrow provision via <i>Flynn v. Holder</i> due to NOTA	Former U.S. Attorney General, Obama Administration, instrumental in the National Initiative to Build Community Trust and Justice	Shares values with: 3,4,15, Values conflict with: 8, 12, 14,	COMMODIFICATION RESEARCH ETHICS RACE
14. Sergey Brin	Advocate for pay for participation genomic databases, history of inherited risk of Parkinson's Disease	Co-founder of Google and supporter of the Parkinson's Progression Markers Initiative.	Shares values with: 4,15,17 Values conflict with: 2, 4,8,19, 20	SCIENCE GENOME BANKS BUSINESS
15. Jo Handelsman or President Barack Obama or Sir Rory Collins	Handelsman and Obama Guiding the US Precision Medicine project seeking 1M voluntary participants Collins, Chief Executive of the UK National Biobank including 500,000 volunteers.	Cancer Researcher, Associate Director for Science in the Office of Science and Technology Policy Epidemiologist of Vascular Disease and Cancer	Shares values with: 4,5, 10, 11,16,20 Values conflict with: 5, 18. 19	SCIENCE BIOBANKS RESEARCH ETHICS
16. Melanie Nix or Elizabeth Yeampierre	BRCA1 gene variant carrier, health advocate and supporter of the Precision Medicine Initiative Puerto Rican environmental health activist	African American BRCA1 gene variant carrier who underwent a bilateral mastectomy due to the unique genetic information concerning her cancer risk Executive Director of United Puertorican Organization of Sunset Park (UPROS)	Shares values with: 2,5, 10, 18, 19,20 Values conflict with: 14,	BIOBANKS COMMUNITY RIGHTS
17. John Wilibanks	Involved in developing open source software and apps for Apple iPhone to collect data for medical research and digital informed consent	Chief Commons Officer of Biosage Network and Apple ResearchKit	Shares values with: 4, 10,11,15 Values conflict with: 2,4,8, 19, 21	BIOBANKS RESEARCH ETHICS BENEFIT SHARING
18. Gail Javitt or Radhika Rao	Health Law and Bioethics scholar addresses regulation of tissues and biobanking and serves on counsel for biotech	Berman Institute of Bioethics, Johns Hopkins University	Shares values with: 4,5,9,10,15, 20 Values conflict with: 5, 8, 14	BIOBANKS RESEARCH ETHICS PATIENT RIGHTS BENEFIT SHARING
19. Ruha Benjamin	Race & Justice; Sociologist Scholar, analyzes the HeLa Cell line and community participation in biomedical research	Assistant Professor of Sociology and African American Studies, Boston University	Shares values with: 2,5,9,11,12,16 Values conflict with: 6,7,8,14,	BIOBANKS COMMUNITY RIGHTS RESEARCH ETHICS BENEFIT SHARING
20. David Winickoff	Charitable Trust Model for Biobanks of US Veterans	Legal Scholar and Director the Berkeley Program in Science and Technology Studies, Associate Professor of Bioethics, UC Berkeley	Shares values with: 4,5,9,10,15,18 Values conflict with: 5, 8, 14	BIOBANKS COMMUNITY RIGHTS RESEARCH ETHICS COMPENSATION

1. Lawrence Lacks (Lacks family member)

Larry Lacks is the eldest son of Henrietta Lacks and the executor of her estate. Since the publication of Rebecca Skloot's book Larry has become increasingly angered by the lack of compensation for the family and also has also taken various family members to task demanding genetic testing and accusing them of falsified kinship. Though he acknowledges Henrietta's contribution to science, he argues that the recognition and compensation his family has received is negligible. For instance, Elsie one of Henrietta's daughters had epilepsy and was institutionalized and died at the age of 15 possibly due to the fact that his family could not afford medical attention. He also resents that his family is depicted as poor and uneducated in the media. The argument put forth by lawyer Larry Palmer regarding liability, is important in this case as Henrietta herself was not harmed by the research though it might be argued that a social contract was not clearly articulated, resulting in downstream harms to her family. In the Hayes video Kimberly captures some of the complexity of the situation. Larry Sacks' greatest concern is a lack of respect by others in the family and has disparaged his cousins for working with the NIH and receiving \$5000 speaking engagements, while his wife has no health home care. He and his son Ron have been involved in lawsuits and other legal proceedings designed to bring recognition and compensation to his family. It is of note, that Ron has been a beneficiary of the Lacks Foundation, a non-profit organization established by Skloot dedicated to providing financial assistance to individuals that have contributed to scientific research without benefiting personally.

1. Hendrix, S. March 29, 2017. On Eve of an Oprah movie About Henrietta Lacks, an Ugly Feud Consumes the Family. *Chicago Times*. [Link](#)
2. Palmer, L. 2005. Should liability play a role in social control of biobanks. *Journal of Law, Medicine, and Ethics*.33(1):70-78. [Link](#)
3. Batts, D. May 19, 2010. Living Legacy. *Style Weekly*. Richmond's alternative news site. [Link](#) (if link broken do a search on Style Weekly)
4. Hunt L. June 21, 2010. The Immortal Life of Henrietta Lacks: A Bittersweet Legacy. *The Telegraph*. [Link](#)
5. Palmer, L. Nov–Dec 2010. Private Reparations. *Hastings Center Report*. 40 (6):49. [Link](#)
6. Lantos, J. July August 2010. A Better Life Through Science? *Hasting Center Report*. 40 (4):22-25. [Link](#)
7. McLaughlin, T. May 31, 2010. An Epitah, At Last. *SoVaNow.com*. [Link](#)
8. Cohen, P. Feb 5, 2011. Returning the Blessing of an Immortal Life. *New York Times*. C1. [Link](#)
9. **Video:** Hayes, S. Sept 26, 2013. At USF, Grandchildren of Henrietta Lacks Tell of Her Family, Famous, Cells. *Tampabay.com*. (2 min) [Video and Article Link](#)
10. Hudson, K. and Collins, F. 2013. Biospecimen policy: Family Matters. *Nature*. 500:141-142. [Link](#)
11. Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21st century. *NEJM.org* [Link](#)
12. **Radiolab.** April 18, 2017. Radiolab: Extra Henrietta Lacks. (35 min). [Link](#)

2. David Lacks Jr, Kimberly Lacks or Jeri Lacks. (Lacks family member and sits on the HeLa Genomic Data Access Working Group)

David Lacks Jr. and Jeri Lacks are the children of Henrietta Lacks' son, "Sonny," while Kimberly is one of David's daughters who is also a recipient of the Lacks Foundation. Sonny was four years old when she died and endured much of the public's attention concerning his mother, when the story broke, but since then his children have taken on the role of outreach. David and Jeri serve on the HeLa Genomic Data Access Working Group, and with others decide which studies have permission to use the HeLa cell line and mandate that all publications acknowledge the family and the source. David Lacks Jr. is a computer technician and both he and Jeri have consulted on the production of the film adaptation of Rebecca Skloot's book "The Immortal Life of Henrietta Lacks." The argument put forth by lawyer Larry Palmer regarding liability, is important in this case as Henrietta herself was not harmed by the research though it might be argued that a social contract was not clearly articulated, resulting in downstream harms to her family. In the Hayes video Kimberly captures some of the complexity of the situation. More recently the use and regulation of biospecimens collected during volunteer actions or clinical treatment has been revisited in the revision of the "Common Rule," which guides research on human subjects.

1. Palmer, L. 2005. Should liability play a role in social control of biobanks. *Journal of Law, Medicine, and Ethics*.33(1):70-78. [Link](#)
2. Batts, D. May 19, 2010. Living Legacy. *Style Weekly*. Richmond's alternative news site. [Link](#) (if link broken do a search on Style Weekly)
3. Hunt L. June 21, 2010. The Immortal Life of Henrietta Lacks: A Bittersweet Legacy. *The Telegraph*. [Link](#)
4. Palmer, L. Nov–Dec 2010. Private Reparations. *Hastings Center Report*. 40 (6):49. [Link](#)

5. Lantos, J. July August 2010. A Better Life Through Science? *Hasting Center Report*. 40 (4):22-25. [Link](#)
6. McLaughlin, T. May 31, 2010. An Epitaph, At Last. SoVaNow.com. [Link](#)
7. Cohen, P. Feb 5, 2011. Returning the Blessing of an Immortal Life. *New York Times*. C1. [Link](#)
8. **Video:** Hayes, S. Sept 26, 2013. At USF, Grandchildren of Henrietta Lacks Tell of Her Family, Famous, Cells. Tampabay.com. (2 min) [Video and Article Link](#)
9. Grondhal, P. April 26, 2012. Cell Case Still Unsettling. Timesunion.com. [Link](#)
10. Callaway, E. Aug 2013. Deal done over HeLa cell line. *Nature*. 500:132-133. [Link](#)
11. **Video/Art:** Wilson-Roe, H. & Roe J. 2013. A Brush With Immortality. Science Museum. [Link](#)
12. Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21st century. *NEJM.org* [Link](#)
13. **Radiolab.** April 18, 2017. Radiolab: Extra Henrietta Lacks. (35 min). [Link](#)

3. Bob Ehrlich/Hopkins U (Republican Congressional Representative of Maryland and former Governor)

Bob Ehrlich is a Republican politician and former governor of Maryland from 2003-2007. Before his time as governor he was the 2nd Congressional district representative. He served on the U.S. House Energy and Commerce Committee. Ehrlich was also a member of the subcommittees on health, telecommunications and the Internet, and environment and hazardous materials, the Congressional Biotechnology Caucus, and the Congressional Steel Caucus. In 1997, he approached Congress to ask for acknowledgement for Henrietta Lacks contributions to biomedical research. His request occurred shortly after the release of “The Way of All Flesh,” the documentary film directed by Adam Curtis that details the history of the establishment of the first human cell line, HeLa. Ehrlich requested that the contributions of Henrietta Lacks be recognized, and though he is not detailed in this statement, the university has created awards that are celebrated annually at the Lacks Memorial Lecture Series. During his time as governor, Ehrlich was described as “unapologetically pro-business,” vetoing the Fair Share Health Care Bill in 2006. However, the bill was passed, making Maryland the first state that requires corporations with more than 10,000 workers to spend eight percent of income on health care for its employees. During 2006, Ehrlich also established the Maryland Stem Cell Research Fund, which allotted \$15M to the project. This investment is part of the largest economic driver in Baltimore, Johns Hopkins University and Hospital. Johns Hopkins was a staunch abolitionist and insisted that a Charity Hospital be established to serve the African American population in Baltimore. Since its inception, some have argued that the Johns Hopkins enterprise has moved away from its charity status, creating wealth and displacing residents as the campus continues to expand. However, as the Zakaria et al perspective highlights the university is a leader in medical school education reform that address racial and class inequities. Ehrlich requested that the contributions of Henrietta Lacks be recognized, and though he is not detailed in this statement, the university has created awards that are celebrated annually at the Lacks Memorial Lecture Series.

1. Ehrlich, B. June 4, 1997. In Memory of Henrietta Lacks. Congressional Record: E1109. [Link](#)
2. Nausika. Oct 14, 2011. The Way of All Flesh: A Broad Introduction to An Unlikely Heroine in the History of Medical Research. *Under Southern Eyes.com*. [Link](#)
3. **Optional:** Curtis, A. 1997. Modern Times: The Way of All Flesh. Aired on BBC. Modern Times Series, Editor Stephen Lambert. 52 minutes. [Link](#)
4. Robert Ehrlich Politician. [Link](#)
5. Zielinski, S. Jan 22, 2010. Henrietta Lacks’ ‘Immortal’ Cells. *Smithsonian Magazine*. (3 pages) [Link](#)
6. **Video:** Sunday Morning: March 15, 2010. The Immortal Henrietta Lacks. CBSnews. [Link](#)
7. Keiger, D. June 2, 2010. Immortal Cells, Enduring Issues. *John Hopkins Magazine* (7 pages) [Link](#)
8. Johns Hopkins Statement on HeLa Cells. [Link](#)
9. Henrietta Lacks Memorial Award Call for Nominations. [Link](#)
10. Henrietta Lacks Dunbar Health Science Scholarship [Link](#)
11. Gallant, Z. 2015. First Do No harm? The Johns Hopkins System’s Toxic Legacy in Baltimore. *The Leveller.com* (First and last sections are most important. (~20 pages) [Link](#)
12. Zakaria, S, et al. Nov 19, 2015. Graduate medical education in the Freddie Gray Era. *NEJM*. 373(21):1998-2000. [Link](#)

4. Christoph Lengauer (Geneticist, Entrepreneur)

Christoph Lengauer, a geneticist, completed postdoctoral research at the Research Institute of Molecular Pathology (IMP) and then in the laboratory of Bert Vogelstein and Ken Kinzler at Johns Hopkins University School of Medicine and received his MBA from Johns Hopkins University Business School. Currently Christoph is the chief scientific officer (CSO) for Blueprint Medicines, a patient driven oncology company, dedicated to developing highlight selective protein kinase inhibitors (drugs) that are matched to specific genomic profiles of each cancer patient. Kinases are enzymes and their activity and inactivity is cyclic as cells respond to environmental cues, and their activity state acts as a checkpoint control for cell division. In cancer cells kinases can be inappropriately activated all the time, leading to uncontrolled cell division. Understanding the genetic mutations associated with a person's cancer can lead to a more specialized approach to therapy. This approach is the one taken by the Precision Medicine Initiative that seeks to create a database of information that can expand the development of drugs for not only cancer but other diseases as well. Prior to Blueprint, Christoph was the vice president and head of oncology at Sanofi, another global healthcare organization, where he contributed to the development of one of the first oncology business units in big pharma. Before joining Sanofi, Dr. Lengauer was the executive director and senior unit head of oncology at the Novartis Institutes for Biomedical Research (NIBR). In 1982, Lengauer characterized a new method of visualizing genomes called fluorescence in situ hybridization (FISH) with HeLa cells. Lengauer has since reached out to the Lacks family and provided informal education to them regarding cell culture. Currently, Dr. Lengauer is lead or senior author of several scientific articles that have been published in highly esteemed journals such as *Cell*, *Nature*, and *Science*.

1. MACUB bio. [Link](#)
2. Lantos, J. July August 2010. A Better Life Through Science? *Hasting Center Report*. 40 (4):22-25. [Link](#)
3. Truog, R. et al. 2012. Paying patients for their tissues: The legacy of Henrietta Lacks. *Science*. 337 (6090): 37-38. [Link](#)
4. Hayflick, L. 2012. Paying for tissue: The case of WI-38. *Science*. 337 (6100): 1292. [Link](#)
5. Kominers, S, and Becker, G. 2012. Paying for tissue: Net benefits. *Science*. 337(6100):1292-93. [Link](#)
6. Truog, R. et al. 2012. Paying for tissue: Net benefits-Response. *Science*. 337(6100):1293. [Link](#)
7. Skloot, R. April 16, 2006. Taking the Least of You. *New York Times Magazine*. (~12 pages) [Link](#)
8. McGraw Hill. FISH Animation. [Link](#)
9. Bohan, M. 2005. Checkpoints and Cell Cycle Control: Normal and Abnormal Cell Division. President and Fellows of Harvard College and MCB-HHMI Outreach. *LearnersTV.com* [Animation Link](#)
10. Taulli, T. April 30, 2015. Blueprint Medicines IPO: More Than a One-Trick Pony. *Forbes*. [Link](#)
11. The White House. Jan 2015. Precision Medicine Initiative. [Link](#)
12. Gross, S. et al. Targeting cancer with kinase inhibitors. May 01, 2015. [Link](#) (for science students)
13. Master, Z. et al. 2015. Scientists' perspectives on consent in the context of biobanking research. *European Journal of Human Genetics* 23:569-574. [Link](#)

or

Lori Andrews (Lawyer, Writer)

Lori Andrews is a Distinguished Professor of Law at Chicago-Kent College of Law and Director of the Institute for Science, Law and Technology and has been an advisor on biomedical law to federal agencies, governments, and Congress. She has long been a supporter of patient rights and has represented patients seeking to retrieve damages or profits from biomedical research conducted on their tissue, blood, or DNA samples. More recently she has become an author of a series of thriller mysteries involving emerging biotechnologies using a fictional female protagonist.

1. Truog, R. et al. 2012. Paying patients for their tissues: The legacy of Henrietta Lacks. *Science*. 337 (6090): 37-38. [Link](#)
2. Hayflick, L. 2012. Paying for tissue: The case of WI-38. *Science*. 337 (6100): 1292. [Link](#)
3. Kominers, S, and Becker, G. 2012. Paying for tissue: Net benefits. *Science*. 337 (6100): 1292-93. [Link](#)
4. Truog, R. et al. 2012. Paying patients for their tissues: Net benefits- **Response**. *Science*. 337(6100): 1293. [Link](#)
5. Skloot, R. April 16, 2006. Taking the Least of You. *New York Times Magazine*. (~12 pages) [Link](#)

6. Andrews, L. Jan 2006. Who owns your body?: A patient's perspective on Washington University v. Catalona. *Journal of Law, Medicine and Ethics*. 34 (2): 398-407. [Link](#)

5. Larry Palmer (Lawyer, Bioethicist, Race Scholar)

Former professor in the Biology and Society Program, former provost at Cornell University, and currently Professor of Health Law and Policy at Williams and Mary and ethics consultant at Weill Cornell Medical College. Palmer was instrumental in the production of the educational documentary film "Susceptible to Kindness: Miss Evers' Boys" and its accompanying study guide, which, through vignettes including interviews and a staged performance of the play on college campuses, highlight the complexity of human subjects research involving minority populations using the Tuskegee Syphilis Study conducted by the US Public Health Service from 1932-1972. In a paper honoring his mentor Jay Katz, Palmer reflects on the risks taken by those who participate in experiments, be they clinical or educational. The Tuskegee study was not the only study conducted on minorities that deliberately inflicted or maintained harm and risk to study participants and the *Nature* editorial discusses others such as the Guatemala Study 1946-48 on sexually transmitted diseases, which upon being revealed by science historian, led to the publication of the report "[Ethically Impossible](#)" published by the Presidential Commission for the Study of Bioethical Issues. Though Henrietta Lacks was not intentionally harmed to advance research, this history serves as an important backdrop to the case as it provide rationale for mistrust and fear of the medical establishment by many minority populations and the lack of an effective social contract.

1. **Podcast:** Ethically Sound. Ethically Impossible. [Link](#)
2. Brandt, A. 1998. Racism and Research: The Case of the Tuskegee Syphilis Study. *Hastings Center Magazine*: 1-13. [Link](#)
3. Palmer, L. 2006. Response- Jay Katz: From Harms to Risks. *William & Mary Law School Scholarship Repository*. V1 (2): 454-564. [Link](#)
4. Palmer, L. Nov-Dec 2010. Private Reparations. *Hastings Center Report*. 40 (6):49. [Link](#)
5. Anonymous. April 2012. Justice for All. *Nature*. 484:287. [Link](#)
6. Arias, J., et al. 2015. Trust, vulnerable populations, and genetic data sharing. *Journal of Law and Biosciences*: 1-7. [Link](#)
7. **Optional** Palmer, L. 2005. Should liability play a role in social control of biobanks. *Journal of Law, Medicine, and Ethics*.33(1):70-78. [Link](#)

6. Darrell Salk (Physician, and Polio Vaccine Test Subject)

Darrell Salk, M.D., is the son of Jonas Salk, the man who developed and tested the first effective polio vaccine in 1952. Jonas was known to say in a television interview with Edward Murrow upon being asked why the vaccine was not patented, "Could you patent the sun?" implying a moral decision to provide the vaccine for "free" however, there are some who believed that the patent was not sought due to the fact that the vaccine was based on prior art. Others state the manufacturing ability was already "given away" to companies before any patent investigation occurred, while still others claim that the vaccine was publicly funded through altruistic donations to the March of Dimes and thus was by its very nature a public good. Some have calculated that the vaccine would have produced \$2B in profits. Poliovirus was a rampant and devastating epidemic in the 1950s. The development of the vaccine required many experimental and procedural steps in the approval process including testing the vaccine on children already exposed to the virus, including the intellectually disabled and elementary school students. Darrell and his siblings were some of the first people administered with the vaccine after these trials. Salk's three children all went on to be physicians and Darrell currently is a pediatrician in Portland, Oregon. Darrell Salk has over thirty-three years of experience as a practicing physician and has taken up his father's passion for widespread use of the injected inactivated dead vaccine. Darrell has also helped lawyers with damage suits related to the vaccine.

1. 2001. Selected Questions from Student Interviews Darrell Salk, M.D. Jonas Salk Center. (3 pages) [Link](#)
2. Paulson, T. April 25, 2004. At The Salk Family Table, A Long Conquest Is Begun. *Seattle Post-intelligence Reporter*. [Link](#)
3. June 14, 2015. Weekend Reader: Jonas Salk "A Life." *The National Memo*. [Link](#)
4. Cook-Deegan, R. and J. Johnston. 2008. "Intellectual Property and Biomedicine," *In From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley. Garrison, NY: The Hastings Center: 93-96. [Link](#)

5. Greideanus, T. 2010. Shot 'Felt Round the World. Producer Kurlander, C. Steeeltown Entertainment. *Napa Valley Film Festival 2011*. [Film Trailer Link](#) and [Film Link \(56 min\)](#)
6. Kurlander, C. October 17, 2010. The Next Page: Saving the World. *Pittsburgh Post-Gazette.com*. [Link](#)
7. Aug 9, 2012. How Much Money Did Jonas Salk Potentially Forfeit By Not Patenting The Polio Vaccine? *Forbes.com* [Link](#)
8. Palmer, B. April 13, 2014. Jonas Salk: Good at Virology, Bad at Economics. *Slate.com* [Link](#)
9. Human Cell Strains in Vaccine Development. *In The History of Vaccines* An educational resources developed by The College of Physicians of Philadelphia. [Link](#)
10. Feldwisch-Drentrup, H. Dec 19, 2015. E.U. frees up data for science. *ScienceInsider*. [Link](#)

7. Jimmy Sarkett (Polio survivor whose body was used to culture polio vaccine components)

Jimmy Sarkett was raised in Pennsylvania until the age of ten when he was diagnosed with polio and transferred to the Municipal Hospital for Contagious Diseases in Pittsburgh for three years. During his time in Pittsburgh, Dr. Jonas Salk met him and used his body as a culturing site for one of three types of poliovirus needed to develop a vaccine against polio. Sarkett, in 1980, stated that he felt he had contributed a little bit to society by serving as a biological incubator for the growth of the poliovirus, resulting in the resources Salk needed to develop his vaccine. Having already been exposed and infected with poliovirus, Sarkett could not benefit from vaccination. Having lived with polio, he is disabled and is challenged economically to purchase new crutches, a fact revealed by journalists preparing a press piece of the 60th anniversary of University of Pittsburgh Medical Center.

1. Fabregras L. and Bails, J. April 3, 2005. A Lasting Link to Discovery. *Triblive*. Pittsburgh. [Link](#)
2. Sugarman, J., Zoloth, L. & Hempel, C. October 4 2010. The Immortal Life of Henrietta Lacks - lessons for stem cell researchers and patients. World Stem Cell Summit, Pasadena, CA. 60 minutes, however, fast forward to the 40 minutes mark to view a 30-minute excerpt of Laurie Zoloth. [Link](#)
3. Cook-Deegan, R and J. Johnston. 2008. "Intellectual Property and Biomedicine," *In From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley. Garrison, NY: The Hastings Center: 93-96. [Link](#)
4. Greideanus, T. 2010. Shot 'Felt Round the World. Producer Kurlander, C. Steeeltown Entertainment. *Napa Valley Film Festival 2011*. [YouTube Film Trailer Link](#)
5. Palmer, B. April 13 2014. Jonas Salk: Good at Virology, Bad at Economics. *The Washington Post*. [Link](#)

8. Kara Saxby (Daughter of John Moore, a patient who sued his physician for rights to his body)

Kara Saxby is the daughter of John Moore. Her father was diagnosed with Hairy Cell Leukemia and in 1976 had his spleen removed by Dr. David Golde. Golde developed and commercialized the Mo cell line without the consent of Mr. Moore. Moore fought for his rights over his biological material in the Moore vs. Regents of the University of California and eventually won on the count of not being informed, but lost with respect to property rights. Kara's father continued to be an advocate for patients' right until his death. Saxby today is outspoken about the commodification of body parts and wishes there was a limit to the profits researchers could make. Kominars and Becker agree with John Moore, that it might be useful to provide financial benefit to patients with unique profiles.

1. McLellan, D. Oct 13, 2001. John Moore, 56; Sued to Share Profits From His Cells. *Los Angeles Times*. [Link](#)
2. Skloot, R. April 16, 2006. Taking the Least of You. *New York Times Magazine*. (~12 pages) [Link](#)
3. Andrews, L. Jan 2006. Who owns your body?: A patient's perspective on Washington University v. Catalona. *Journal of Law, Medicine and Ethics*. 34 (2): 398-407. [Link](#)
4. Truog, R. et al. 2012. Paying patients for their tissues: The legacy of Henrietta Lacks. *Science*. 337 (6090): 37-38. [Link](#)
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7. Truog, R. et al. 2012. Paying patients for their tissues: Net benefits- **Response**. *Science*. 337(6100): 1293. [Link](#)
8. Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21st century. *NEJM.org* [Link](#)

9. Wendy Chung (American Civil Liberties Union (ACLU) Plaintiff in the case against Myriad)

American Civil Liberties Union (ACLU) is an organization that works to defend individual rights and liberties that the Constitution and US guarantee. Their slogan is "Because Freedom Can't Protect Itself." The ACLU targets many defenses of discrimination including reproductive freedom, voting rights, religion and belief, racial justice, LGBT rights, and women's rights. In 2009, the ACLU and Public Patent Foundation (PYBPAT) filed a lawsuit against the company Myriad for patenting two genes associated with risk for breast and ovarian cancer on the claim that these patents are unconstitutional and invalid as genes are part of nature. Wendy is a practicing physician and research scientists in the area of genetics and diseases served as the original plaintiff in the case. ACLU claims the patenting prohibits research and restricts women's options. In 2010 judges ruled that the gene patents were invalid. However, during the appeals process in 2011, it was reversed. In 2012, the Supreme Court vacated the appeals decision and the case was finally settled in June 2013. However, as Hernandez and Marshall point out there is a big loophole in the decision allowing cDNA (the expressed DNA used to build proteins) to be patented. Wendy enjoys the challenges of genetics as a rapidly changing field of medicine and strives to facilitate the integration of genetic medicine into all areas of health care in a medically, scientifically, and ethically sound, accessible, and cost effective manner.

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2. Spector, M. April 1, 2013. Can We Patent Life? *The New Yorker*. [Link](#)
3. **Video:** ACLU. Association for Molecular Pathology v. Myriad Genetics. [Link to case information and video](#) [Link](#)
4. Hernandez, D. April 18, 2013. Gene Patents are Sabotaging the Future of Medicine. *Wired.com*. [Link](#)
5. Hernandez, D. April 18, 2013. Killing Gene Patents Could Revitalize Biotech. *Wired.com*. [Link](#)
6. ACLU. June 2013. The Fight to Take Back Our Genes. ACLU.org. [Link](#)
7. ACLU. June 2013 Plaintiffs' Statements. [Link](#)
8. Marshall, E. 2013. Supreme court rules out patents on 'natural' genes. *Science*. 340(6139):1387-1388. [Link](#)
9. Martin-Rendon, E. and Blake, D. 2007. Patenting human genes and stem cells. *Recent Patents on DNA & Gene Sequences*. Bentham Science. 1: 25-34. [Link](#) (appropriate for science students)

10. Mary Claire King (Geneticist and Social Justice Activist)

Mary Claire King employs her skills as a geneticist to promote social justice regarding genetic disease testing, lineage tracing, and war crimes. She uses classical and molecular genetics and develops strong relationships with families and communities to address their needs. In the 1980s she used genetic lineage tracing to reunite children with their families that had been criminally displaced during the Dirty War in Argentina, to reveal that people across different racial groups are genetically more similar than those within a group, and to identify the genetic link to inherited breast cancer (BRCA1). In 2009, the ACLU and Public Patent Foundation (PYBPAT) filed a lawsuit against the company Myriad for patenting BRCA1 and BRCA2 associated with risk for breast and ovarian cancer on the claim that these patents are unconstitutional and invalid as genes are part of nature. King having worked on inherited breast cancer fought the Myriad claim for many years, and alongside the ACLU claimed the patenting prohibits research and restricts women's options. In 2010 judges ruled that the gene patents were invalid and the case settled in June 2013. However, as Hernandez and Marshall point out there is a big loophole in the decision allowing cDNA (the expressed DNA used to build proteins) to be patented. She also published an article in JAMA and proposes that all women be screened for BRCA1/2 and serves as an unpaid advisor to the company Color Genomics which claims to provide the test for \$299 and contributes all genetic data to Clinvar, an open access NIH funded database.

1. Cook-Deegan, R and J. Johnston. 2008.. "Intellectual Property and Biomedicine," *In From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley. Garrison, NY: The Hastings Center: 93-96. [Link](#)
2. Spector, M. April 1, 2013. Can We Patent Life? *The New Yorker*. [Link](#)

3. ACLU. Association for Molecular Pathology v. Myriad Genetics. [Link to case information and video](#)
4. Hernadez, D. April 18, 2013. Gene Patents are Sabotaging the Future of Medicine. *Wired.com*. [Link](#)
5. Hernadez, D. June 14, 2013. Killing Gene Patents Could Revitalize Biotech. *Wired.com*. [Link](#)
6. Marshall, E. 2013. Supreme court rules out patents on 'natural' genes. *Science*. 340(6139):1387-1388. [Link](#)
7. Charles, C. 1993. Interview: Mary Claire King. *Omni Magazine*. 15 (9): 68-70, 71-72, 93-94. [Link](#)
8. Reardon, S. June 2013. I Discovered the BRCA1 Gene. *Slate.com*, originally published in *The Scientist*. [Link](#)
9. Feb 9, 2015. The Never Ending Genetic Quest. *New York Times*: D3. [Link](#)
10. Pollack, A. April 21, 2015. New Genetic Test for Breast Cancer Hold Promise. *New York Times*:B1. [Link](#)
11. April 28, 2015. Thank you for sharing. *Nature*. 520: 585. [Link](#)
12. Martin-Rendon, E. and Blake, D. 2007. Patenting human genes and stem cells. *Recent Patents on DNA & Gene Sequences*. Bentham Science. 1: 25-34. [Link](#) (appropriate for science students)
- 13. Optional Podcast.** The Moth. Mary Clair King. (12min) [Link](#)

Or

Jeanne Loring (Stem Cell Scientist)

Jeanne Loring is a basic scientific researcher who studies developmental biology and molecular pathways of cell differentiation. Cell cultures are vital to her work, and in particular, human embryonic stem cell lines (hESCs). When Jamie Thomson and his research team first derived these cell cultures at the University of Wisconsin, other scientists, including Loring, were working on techniques to accomplish the same goal. However, when WARF-WiCell the profit making arm of the University of Wisconsin filed patents on the hESCs, it prohibited researchers such as Loring to use these cells in research without paying licensing fees. Loring took it upon herself to challenge the patents and this challenge is similar to that of others who challenged the patenting of DNA sequences by 23andMe and biotech companies like Myriad. Over the last 15 years the patent has been challenged and though the scope was narrowed by these challenges, WARF continues to hold the patents on these lines.

1. Cook-Deegan, R and J. Johnston. 2008. "Intellectual Property and Biomedicine," *In From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley. Garrison, NY: The Hastings Center: 93-96. [Link](#)
2. Thursby, J. & Thursby, M. 2003. University licensing and the Bayh-Dole act. *Science*. 301(5636):1052. [Link](#)
3. Spector, M. April 1, 2013. Can We Patent Life? *The New Yorker*. [Link](#)
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6. Marshall, E. 2013. Supreme court rules out patents on 'natural' genes. *Science*. 340(6139):1387-1388. [Link](#)
7. Loring, J. Nov 8, 2007. A patent challenge for human embryonic stem cell research. *Nature Reports Stem Cells*. [Link](#)
8. Fikes, B. Feb 24, 2015. Court Rejects Stem Cell Patent Case. *The San Diego Union Tribune*. [Link](#)
9. Master, Z. et al. 2015. Scientists' perspectives on consent in the context of biobanking research. *European Journal of Human Genetics* 23:569-574. [Link](#)
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11. Bohan, M. 2005. Checkpoints and Cell Cycle Control: Normal and Abnormal Cell Division. President and Fellows of Harvard College and MCB-HHMI Outreach. *LearnersTV.com* [Animation Link](#)

11. Jill Peters or Nanibaa Garrison or Abigail Echo-Hawk (Scientists, Activists, and Policy Makers that support Native Americans)

Jill Peters is a native of the Navajo Community, a bioethicist, and policy specialist who works in Washington DC with those responsible for shaping policy regarding environment, energy and American Indian Affairs. She directs the community outreach and legislative affairs of TGen working with the Salt River Pima Community on a research project for which the tribe donated \$5million and redirected the research focus away from diabetes towards their own community concerns of cancer. Her approach involves helping researchers in academia and industry to practice responsive justice- to involve the community in research decisions and to move away from a deficit model of addressing disease to one that identifies strengths and focuses on wellness. Nanibaa Garrison is also Navajo and a trained geneticist but has expanded her expertise in the area of bioethics. She served as a contributing author for an Online Genetics Resource Center for tribes developed by the National Congress of Native American Indians (NCAI) which focuses not only on the science, but provides information regarding informed consent, control of data, templates for an interactive decision guide. One of the most contentious cases involving informed consent and indigenous populations involved the Havasupai. This case involved the DNA sequencing and analysis of the Havasupai DNA for studies to which they had not agreed. Abigail Echo-Hawk is a member of the Pawnee Nation and is the Associate Director for the Partnerships for Native Health and Tribal Liaison at the Institute for Translational Health Sciences at U of Washington and was a [speaker](#) at the NAWBR conference “Revolutionizing Informed Consent” where various consent models were discussed such as tiered, dynamic, front door, global, community, simplified, and short form consent.

1. **Video:** Bracken, K. and Harmon, A. April 22, 2010. Blood Journey. *The New York Times*. [Video Link](#) (6:04 min)
2. Harmon, A. April 24, 2010. Where'd You Go With My DNA? *The New York Times*: WK1. [Link](#)
3. **Video:** Peters, J. Fostering Productive Intergovernmental Relations. Indigenous Governance Database. University of Arizona. [Video](#) (22 min)
4. McInnes, R. March 11, 2011. 2010: Presidential Address: Culture: The Silent Language Geneticists Must Learn- Genetic Research with Indigenous Populations. *The American Journal of Human Genetics*. 88(3):354-261. [Link](#)
5. Lehrman, S. Jan 16, 2013. Shifting Roles and Shifting Research: Collaborative Genetic Studies with Indigenous Communities. SACNAS. [Link](#)
6. Garrison, N. March 2013. Genomic justice for Native Americans: Impact of the Havasupai case on genetic research. *Science, Technology, and Values*. 38: 201-223. [Link](#)
7. Reardon, S. July 21, 2015. US tailored-medicine project aims for ethnic balance. *Nature.com*. [Link](#)
8. Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21st century. *NEJM.org* [Link](#)
9. Berskow, L. 2016. Lessons from HeLa cells: The ethics and policy of biospecimens. *Annual Review of Genomics and Human Genetics*. 17:395-417. [Link](#) (regrading proposed changes to Common Rule for de-identified specimens)

12. Shaka Mitchell (Lawyer and MoreMarrowDonors.org representative)

MoreMarrowDonors.org is a Californian non-profit organization seeking to increase the diversity of the bone marrow pool for people in need of hematopoietic stem cells. MoreMarrowDonors provides small scholarships, housing allowances, compensation and gifts to charity in exchange for bone marrow donation. This organization points to the fact that it is increasingly difficult to find a donor match for minorities and people of mixed ethnic backgrounds in some countries and regions of the US. Furthermore, serious complications can arise from a partial donor match, which is avoidable if there were a more diverse pool. Shaka Mitchell, Akiim DeShay and Mike Hame founded this organization after they realized the great need in the national donor registry and the fact that profits were being made by some companies banking blood such as Pharmastem as described in the Kurtzberg article. The recent case of Flynn v. Holder involved this non-profit and though the decision to compensate donors was appealed by U.S. Attorney General Eric Holder, the appeal was denied in March 2012.

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3. MoreMarrowDonors. “MoreMarrowDonors.org.” About Us. [Link](#)
4. La Pook, J. May 29, 2010. Leukemia Patient at 4 Highlights Marrow Need. Producer Phil Hirschhorn. *CBSnews.com*. Link to Video on [YouTube](#)
Link to [Article](#)
5. NBMP (National Bone Marrow Program). HLA Matching. [Link](#)
6. Cohen, G. Jan 26, 2012. Selling bone marrow-Flynn v. Holder. *NEJM*. 366:296-297. [Link](#)

7. Truog, R. et al. 2012. Paying patients for their tissues: The legacy of Henrietta Lacks. *Science*. 337 (6090): 37-38. [Link](#)
8. Kominers, S, and Becker, G. 2012. Paying for tissue: Net benefits. *Science*. 337 (6100): 1292-93. [Link](#)
9. Lacetera, N., et al. May 24, 2013. Economic rewards to motivate blood donations. *Science*. 340(6235):927-28. [Article Link](#) and [Podcast Interview](#)

13. Eric Holder (Lawyer, US Attorney General)

Eric Holder was the third longest serving US Attorney General. He was the sitting General Attorney General when plaintiffs Flynn and MoreMarrowDonors sued the US government claiming that the ban against compensation for bone marrow donation via apheresis was a form of discrimination against those of mixed race. Holder upheld the ethos of the National Organ Transplant Act (NOTA) and argued that only altruistic donation was appropriate in an effort to ensure that patients would not empty bank accounts in an effort to pay a donor. MoreMarrowDonors provides small scholarships, housing allowances, compensation and gifts to charity in exchange for bone marrow donation from those of diverse backgrounds in an effort to address the difficulty in finding a donor match for minorities and people of mixed ethnic backgrounds in some countries and regions of the US. The recent case of Flynn v. Holder involved this non-profit and though the decision to compensate donors was appealed by U.S. Attorney General Eric Holder, the appeal was denied in March 2012. Since he has stepped down as Attorney General he has continued to stay involved in building community trust.

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2. NBMP (National Bone Marrow Program). HLA Matching. [Link](#)
3. Cohen, G. Jan 26, 2012. Selling bone marrow-Flynn v. Holder. *NEJM*. 366:296-297. [Link](#)
4. Williams, C.J. March 28, 2012. Court Rejects Obama Plea to Reconsider Bone Marrow Ruling. *Los Angeles Times*. [Link](#)
5. Barnes, R. Jan 22, 2012. Government Fights Court Decision That Says Bone Marrow Donors Can Be Paid. *The Washington Post*. [Link](#)
6. Truog, R. et al. 2012. Paying patients for their tissues: The legacy of Henrietta Lacks. *Science*. 337 (6090): 37-38. [Link](#)
7. Kominers, S, and Becker, G. 2012. Paying for tissue: Net benefits. *Science*. 337 (6100): 1292-93. [Link](#)
9. Lacetera, N., et al. May 24, 2013. Economic rewards to motivate blood donations. *Science* 340(6235):927-28. [Article Link](#) and [Podcast Interview](#)
10. Lee, T. Sept 25, 2014. America's First Black Attorney General: Eric Holder's Legacy. MSNBC.com [Link](#)

14. Sergey Brin (Google cofounder and Genomics investor) or Ann Wojcicki (founder of 23andMe)

Sergey Brin comes from mathematician parents and has studied genetics, statistics, and mathematics. Brin is co-founder of Google and founder for the Parkinson's Genetic Initiative (PGI). Brin uses a novel research methods approach, which collects information first and based on these observations and findings develops hypotheses to investigate genetic and environmental links to disease. Brin looks to stem cell research as one avenue for curing Parkinson's disease partly because he regards genetics as a computing problem, as does his former wife, Anne Wojcicki, who co-founded 23andMe. 23andMe allows people to analyze and compare their genomic information to a reference set of genomes. Brin's PGI project subsidizes those who participate in their study from paying the \$399 fee to have their genome sequenced by 23andMe but will not sell the anonymized DNA once it enters the research study. Brin's other interests include solving the world's energy crisis and space tourism.

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2. Thomas, O. March 12, 2009. Google Founder Sacrifices Son, Last Shreds of Integrity to Science. *Gawker.com*. [Link](#)
3. Loise, V. & Stevens, A. Oct 6, 2010..The Bayh-Dole act turns 30. *Science Translational Medicine*. 2(52):52. [Link](#)
4. Goetz, T. June 22, 2010. Sergey Brin's Search for A Parkinson's Cure. *Wired Magazine*. 18(07). ~12 pages. [Link](#)
5. Truog, R. et al. 2012. Paying patients for their tissue. The Legacy of Henrietta Lacks. *Science*. 337:37-38. [Link](#)
6. Sipp, D. 2012. Pay-to-participate funding schemes in human cell and tissue clinical studies. *Regenerative Medicine*.7(6 Suppl):106-111. [Link](#)
7. Duhaime-Ross, A. March 10, 2015. Apple's New ResearchKit: "Ethics Quagmire or Medical Research Aid? *TheVerge.com*. [Link](#)
8. Bushley, R. May 28, 2015. 23andMe's Plan to Harness Data for Disease Treatments. *Biosciencetechnology.com*. [Link](#)
9. Servick, K. Sept 25, 2015. Can 23andMe have it all? *Science*. 349(6255):1472-1477. [Link](#)

10. Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21st century. *NEJM.org* [Link](#)
11. Feldwisch-Drentrup, H. Dec 19, 2015. E.U. frees up data for science. *ScienceInsider*. [Link](#)
12. Gent, E, Feb 16, 2017. Our Health Data Can Save Lives, But We Have to Be Willing to Share. SingularityHub. [Link](#)

15. Jo Handelsman (Microbiologist, Science Educator, Associate Director for US Science in the Office of Science and Technology Policy Precision Medicine) OR President Barack Obama or Sir Rory Collins

Jo Handelsman, studies microbial diversity and novel antibiotics, and serves as Howard Hughes Medical Institute Professor in the Department of Molecular, Cellular and Development Biology at Yale University. In July 2014, she was appointed Associate Director for Science at the Office of Science and Technology Policy (OSTP) to advise President Barack Obama on the impacts of science and technology on domestic and international affairs for two years. Her work in this position has been focused on the launch of the Precision Medicine Initiative (PMI), an effort to combine data from 1M volunteers from existing and new biomedical studies. The information in the PMI database will include genomics, lifestyle, and environmental factors to develop improved diagnostics, treatments, and preventions for diseases such as cancer and diabetes. The project is one of the first of its kind in a country without a national health care system, and is similar but much larger than the UK National Biobank, headed up by epidemiologist Sir Rory Collins. PMI builds on President Obama's earlier interest in personalized medicine; in 2006 as a Senator of Illinois he proposed a bill focused on personalized medicine. Given Obama's interest is bringing better health to all, and his attention to issues of the marginalized, his PMI team is focused on improving the practice and principles associated with participatory research that is transparent and respectful of the volunteer's contributions including issues of privacy. Gaining trust with the volunteers of PMI is at the fore of some of the revisions to the "Common Rule" which addresses research using human subjects and biospecimens, and comes in the wake of a recent report on egregious research practices by the US Public Health Service in the Tuskegee and Guatemala studies on sexually transmitted diseases. These concerns are outlined in the letter exchange between Obama and the Committee for Bioethical Issues, which is in the front matter of the report "[Ethically Impossible](#)." Jo has worked with Francis Collins, Director of the National Institutes of Health, who established the HeLa Genomic Data Access Working Group. This group decides which studies have permission to use the HeLa cell line and requires that all publications acknowledge the family and the source. Jo is known not only for her outstanding work in microbial genomics, but as a mentor for women and under represented minorities in science, technology, engineering, and math (STEM) and formed the Center for Scientific Teaching at Yale in an effort to improve STEM education at all levels. She has won many awards for her scientific research, mentoring and impact on teaching.

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2. De Melo-Martin, I. et al. 2007. Viewpoint: Developing a Research Ethics Consultation Service to Foster Responsive and Responsible Clinical Research. *Academic Medicine* 82 (9): 900-904. [Link](#)
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6. Javitt, G. 2013. Take another little piece of my heart: Regulating the research use of human biospecimens. *Journal of Law, Medicine & Ethics*. 41(12):424-39. [Link](#)
7. Lewis, R. Oct 24, 2015. Medicine: Much More Than Just Genetics. *PLOS. DNA Science Blog*. [Link](#)
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11. Master, Z. et al. 2015. Scientists' perspectives on consent in the context of biobanking research. *European Journal of Human Genetics* 23:569-574. [Link](#)
12. Chamany, K. Nov 19, 2015. New Rules Proposed to Address Privacy and Trust in the Precision Medicine Initiative. *Biopolitical Times*. Center for Genetics and Society. [Link](#)

16. Melanie Nix (Minorities health advocate, Breast Cancer Survivor)

Melanie Nix is a fifth generation breast cancer survivor and carrier of the BRCA1 gene variant, which contributes to 5-10% of all inherited breast cancers. Because of her strong family history with breast cancer, Melanie received early testing and was diagnosed as positive for the BRCA gene variant in 2008 and triple-negative breast cancer, an aggressive type that disproportionately affects African American women and younger women. Because the cancer cells lack three different hormone receptors, conventional drug therapy using hormones or antibodies to block these receptors cannot be used, and some women, like Melanie, choose to have a bilateral mastectomy and oophorectomy in an effort to reduce risk of cancer progression. These choices often influence reproductive choices as well and the BRCA1/2 gene variants can be screened in embryos created through IVF, using Preimplantation Genetic Diagnosis (PGD). Families like Melanie's were used by Mary Claire King to identify the BRCA1/2 gene variants using classical genetics and molecular genetics. Melanie has an MBA from the University of Maryland and is a health advocate who works to address health disparities through projects like the [Patient Powered Research Networks](#) and the non-profit she founded Breast Cancer Comfort. These projects are examples of community driven research, and address some of the challenges raised by Michael Montoya in his article about bioethnic conscriptions in health research. Melanie's story is one used to support the Precision Medicine Initiative (PMI), an effort to combine data from 1M volunteers from existing and new biomedical studies. The information in the PMI database will include genomics, lifestyle, and environmental factors to develop improved diagnostics, treatments, and preventions for diseases such as cancer and diabetes. The PMI team is focused on improving the practice and principles associated with participatory research that is transparent and respectful of the volunteer's contributions including issues of privacy. Gaining trust with the volunteers of PMI is at the fore of some of the revisions to the "Common Rule" which addresses research using human subjects and biospecimens, and comes in the wake of a recent report on egregious research practices by the US Public Health Service in the Tuskegee and Guatemala studies on sexually transmitted diseases. These concerns are outlined in the letter exchange between Obama and the Committee for Bioethical Issues, which is in the front matter of the report "[Ethically Impossible](#)."

1. NIH. An African American Triple Negative Breast Cancer Survivor: Melanie Nix's Story. National Cancer Institute Life Lines Cancer Education Series: Resources for Multicultural Media. [Video Link](#)
2. Montoya, M. 2007. Bioethnic conscription: Genes, race, and Mexicana/o ethnicity in diabetes research. *Cultural Anthropology*. 22(1):93-128. [Link](#)
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7. Kaiser, J. Jan 20, 2015. White House fleshes out Obama's \$215 million plan for precision medicine. *Science*. [Link](#)
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9. Pollack, A. April 21, 2015. New Genetic Test for Breast Cancer Hold Promise. *New York Times*:B1. [Link](#)
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11. Reardon, S. July 21, 2015. US tailored-medicine project aims for ethnic balance. *Nature*. [Link](#)
12. The White House. November 9, 2015. Precision Medicine. Privacy and Trust Principles. [Link](#)

Or

Elizabeth Yeampierre (Lawyer and Executive Director of United Puertorican Organization of Sunset Park)

Elizabeth is a nationally recognized Puerto Rican attorney and environmental justice leader of African and Indigenous ancestry born and raised in New York City. She brings a social justice voice to citizen science projects championing the role of community in driving the direction of research projects through collaboration and partnerships with scientists. UPROS involves capacity building in the community, and has a strong focus on environmental health. Her organization is mindful of the health and environmental injustice that has origins in colonization, oppression, and slavery. Elizabeth's work was brought to a [Trans NIH-conference focused on citizen science](#) just after the President's Precision Medicine Initiative (PMI) was

launched, an effort to combine data from 1M volunteers from existing and new biomedical studies. The information in the PMI database will include genomics, lifestyle, and environmental factors to develop improved diagnostics, treatments, and preventions for diseases such as cancer and diabetes. The PMI team is focused on improving the practice and principles associated with participatory research that is transparent and respectful of the volunteer's contributions including issues of privacy. Gaining trust with the volunteers of PMI is at the fore of some of the revisions to the "Common Rule" which addresses research using human subjects and biospecimens, and comes in the wake of a recent report on egregious research practices by the US Public Health Service in the Tuskegee and Guatemala studies on sexually transmitted diseases. These concerns are outlined in the letter exchange between Obama and the Committee for Bioethical Issues, which is in the front matter of the report "[Ethically Impossible](#)."

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2. Yeampierre, E. Jan 2015. Building the Relationship: Citizen and Community Engagement in the Development of Research Projects. Trans-NIH Workshop to Explore the Ethical, Legal, and Social Implications (ELSI) of Citizen Science. [Video Link](#) (10min)
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9. Lynch, H. and Joffe, S. April 2, 2017. A Lesson From the Henrietta Lacks Story: Science Needs Your Cells. *New York Times*: A27. [Link](#)

17. John Willibanks (Chief Commons Officer of Biosage Network and Apple ResearchKit)

John Willibanks is a champion of open source data and scientific publications and has been involved in developing open source software and apps for Apple iPhone to collect data for medical research and digital informed consent. ResearchKit was launched in the spring of 2015, and within six months registered 100,000 volunteers through five new applications offered through social media. The launch of this project has preceded the public effort by the National Institutes of Health in the form of the Precision Medicine Initiative (PMI). PMI aims to combine data from 1M volunteers from existing and new biomedical studies. Like the apps using ResearchKit, the PMI database will include genomics, lifestyle, and environmental factors to develop improved diagnostics, treatments, and preventions for diseases such as cancer and diabetes. The PMI team is focused on improving the practice and principles associated with participatory research that is transparent and respectful of the volunteer's contributions including issues of privacy, while ResearchKit and other initiatives are tackling this by increasing transparency. Gaining trust with the volunteers of these open source databases is at the fore of some of the revisions to the "Common Rule" which addresses research using human subjects and biospecimens, and comes in the wake of a recent report on egregious research practices by the US Public Health Service in the Tuskegee and Guatemala studies on sexually transmitted diseases. These concerns are outlined in the letter exchange between Obama and the Committee for Bioethical Issues, which is in the front matter of the report "[Ethically Impossible](#)." Jeffrey Kahn, a bioethicist at John Hopkins University, spoke at the [Trans NIH-conference focused on citizen science](#) and reviewed some of the ethical, legal, and social implications and the exploration of funding initiatives to train a future cohort of bioethicists to handle this large scale data collection.

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18. Gail Javitt (Health Law and Bioethics scholar) or Radhika Rao (Health Law and Bioethics Scholar)

Both Gail and Radhika examine property rights as it applies to life science research. Gail addresses regulation of tissues and biobanking and serves on counsel for biotechnology companies and is on the faculty at the Berman Institute of Bioethics, Johns Hopkins University, and Radhika is on the faculty of the UC Hastings Law Center. They both have expertise in law, science, and public health. Gail has a specific focus on FDA regulations and genetic technologies, especially in the context of direct-to-consumer genetic testing. She has been critical of the ways in which the current "Common Rule" regulating human subjects research fall short in the contemporary era of biospecimen collected during clinical treatment or large scale database construction. In her analysis, she focuses on the two principles of protections involving privacy and property and explains how each is not a comprehensive approach to the complexities involved in the longitudinal use of these biospecimens. Though her view is presented prior to the launch of the Precision Medicine Initiative, it anticipates some of the concerns associated with this large-scale meta project. Gaining trust with the volunteers of open source medical databases is at the fore of some of the revisions to the "Common Rule" which addresses research using human subjects and biospecimens, and comes in the wake of a recent report on egregious research practices by the US Public Health Service in the Tuskegee and Guatemala studies on sexually transmitted diseases. These concerns are outlined in the letter exchange between Obama and the Committee for Bioethical Issues, which is in the front matter of the report "[Ethically Impossible](#)." Her work extends that of [Radhika Rao](#), who earlier raised the idea that individuals providing biological resources to life science research should be treated as both donors and human research subjects if the collection occurs during clinical treatment, diagnosis, or surveillance. More recently, Radhika in her role as a member of the California Human Embryonic Stem Cell Research Advisory Committee explored the challenges of informed consent in the context of biobanking and stem cell research during a symposium at UC Irvine held in November 2015 where she recalls the case of Henrietta Lacks to analyze the role of privacy and property in the context of commerce as well as the biotrust model pilot project in Michigan which is a perspective that David Winickoff supports.

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For Javitt specifically:

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8. Javitt, G. 2013. Take another little piece of my heart: Regulating the research use of human biospecimens. *Journal of Law, Medicine & Ethics*. 41(12):424-39. [Link](#) (shares content with Javitt 2010 but Javitt updates in the context of the new proposed guidelines for informed consent)

For Rao specifically

9. Rao, R. 2007. Genes and spleens: Property, contract, or privacy rights in the human body?. *The Journal of Law, Medicine & Ethics*. 35 (3): 371-382. [Link](#)
10. Arias, J., et al. 2015. Trust, vulnerable populations, and genetic data sharing. *Journal of Law and Biosciences*: 1-7. [Link](#)
11. Berskow, L. 2016. Lessons from HeLa cells: The ethics and policy of biospecimens. *Annual Review of Genomics and Human Genetics*. 17:395-417. [Link](#) (regrading proposed changes to Common Rule for de-identified specimens)

19. Ruha Benjamin (Sociologist/Race Scholar)

A graduate of Spelman College in anthropology Ruha received her PhD in sociology from UC Berkeley in 2008 and completed a postdoctoral fellowship at UCLA's Center for Society and Genetics in 2010. She is an assistant professor of American Studies at Princeton where her research interests span science, race, medicine, biotechnology, public health and critical social theory. She recently published a book titled *People's Science: Bodies and Rights on the Stem Cell Frontier*, which eloquently describes how society can support equity and innovation and critically analyzed the establishment and operation of the California Institute for Regenerative Medicine (CIRM), and some of this work regarding diversity is captured in the *Sociology Compass* article. Her TEDx talk provides a case study on the development of the HeLa Cell line. She also has a [twitter](#) feed.

1. Callaway, E. Aug 2013. Deal done over HeLa cell line. *Nature*. 500:132-133. [Link](#)
2. Benjamin, R. 2014. Race for cures: Rethinking the racial logics of 'trust' in biomedicine. *Sociology Compass*. 8(6): 755-769. [Link](#)
3. VIDEO Benjamin, R. 2015. From park bench to lab bench- what kind of future are we designing? TEDxBaltimore. (5-6 min, and 15-21:25 min). VIDEO [Link](#)
4. Lee, S. March 20, 2015. Why Apple's New ResearchKit Could Have a Diversity Problem. *Buzzfeednews.com*. [Link](#)
5. Kaiser, J. Jan 20, 2015. White House fleshes out Obama's \$215 million plan for precision medicine. *Science*. [Link](#)
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20. David Winickoff (Legal Scholar, and Science and Technology)

David Winickoff is the Director the Berkeley Program in Science and Technology Studies, and an Associate Professor of Bioethics at UC Berkeley. He received his law degree from Harvard and has proposed a BioTrust Model for population based genomics projects to address the controversies regarding the distribution of property rights, data access, risk, and benefits across different stakeholders such as researchers, human subjects, funders, medical institutions and private sector partners. By using the Biotrust model, a person is in control of the use of the tissue they donate to such projects, though they may not own the tissues themselves. Additionally, because DNA data from one person or donor can implicate related persons especially those of a homogenous community, the trust provides protection for all members of the community and thus, moves away from an individual rights approach to privacy and property to a communal approach. So unlike the HeLa Genome Access Working Group, a Donors Advisory Committee would determine which research projects could be conducted using the population's samples, not a single person's sample. This approach is discussed within the context of the "property rights bundle" by bioethicist Alta Charo in a short editorial included here that once

again references the tissues rights cases of John Moore, Greenberg (Canavan Disease), and Catalona (prostate cancer samples). David's model is based on capita in that biological resources serve as capital for the development of public goods, and he reflects on the Icelandic database project and the UK National Biobank as examples. However, others such as Fortun, address the use of labor-based models to involve participants/ donors in the decision making processes as described in the short review of the UK National Biobank.

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5. Winickoff, D. 2007. Partnership in U.K. Biobank: A third way for genomic property. *Journal of Law, Medicine, and Ethics*. 35 (3):440-56. [Link](#)
6. Arias, J., et al. 2015. Trust, vulnerable populations, and genetic data sharing. *Journal of Law and Biosciences*: 1-7. [Link](#)

21. Hannah Landecker (Science and Technology Scholar)

Hannah is the Director of the Institute for Society and Genetics at UCLA and an Associate Professor in the Sociology Department. Her work looks at the intersection of emerging technologies such as cell culture and the impact on society. In her book, *Culturing Life: How Cells Became Technologies*, she details the establishment of the HeLa cell line using an intersectional analysis applying gender and race perspectives. She also details the cases of John Moore and others in her paper below.

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