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PROTECTED GENETICS: A CASE FOR PROPERTY AND PRIVACY INTERESTS IN ONE'S OWN GENETIC MATERIAL

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I. HENRIETTA AND HER CELLS

[1] In 1951, a young black woman named Henrietta Lacks entered Johns Hopkins Hospital, having been diagnosed with cervical cancer.[1] There, a biopsy of her cancerous tissue was, without her knowledge or consent, taken.[2] The biological human tissue sample, produced from that biopsy procedure[3] would ultimately become more celebrated and influential than anyone present at that extraction might have dared to imagine.[4]

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[1] *See* REBECCA SKLOOT, THE IMMORTAL LIFE OF HENRIETTA LACKS 27–28 (Broadway Books 2010).

[2] *See id.* at 33.

[3] *See id.*

[4] *See* Catherine K. Dunn, *Protecting the Silent Third Party: The Need for Legislative Reform with Respect to Informed Consent and Research on Human Biological Materials*, 6 CHARLESTON L. REV. 635, 639 (2012).

[2] In her 2010 book, author Rebecca Skloot recounts this story of how a small cluster of cells scraped from the cervix of this impoverished woman from rural Virginia—a woman who grew to adulthood on the land her ancestors had once worked as slaves—became the cornerstone of millions, if not billions, of dollars worth of scientific research.[5] Looking back at the second half of the twentieth century, it would be an extraordinary challenge to find a discovery, innovation, or breakthrough involving human biology that did not, at some point, rely on these cells.[6]

A. The Cells

[3] HeLa cells, aptly named after the woman from which they derived, were developed into the world's first line of immortal human cells.[7] Immortal cells are cells that can reproduce continuously without degrading or dying out.[8] Typical human cells have a reproductive lifespan, just as human beings do, limiting the timeframe in which they can replicate themselves. Eventually, the copies that cells make of themselves begin to degrade, contaminated by bacteria or other microorganisms, producing corrupted replicas, ultimately becoming incapable of cellular reproduction and dying out.[9] Immortal cells are different. An immortal cell line reproduces indefinitely and constantly—almost obsessively—never dying out entirely.[10]

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[5] *See generally* SKLOOT, *supra* note 1 at 31–33 (describing the breakthrough scientific achievements of HeLa cells).

[6] *See id.* at 2.

[7] *See id.* at 41.

[8] *See id.* at 40–41.

[9] *See* SKLOOT, *supra* note 1 at 35–37.

[10] *See id.* at 40–41.

[4] Henrietta's cancer cells did just that, duplicating themselves at an impressive rate and continuing to do so indefinitely, unless frozen.[11] Her cells were the first to be capable of such a feat.[12]

[5] Before Henrietta Lacks, the ideal of an immortal line of human cells was nothing more than wishful thinking—a pipe dream of the scientific community–the stuff of science fiction.

[6] Her cells were unique and represented a major breakthrough for scientific research. For years, researchers had been attempting to grow human cells in culture, largely without success.[13] Using the same techniques and the same procedures they had been employing unsuccessfully, researchers expected the same results—eventual death of the cells.[14] Henrietta's normal cells performed as anticipated, dying just a few days after being put into culture.[15] Her cancer, however, grew at an indefatigable rate.[16] The very cancer that killed Henrietta would, inexplicably, lead to her immortality, and when it became clear to those with access to those cells just what it was that they had in their possession–the first ever line of immortal human cells–little time was wasted in announcing the breakthrough to the world.[17] HeLa cells made their debut on national television, a vial of them held out for the world to

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[11] *See, e.g.*, *id.* at 4 (discussing the proliferation of cell retention in laboratories).

[12] *See id.* at 40–41.

[13] *See generally* Skloot, supra note 1, at 34–41 (describing the laboratory environment of the cell culturist who developed HeLa).

[14] *See id.* at 40.

[15] *See id.* at 40–41.

[16] *See id.* at 41.

[17] *See* Rebecca Skloot, *Henrietta's Dance*, JOHNS HOPKINS MAG. (Apr. 2000), http://pages.jh.edu/jhumag/0400web/01.html, https://perma.cc/6DR4-NSDN.

see—a victory for science and for mankind, heralding a new age of medicine and discovery.[18]

[7] At the same time, Henrietta lay prostrate in a hospital bed at Johns Hopkins, succumbing to the same cancer contained in that vial.[19] After she passed away, she was "buried in an unmarked grave."[20]

[8] For most of the HeLa cells' history, they were not connected to Henrietta, the person, in any meaningful way.[21] A chance mention of her name by a professor in a community college class inspired a teenager named Rebecca Skloot to embark on a years-long journey to remedy that—looking beyond the cells themselves, to the life that had produced them.[22] Skloot sought to know and to make known the woman whose cancerous misfortune led to such astonishing and important things as the polio vaccine and chemotherapy.[23] Skloot succeeded in that endeavor when in 2010, twenty-two years after first hearing Henrietta's name, she

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[18] *See* SKLOOT, *supra* note 1, at 56–58.

[19] *See* Dunn, *supra* note 4, at 637–38.

[20] Denise Watson Batts, *After 60 Years of Anonymity, Henrietta Lacks Has a Headstone*, VIRGINIAN-PILOT ONLINE (May 30, 2010), http://pilotonline.com/news/local/after-years-of-anonymity-henrietta-lacks-has-a-headstone/article_5bb9a40e-8cd5-5ed7-927e-736d80972099.html, https://perma.cc/S34Y-CFGR (stating that Henrietta Lacks was buried in an unmarked grave. In 2010, Dr. Roland Pattillo, who had worked with HeLa cells, donated the money necessary to give her a headstone).

[21] *See generally* SKLOOT, *supra* note 1, at 1–6 (describing the ubiquity of information about the cells and contrasting it with the scarcity of information about Henrietta).

[22] *See id.* at 2–4, 7.

[23] *See* Alexandra del Carpio, *The Good, The Bad, and The HeLa*, BERKLEY SCI. REV. (Apr. 27, 2014), http://berkeleysciencereview.com/article/good-bad-hela/, https://perma.cc/VFU8-KKLL; *see also* SKLOOT, *supra* note 1, at 2–4.

published her biography of Henrietta, Henrietta's family, and the HeLa legacy.[24]

[9] *The Immortal Life of Henrietta Lacks* catapulted Henrietta, her cells, and her family into the national spotlight. It spent seventy-five weeks on the New York Time's bestseller list,[25] became required reading at educational institutions across the country,[26] and in April 2017 HBO premiered a film version starring Oprah Winfrey.[27]

[10] Henrietta's story has captured the imagination of almost everyone it is exposed to. However, reactions to her story vary–from awe at all that arose from such seemingly unremarkable circumstances, to gratitude for all that her cells have made possible, to indignation and outrage on her behalf.[28] For many, the harsh reality that Henrietta died impoverished and in pain, her contributions unknown, while so many strangers benefited

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[24] Skloot first heard of Henrietta Lacks in a community college class she attended as a high school student in 1988. *See* SKLOOT *supra* note 1, at 2; *see* Patricia Cohen, *Returning the Blessings of an Immortal Life*, N.Y. TIMES (Feb. 4, 2011), http://www.nytimes.com/2011/02/05/books/05lacks.html, https://perma.cc/724L-YXJX.

[25] *See Books - Best Sellers Paperback Nonfiction*, N.Y. TIMES (Aug. 26, 2012), https://www.nytimes.com/books/best-sellers/2012/08/26/paperback-nonfiction/, https://perma.cc/KDN2-STZ6.

[26] *See Online Catalog*, RANDOM HOUSE FOR HIGH SCHOOL TEACHERS (Apr. 7, 2017), http://www.randomhouse.com/highschool/catalog/display.pperl?isbn=9781400052189, https://perma.cc/RPV2-YEA9.

[27] *See* Erik Pedersen, *Oprah Winfrey Starrer 'The Immortal Life of Henrietta Lacks' Gets HBO Premiere Date*, DEADLINE HOLLYWOOD (Feb. 14, 2017, 10:42 AM), http://deadline.com/2017/02/oprah-winfrey-immortal-life-of-henrietta-lacks-premiere-date-hbo-rose-byrne-1201911527/, https://perma.cc/8TNG-WUDA.

[28] *See generally* Robin McKie, *Henrietta Lacks's Cells Were Priceless, but Her Family Can't Afford a Hospital*, GUARDIAN (Apr. 3, 2010), https://www.theguardian.com/world/2010/apr/04/henrietta-lacks-cancer-cells, https://perma.cc/P7HW-5SEJ (describing her story as "disturbing").

from the products of her body–taken without her knowledge and without her consent—is difficult to accept.

B. Henrietta Lacks, The Woman

[11] Henrietta was born as Loretta Pleasant in Roanoke, Virginia in 1920.[29] It is unclear why or when she came to be called Henrietta.[30] She was one of ten siblings, and following her mother's death in 1924, her father moved the entire family to Clover, Virginia, where the siblings were divided amongst relatives to be cared for.[31] There, Henrietta shared a cabin with her grandfather and cousin.[32]

[12] Henrietta later married that cousin, David Lacks, in 1941.[33] The couple already had two children.[34] After marrying, they moved to Baltimore, Maryland.[35] It was there, after giving birth to their fifth child, that Henrietta sought medical attention for vaginal pain and bleeding.[36] At that time, Johns Hopkins was the only hospital in the area that treated black patients, particularly poor ones like Henrietta who could not afford medical care.[37]

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[29] SKLOOT, *supra* note 1, at 18.

[30] *See id.*

[31] *See id.*

[32] The cabin Henrietta grew up in was situated on land that had once belonged to her great-grandfather, a white slaveholder. The cabin itself had once housed his slaves. *See id.* at 18, 122–24.

[33] *See id.* at 24.

[34] *See* SKLOOT, *supra* note 1, at 23.

[35] *See id.* at 24–26.

[36] *See id.* at 13–15.

[37] *See* SKLOOT, *supra* note 1, at 15.

[13] In many ways, an intersection of two major themes of Henrietta's life—poverty and being a black minority—created the circumstances that allowed her cells to be harvested and commercialized. It is worth questioning whether an affluent white woman would have had the same experiences as Henrietta, or been taken advantage of quite so easily.[38]

[14] Back in that day, many physicians and researchers believed that poor patients who received reduced or no-cost medical care were freely available for testing–consensual or otherwise–almost as a form of payment.[39] In general, very few people felt that it was morally necessary to gain a patient's permission before obtaining, storing, or analyzing any tissue sample.[40] It is extremely unlikely that anyone would have thought of it as being so much as a common courtesy, let alone a prerequisite to the maintenance of her human rights, to inform someone like Henrietta of what had been done to her.[41]

[15] This is no longer the way of the world. Today, it would be an appalling violation of ethical and legal standards for a physician to perform a biopsy without the informed consent of his patient.[42] One might hope that modern standards would extend beyond the biopsy itself to the usage of tissue samples. That modern legal, social, and moral standards would mandate a different result. It might be expected that, in today's world, Henrietta would have had the right to decide for herself. That she

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[38] *See id.* at 64.

[39] *See id.* at 29–30.

[40] *See* Gail Javitt, *Why Not Take All of Me? Reflections on The Immortal Life of Henrietta Lacks and the Status of Participants in Research Using Human Specimens*, 11 MINN. J.L. SCI. & TECH. 713, 718 (2010).

[41] *See* Natalie Ram, *Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research*, 23 HARV. J. LAW & TECH. 119, 134 (2009).

[42] *See* Dunn, *supra* note 4, at 645–47.

would have been legally entitled to choose whether her cells were used for research. It is uncertain whether she would have.

[16] Despite these changes in expectations over a person's right to full control over their body, it is possible that in today's world, there isn't much about Henrietta's story that would turn out differently. Granted, the initial biopsy would not have been undertaken without her knowledge or consent.[43] However, there is not much reason to believe that once a sample was taken, she would have had any control over what happened to it.[44] In fact, the evidence suggests otherwise; that she, or any other person, would have very little control at that point.[45]

II. BIOBANKS

[17] Today, biopsies are regularly performed medical procedures,[46] and although Henrietta never had the opportunity to consent to hers, it is fair to speculate that her modern-day counterpart would consent without second thought.[47] Biopsies are a routine part of cancer treatments, used to diagnose, assess, and provide individualized care.[48] The biopsy itself does not present a challenge. The challenge lies in what is done, and what ought to be done, with leftover human tissue that is no longer needed for the purpose for which it was originally taken?

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[43] *See id.* at 646.

[44] *See id.* at 635,647.

[45] *See id.* at 647.

[46] *See* Elizabeth R. Pike, *Securing Sequences: Ensuring Adequate Protections for Genetic Samples in the Age of Big Data*, 37 CARDOZO L. REV. 1977, 1988 (2016).

[47] *See* Lori B. Andrews, *Harnessing the Benefits of Biobanks*, 33 J.L. MED. & ETHICS 22, 23 (2005).

[48] *See* Pike, *supra* note 46, at 2032.

[18] The following section discusses what becomes of our biological leftovers, and whether any individual should have the right to decide for themselves whether their tissue is saved or discarded.

[19] Every day, individuals across the country and around the world consent to a variety of medical tests and procedures, many of which require the extraction of their body tissue.[49] These tests range from the commonplace (drawing blood at an annual physical) to the unexpected (an emergency appendectomy).[50] Very few of these individuals will wonder what happens to their leftover tissue: what becomes of the blood, the bone marrow, the appendix that goes unused? Unfailingly, many just assume it is discarded.[51] Sometimes, it is. However, often it is not. Rather, it is stored.[52]

[20] Biobanks are institutions that collect and distribute biological materials—often human tissue or blood—for research purposes.[53] When researchers need human material, they peruse a catalogue and order what they need.[54] Specimens are sorted by type (blood, bone marrow, etc.), and labelled with their demographical designations ("male", "thirty years old", and "Caucasian").[55] The source's name, or other "identifying" information, is not included.[56]

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[49] *See* Andrews, *supra* note 47, at 25.

[50] *See* Pike, *supra* note 46, at 1988.

[51] *See id.*

[52] *See* Dunn, *supra* note 4, at 642–43.

[53] *See* Andrews, *supra* note 47, at 23.

[54] *See id.*

[55] *See, e.g.,* HS-5 (ATCC® CRL-11882™), AMERICAN TISSUE CULTURE CATALOGUE, https://www.atcc.org/Products/Cells_and_Microorganisms/By_Tissue/Bone_Marrow/CRL-11882.aspx, https://perma.cc/P3GM-7LHL (last visited Apr. 2 2017) (stating that CRL-11882 is a human bone marrow sample taken from a thirty year old white man and can be purchased by a for-profit company for $431 USD, or by a non-profit organization for $359.15).

[21] Biobanks are an invaluable resource for the scientific community.[57] Without them, researchers might waste invaluable time, money, and resources in acquiring enough specimens–of appropriate type and variety–necessary to conduct their studies. This comment does not argue against the existence of biobanks. They are a necessary resource and should exist. Instead, this comment critically examines the methodology employed in the creation of these biobanks, arguing that the methodology must change to protect the rights of ordinary individuals whose bodily products are bought and sold without their knowledge.

[22] Most of the human samples stored and sold by biobanks are the leftover byproducts of medical testing.[58] As described above, a person goes to the doctor, and has blood work done. Once the testing has concluded, the unused blood is often sent for storage at a biobank, where it is accessible to researchers across the country—perhaps even the world.[59]

[23] Henrietta's story, a half-century ago, is achingly similar to this modern process. She went to a hospital, received medical care, and died, none the wiser that some small piece of her had been taken and stored for future use.[60]

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[56] *See id.* (demonstrating that the source's name and other personal information is not included).

[57] *See generally* J.E. Olson, et al., *Biobanks and Personalized Medicine*, 86 CLINICAL GENETICS 51, 51 (2014) (describing how biobanks provide crucial infrastructure and support for clinical genetics).

[58] *See* Pike, *supra* note 46, at 1979.

[59] *See id.*

[60] *See generally* SKLOOT, *supra* note 1, at 32-33, 40, 66 (telling the story of Henrietta's life, her experience at Johns Hopkins, and her eventual death).

[24] Most people would hope to have control over whether their tissue is taken and stored like this,[61] or that they would at least *know* that their biological materials—their genetic information, something so intrinsically *theirs*—was being used for this purpose.

[25] Unfortunately, that is not the case.[62] More than likely, any person alive today is no more protected in this regard than Henrietta Lacks was when she walked into Johns Hopkins.

[26] Very few people are aware that their unused biological material is saved at all, let alone saved for the purpose of sale and distribution to scientists and researchers. Many would hope that they would be asked, or at least informed, before their samples were kept or sold.[63] Despite this, it is not common practice to inform someone when their medical waste is saved instead of being discarded, let alone request permission to do so. This comment argues that consumers and patients have the right to be informed, and the right to control what becomes of their own genetic materials.

A. A Moore Modern Henrietta?

[27] In 1976, a man named John Moore was diagnosed with leukemia.[64] While treated, copious amounts of blood and other samples were taken from his body.[65] Without his consent, some of Moore's cells were turned into commercial cell lines—similar to Henrietta's.[66] Despite the fact that the doctor who treated him and the hospital where he was being treated

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[61] *See* Dunn, *supra* note 4, at 644–45.

[62] *See* Andrews, *supra* note 47, at 23.

[63] *See* Dunn, *supra* note 4, at 645.

[64] *See* Moore v. Regents of University of California, 51 Cal. 3d 120, 125 (Cal. 1990).

[65] *See id.* at 125–26.

[66] *See id*. at 126–27.

profited substantially from the sale of his cells, Moore did not receive any compensation.[67]

[28] Moore brought several claims, among them a claim for a breach of informed consent, a breach of fiduciary duty, and a claim of conversion.[68] The California court addressed the merits of the conversion claim, finding that Moore did not have a sufficient property interest in his cells to sustain the claim.[69]

[29] The story of John Moore eerily echoes that of Henrietta Lacks. Both should be taken as cautionary tales, and as clear examples of why there exists a need for extensive protections for the rights of individuals to have control over their own genetic information and materials.

B. Proposed Protections

[30] Protections of this kind are generally conceived under one of two already-existing legal frameworks: privacy or property.[70] Property regimes orient around the right to patent, commercialize, or otherwise control genetic information or genetic materials themselves,[71] while privacy regimes focus on disclosure or dissemination of genetic information found in human tissue samples.[72] Scholarship on the matter tends to pit these frameworks against one another,[73] asking the question of whether a

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[67] *See id.* at 127–28

[68] *See Moore*, 51 Cal. 3d 120 at 128 n.4.

[69] *See id.* at 136–38.

[70] *See* Anya E.R. Prince, *Comprehensive Protection of Genetic Information: One Size Privacy or Property Models May Not Fit All*, 79 BROOK. L. REV. 175, 175 (2013).

[71] *See id.* at 183.

[72] *See id.* at 184–85.

[73] *See generally* Jaclyn G. Ambriscoe, Note, *Massachusetts Genetic Bill of Rights: Chipping Away at Genetic Privacy*, 45 SUFFOLK L. REV. 1177, 1209–11 (2012)

privacy right or a property interest best protects individuals against the sort of infringement and violation suffered by Henrietta Lacks.[74]

[31] Proposed here is not solely a property or a privacy regime, but rather an attempt to weave the two types of rights together in an effort to comprehensively protect a right that most Americans believe ought to exist.

[32] In what ways might a modern Henrietta be protected from a transgressional, trespassory use of her body, her cellular being, and her very DNA? This comment seeks to use existing legal structures and the promulgation of newly recognized rights to create a framework through which a person in Henrietta's situation would not only have their rights vindicated, but would have rights to assert in the first place.

[33] The law is lagging, falling woefully short of protecting rights of individuals when it comes to their DNA, their genetic materials, and their genetic information. This next section briefly explores current law at the federal level, noting its shortcomings and inadequacies, to showcase the need for new law. Then, a sampling of state legislation is discussed, with particular focus on those states, which have created a statutorily designated property interest in genetic information. The designation of a property interest in genetic information ultimately forms the backbone of my proposed legislation, with a supplementary privacy right encompassed within it.

III. CURRENT FEDERAL LAW

[34] Federal protections for the genetic information of individuals as a privacy right are found mainly in the Genetic Information Nondiscrimination Act ("GINA"), which prohibits genetic discrimination in the health insurance and employment contexts.[75] Under GINA, health

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(describing the ways in which combining privacy and property rights is like mixing "oil and water").

[74] *See id.* at 1185–87.

insurance companies may not deny benefits to anyone because of any genetic predisposition they may have to certain illnesses or afflictions.[76] Similarly, it is against the law for employers to use genetic testing to determine any aspect of a person's employment.[77]

[35] Notably, the focus of GINA (and of many other statutes designed to protect individuals in this realm) is the prevention of discrimination based on an individual's genetic information.[78] This is not the focus here—Henrietta was not discriminated against because of anything found in her genes. While admirable, protection against genetic discrimination does not solve the problem found in Henrietta's story.

[36] In the field of medical and scientific research, individual protections reach no further than the Common Rule.[79] The Common Rule regulates federally-funded research whenever that research uses human being as subjects.[80] The Common Rule requires informed consent—a concept taken from doctor-patient interactions and requirements—as its strongest protection for otherwise-vulnerable subjects.[81] Consent is only informed, and therefore valid, when it is given after a potential subject is made aware of all information relevant to her decision to participate (or

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[75] *See* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

[76] *See id.*

[77] *See id.*; *see also,* H.R. 1313, 115th Cong. (1st Sess. 2017) (permitting employers to demand genetic test results from their workers).

[78] *See* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

[79] *See* 45 C.F.R. § 46.101(a) (2017).

[80] *See id.*

[81] *See* 45 C.F.R. § 46.116(a)(1)–(5) (2017).

not) in any given study.[82] Consent is not informed if, for instance, potential side effects are not disclosed beforehand.[83]

[37] The Common Rule expands on the principle of informed consent, articulating the specific disclosures required for the use of human test subjects.[84] Subjects must be told that their consent can be withdrawn at any time; that agreement to participate at the onset of a study never requires someone to continue their participation if, at any time, they wish to stop.[85] The Common Rule also requires certain findings of ongoing studies to be disclosed to the subjects of those studies, if preliminary findings might affect a person's willingness to continue to participate.[86]

[38] The U.S. Food and Drug Administration imposes similar standards on the studies it reviews,[87] effectively extending the Common Rule beyond those studies that are federally-funded.[88]

[39] This is the extent to which human research is governed at the federal level, and while the Common Rule provides extensive protections to human beings engaged in scientific studies, it does not extend to research using human tissue.[89] Under guidance issued by the federal Office of Human Research Protections in 2004, tissue samples collected for present or future research are *not* covered by the consent provisions of

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[82] *See id.*

[83] *See* 45 C.F.R. § 46.116(a)(2)–(3) (2017).

[84] *See* 45 C.F.R. § 46.116(a)(1)–(8) (2017).

[85] *See id.* at (a)(8).

[86] *See id.* at (b)(5).

[87] *See generally* 21 C.F.R. § 50.1 (2017) (discussing standards for clinical investigations run by the Food and Drug Administration).

[88] *See* 21 C.F.R. §§ 56.109, 812.25 (2017).

[89] *See* Ram, *supra* note 41, at 140.

the Common Rule, as long as those samples are without personally identifying information.[90] If a sample is not linked to an individual, then it is not protected by federal regulation.[91]

[40] The existence of the Common Rule during Henrietta's lifetime would not have stalled the events that culminated in the world's first immortal cell line. The story of Henrietta Lacks is a helpful rubric against which the legislation proposed by this comment is graded. In what ways could federal law protect a modern Henrietta?

IV. CURRENT STATE LAW

[41] Without federal protection, the onus of protecting the rights of individuals in their genetic material has fallen to the states. Many states have genetic privacy laws requiring informed consent to *disclose* genetic information,[92] but just eight states require that *same* consent to retain that *same* information.[93] Only five states recognize a personal property interest in genetic information for the individual to whom that information pertains.[94] This section first addresses these different state-level property regimes, assessing their strengths and weaknesses and using them to build

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[90] *See id.*

[91] A question must be asked whether, in an age of DNA testing, a tissue sample containing genetic information can ever be truly anonymous. Research has shown that even an incomplete DNA sample can be matched to the unique individual from whom it was taken, which renders the concept of 'anonymous genetic material' somewhat obsolete. *See generally* Amy L. McGuire & Richard A. Gibbs, *Genetics: No Longer De-Identified*, 312 SCIENCE MAG. 370, 370–71 (2006) (discussing research finding that an individual can be identified with just 75 single-nucleotide polymorphisms).

[92] *See* NAT'L CONF. OF STATE LEGS., GENETIC PRIVACY LAWS, NCSL, http://www.ncsl.org/research/health/genetic-privacy-laws.aspx, https://perma.cc/ZB3Q-RQT9 (last updated Jan. 2008) (stating that 17 states required informed consent).

[93] *See id*.

[94] These states are Alaska, Colorado, Florida, Georgia, and Louisiana. *See id.*

the foundation for a federal rule recognizing a similar right. From there, I take a broader look at state-level privacy regimes to consider how the right of privacy might be expanded beyond the realm of discrimination to strengthen my proposed protections.

[42] Of the states that recognize some sort of property interest related to genetic data, three states–Colorado,[95] Georgia,[96] and Louisiana[97] – recognize the interest as inhering only in the genetic information and not in the genetic samples themselves.[98] These statutes provide a civil remedies for violations (i.e. the unauthorized disclosure of genetic information), but those protections extend only to instances of discrimination in the health insurance context.[99] As currently written and enforced, these state statutes provide no more protection than current federal regulation, and so do not solve the problem raised by the story of Henrietta Lacks. Statutes that do not reach beyond employment and insurance discrimination and into the realm of research conducted using human tissue samples would not have helped Henrietta.

[43] Of the remaining states that recognize a property interest in genetic information, we can learn several things. First, the most comprehensive state system currently enacted shows us just how far legislation needs to

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[95] *See* COLO. REV. STAT. § 10-3-1104.7(1)(a) (2016) (holding genetic information as property and imposing remedies for a violation of such property).

[96] *See* GA. CODE. ANN. § 33-54-1 (2016) (holding genetic information as property and imposing remedies for a violation of such property).

[97] *See* LA STAT. ANN. § 22:2013(E) (2017) (imposing remedies for a violation of such property).

[98] *See generally* NAT'L CONF. OF STATE LEGS., *supra* note 92 (discussing the eight states require informed consent for the retention of genetic information—Alaska, Delaware, Minnesota, Nevada, New Jersey, New Mexico, New York, and Oregon. Five states identify a personal property interest in genetic information: Alaska, Colorado, Florida, Georgia, and Louisiana).

[99] *See* COLO. REV. STAT. § 10-3-1104.7(12)-(13) (2016); GA. CODE. ANN. § 33-54-8 (2016); LA STAT. ANN. § 22:2013(E)–(F) (2017).

go to truly protect the interests of individuals in this context. Second, is a bit of a cautionary tale, a lesson in how it is not enough for statutory language to be broad enough that it *could* encompass research. Statutes must specifically address the use of human tissue in research, explicitly subjecting researchers to the same standards imposed upon physicians and others when it comes to the use and misuse of someone's genetic material. Finally, we will briefly confront a common policy argument against the promulgation of the rights suggested in this comment.

A. The Model Case

[44] Of the states that recognize a property interest in genetic data, just one explicitly identifies a physical genetic *sample* in and of itself as the personal property of the individual from whom the sample is derived—Alaska.[100]

[45] The Alaska statute provides that a DNA sample and the results of any analysis of that sample are the "exclusive property" of the individual sampled.[101] The collection, analysis, or retention of a DNA sample without the informed consent of that individual is a violation of Alaska law, as is the intentional disclosure of any such analysis without the requisite consent.[102] While there are exemptions to this standard,[103] Alaska has the most comprehensive protection regime for individuals' rights over their own genetic material.

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[100] *See* ALASKA STAT. § 18.13.010(a)(2) (2016).

[101] *See id.*

[102] *See* ALASKA STAT. § 18.13.010(a)(1) (2016).

[103] Such as samples collected for law enforcement purposes; the collection of DNA samples in this realm is a common exception to most all legislation on the matter. Whether this should be the case is a question worth asking, but is not within the scope of this comment. *See* ALASKA STAT. § 18.13.010(b)(1)–(5) (2016).

[46] Creating these rights are one thing, and enforcing them is another. To that end, Alaska created both a private cause of action[104] and a criminal penalty–enforceable against those who collect, analyze, retain, or disclose genetic information in violation of the statute.[105] If a violation results in profit or monetary gain for the violator, he may be civilly liable for up to $100,000.[106]

[47] Had Henrietta's cells been taken, tested, and commercialized without her knowledge in modern day Alaska, she could have recovered hundreds of thousands of dollars from those who profited from the extensive research conducted using her cells. She may not have died impoverished, when so many profited from her cells. She may not have gone unacknowledged for decades after. She might have had a headstone.[107]

B. A Cautionary Tale

[48] Florida is the fifth and final state recognizing a property interest in genetic information.[108] Like Alaska, Florida recognizes a criminal penalty for violations of these protections.[109]

[49] Under Florida law, challenges arise not from the inadequacy of legislation, but from courts' narrow interpretations of the legislation–restricting its scope, rendering it ineffective at protecting individuals in the context of scientific research. Florida's law is broad enough to form an

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[104] *See* ALASKA STAT. § 18.13.020 (2016).

[105] *See* ALASKA STAT. § 18.13.030(a), (c) (2016).

[106] *See* ALASKA STAT. § 18.13.020 (2016).

[107] *See* Batts, *supra* note 20.

[108] *See* FLA. STAT. § 760.40 (2)(a) (2016).

[109] *See* FLA. STAT. § 760.40 (2)(b) (2016) .

attempted extension of the desired protections. However, it still fails the public, as it must also be specific enough that it cannot be interpreted otherwise.

[50] The Florida legislature approaches genetic information as a civil rights issue, protecting its citizens from discrimination in areas such as "insurance, employment, mortgage, loan, credit, or educational opportunity"[110] based on their genetics. It is the specificity of this objective that allows courts to interpret the statute as narrowly as possible.

[51] As a result, despite seemingly enthusiastic protection provided by the Florida statute, practically these rights are nearly unenforceable when violated for the purpose of scientific research.

[52] Use in scientific research is not one of the several exceptions[111] built into the Florida statute for certain uses of genetic information. A literal reading might lead to the belief that individuals *are* protected against unauthorized use of their genetic information in that context. Courts have not agreed with this interpretation.[112]

[53] In 2003, a federal district court for the Southern District of Florida held that protections offered to individuals regarding their genetic

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[110] FLA. STAT. § 760.40 (3) (2016).

[111] *See* FLA. STAT. § 760.40 (2)(a) (2016) ("Except for purposes of criminal prosecution, except for purposes of determining paternity as provided in s. 409.256 or s. 742.12(1), and except for purposes of acquiring specimens as provided in s. 943.325, DNA analysis may be performed only with the informed consent of the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.").

[112] *See generally* Greenberg v. Miami Children's Hosp. Research Inst., Inc., 264 F. Supp. 2d 1064 (S.D. Fla. 2003) (holding that plaintiffs could not recover under the Florida statute protecting against misuse of genetic information).

information did *not* extend to the realm of scientific research.[113] For the court, informed consent principles apply only in the context of patient-doctor relationships, and do not extend to the researcher-subject relationship.[114]

[54] The *Greenberg* case addressed a dispute arising from the patent of a gene sequence[115] discovered as a result of research conducted using tissue samples from children born with Canavan[116] disease.[117] Plaintiffs were the parents of those children.[118] They claimed that the eventual patenting and commercialization of the research product–made possible by their children's genetic information–was beyond the scope of what they had consented to.[119] Plaintiffs argued that because the researchers' economic interest had not been revealed to them at the outset, the patenting of the genetic sequence amounted to unlawful conversion of plaintiff's property, and any money made subsequent to that patent was unjust enrichment.[120]

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[113] *See id.* at 1075.

[114] *See id.* at 1069.

[115] Today, this case might have resolved slightly differently. In 2013, the Supreme Court ruled that genes found in nature are not patentable merely because a particular person or institution has isolated any particular gene. *See* Association for Molecular Pathology, et al. v. Myriad Genetics, Inc., et al., 133 S. Ct. 2107, 2120 (2013).

[116] Canavan disease is a neurological genetic disorder. Children born with Canavan disease typically die before age ten. *See* NAT'L INST. OF NEUROLOGICAL DISORDERS AND STROKE, *Canavan Disease Information Page*, NIH, https://www.ninds.nih.gov/Disorders/All-Disorders/Canavan-Disease-Information-Page, https://perma.cc/HHW7-VT7D (last visited Apr. 1, 2017).

[117] *See Greenberg*, at 264 F. Supp. 2d 1064 (S.D. Fla. 2003)

[118] *See id.* at 1066.

[119] *See id.* at 1068.

[120] *See id.* at 1072.

[55] Despite the statutory language regarding genetic information being broad enough to encompass this circumstance,[121] and despite the designation of a property interest in genetic information,[122] the court ultimately declined to find a property right for the *Greenberg* plaintiffs.[123] Ultimately, their suit was dismissed.[124]

[56] The court in *Greenberg* failed to cite statutory language supporting its decision, instead leaning heavily on policy arguments.[125] The court reasoned that the links between the physical samples, to the information in those samples, to the research conducted using that information, to the results of that research, to the ultimate commercialization of those results were too attenuated to fall within the intended scope of the statute.[126] This argument is not entirely without merit but does not fully justify the decision.

[57] To supplement this justification, the court raised a concern commonly invoked whenever a restriction on research is proposed—that recognizing this sort of right would too heavily burden research, resulting in a negative impact to society as a whole.[127] The court goes so far as to

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[121] *See* FLA. STAT. § 760.40(1) (2016).

[122] *See id.* at (2)(a).

[123] *See* Greenberg v. Miami Children's Hosp. Research Inst., Inc., 264 F. Supp. 2d 1064, 1075 (S.D. Fla. 2003).

[124] *See id.* at 1077.

[125] *See id.* at 1076.

[126] *See id.*

[127] *See generally* Natalie Anne Stepanuk, *Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U. L. REV. 1105, 1135 (1998) (discussing how legislation must take into account the interests of researchers and the public, as well as the donors of any biological material); *see also* Ram, *supra* note 41, at 121–22 (noting

claim that permitting plaintiffs to bring a cause of action for conversion would "cripple" medical research.[128]

[58] This is a common policy argument made against the sorts of rights and protections proposed by the plaintiffs in *Greenberg*, in this comment, and elsewhere. This argument weighs the good done by scientific research against the infringement of the natural rights of any one person, deciding that the good of society must outweigh the rights of any individual person.[129]

[59] This sort of values judgment can certainly be appealing. But in an ethical context, an argument that pits the ease of research against the personal rights and liberties of individual people unreasonably relies upon the specter of a negative outcome that is not certain. A requirement to acquire informed consent before conducting research on any one person's genetic materials would hinder research, this is true—but so did requiring informed consent before conducting experiments on human beings;[130] so did the abolition of slavery, when research could no longer be conducted on unwilling human chattel.[131] Research will persist, regardless.

C. States Without a Property Interest

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that researchers and society have strong interests in tissue research, and that the interests of donors, researches, and society as a whole deserve respect and protection).

[128] *See* Greenberg v. Miami Children's Hosp. Research Inst., Inc., 264 F. Supp. 2d 1064, 1076 (S.D. Fla. 2003).

[129] *See generally id.* at 1074–76 (discussing the impact a property right in genetic material would have on research).

[130] *See, e.g.*, SKLOOT, *supra* note 1, at 131–33 (describing how the term 'informed consent' did not arise until the mid-1900s).

[131] *See, e.g.,* L.L. Wall, *The Medical Ethics of Dr. J. Marion Sims: A Fresh Look at the Historical Record*, 32 J. MED. ETHICS 346, 348 (2006) (describing how the father of gynecology relied on slaves as research subjects).

[60] State genetic privacy statutes are somewhat more common than statutes identifying a personal property right in genetic information. However, of the twenty-seven states that require consent for the dissemination of an individual's genetic information, only twelve require that same consent for the performance of a genetic test, and even fewer require consent to obtain, access, or retain genetic information.[132] This inconsistency speaks to the need for federal regulation to standardize the rights of all Americans in the realm of genetic information.

[61] Of all the states, only two (Alaska and New Mexico) require consent for performing a genetic test; obtaining, accessing, or retaining genetic information; *and* disseminating that information.[133] New Mexico provides a civil remedy for those whose genetic information has been acquired or used in violation of the statute, although the damages are restricted to actual damages plus $5,000[134]—a relatively small sum.

[62] In any state other than Alaska, a modern day Henrietta would be unable to vindicate her rights, as she would likely have no rights to vindicate. Her cells were made anonymous and no information gleaned from them was used to discriminate against her in any way. As the cells were studied and distributed, information gleaned from them was not linked to Henrietta or to the Lacks family. Most information gleaned from the cells had nothing to do with Henrietta at all—the use of the cells was their ability to reproduce and be used as test subjects,[135] not in any secrets hidden in the strands of her DNA.

[63] Federal recognition of a property interest in one's own genetic information and material, extending fully into the realm of research, is

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[132] *See* NAT'L CONF. OF STATE LEGS., *supra* note 92.

[133] *See id.*

[134] *See* N.M. STAT. ANN. § 24-21-6(c)(3) (2016).

[135] *See* SKLOOT, *supra* note 1, at 41.

necessary to prevent injustice. A property regime gives individuals the legal structure necessary to truly exercise control over their own genetic material.

V. THEORIES OF PROPERTY AND PRIVACY

[64] The Alaskan structure for protecting individual rights in the realm of genetic information is the most comprehensive of any state, as it recognizes both a property interest in one's[1] own genetic information as well as privacy right protection against unwarranted obtainment and disclosure of that same information.[136]

A. Property

[65] At a most fundamental level, to own something as one's own property is to have complete dominion and control over that thing.[137] In the context of one's own body and body products, there is a natural inclination to want that sort of control. Many people may even feel some degree of discomfort with the idea that human bodies can be property in the way that a house or a car are. This could be because there is an implicit understanding that if something is property, it is therefore alienable.[138] Property, as we understand it, has economic value.[139] It can be bought, and it can be sold.[140]

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[136] *See* ALASKA STAT. § 18.13.020 (2016).

[137] *See* LAWRENCE LESSIG, CODE: AND OTHER LAWS OF CYBERSPACE 161 (2nd ed. 1999).

[138] *See* Sonia M. Suter, *Disentangling Privacy from Property: Towards a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 755 (2004).

[139] *See id.* at 746.

[140] *See id.* at 758.

[66] The idea that a human body, or any part of it, can be bought or sold is an uncomfortable one, and for good reason.[141] Moving beyond that initial reaction, however, allows us to view property regimes with a more open mind.

[67] Strong public policy working against alienation of a particular type of property can ultimately counteract the alienability of that property.[142] This theory of property is underutilized in American jurisprudence, largely because of the belief that free alienation of property best serves the interests of society as a whole.[143] Public policy is therefore rarely interpreted as favoring any restriction on alienability. In the instance of human bodies, an exception should be made.

[68] Human tissue samples hold immense economic value.[144] We live in a world where biological samples and genetic data is collected, aggregated, analyzed, and commercialized.[145] It is insincere to pretend otherwise, and placing an arbitrary restriction solely on individuals seeking to commercialize their *own* biological materials serves to remove them from the market without impacting the existence or the robustness of that market.[146] This makes donors of genetic material vulnerable, as they

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[141] *See generally* Suter, *id.* at 809. The United States has a culture of deep shame surrounding its history with the slave trade, leading many to feel generally uncomfortable with the idea of selling people, or parts of people, and the coercive effects this could have on the impoverished. *See also* Ambriscoe, *supra* note 73, at 1211 (arguing that there is a risk individuals would be coerced into selling their genetic information).

[142] *See* RESTATEMENT (FIRST) OF PROP. § 489 cmt. a (1944).

[143] *See* Suter, *supra* note 138, at 755.

[144] *See id*. at 758.

[145] *See id*.

[146] *See* Suter, *supra* note 138, at 757.

are the only ones who are unable to profit off of something that is, in all conventional senses, very much "theirs."[147]

[69] If the goal is to give individuals autonomy over their own genetic information and material, a property interest feels almost essential. Property doctrine is an efficient device for allowing individuals to express and enforce preferences over who may and may not access what information.[148]

[70] Without a property interest, Henrietta had no right to any of the profits resulting from the development and commercialization of her cell line. She remained poor, and her family still wondered: "If our mother so important to science, why can't we get health insurance?"[149]

B. Privacy

[71] Practically however, a property interest is not enough, and would do little for the person whose material is stored and analyzed absent their consent, but never commercialized—why should a person whose tissue yielded something worthy of commercialization be entitled to greater recovery (or recovery at all) than a person whose tissue yielded naught but a test subject? Each person received an equal amount of harm to their dignity and to their personal autonomy. These are the types of harms we are seeking to prevent.

[72] A flaw of any property regime on its own is that it emancipates the part from the whole, ignoring the incalculable value of an entire person.[150] It is impossible to quantify the indignity done to a person when her injury is reduced to the conversion of a good with an often unquantifiable

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[147] *See id.*

[148] *See id.*

[149] SKLOOT, *supra* note 1, at 168.

[150] *See* Suter, *supra* note 138, at 748.

economic value. The right to privacy is crucial to effectively legislating genetic information protections.

[73] Privacy doctrine is traceable to the work of Justices Warren and Brandeis in their 1890 work, *The Right to Privacy*.[151] They sought to expand and redefine the scope of the protections offered by traditional property doctrine, creating a new right of privacy in the process.[152] Although the right to privacy is typically understood be to rooted in the theory of natural law,[153] any right to privacy as we currently understand it is derived from and wholly reliant on the fundamental right of property ownership that serves as a lynchpin of American law.[154] If "property doctrine" is a toolbox, the "right of privacy" is just one of the many tools within.[155]

[74] Many legal scholars who have taken a hard look at the protection of genetic information have cast doubt upon the idea that privacy and property protections can peacefully co-exist, to create truly comprehensive genetic protection doctrines.[156] For these individuals, privacy exists as an entirely independent right, regardless of its property law origins.[157]

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[151] *See* Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 193 (1890).

[152] *See id.* at 193, 197.

[153] *See, e.g.*, Pavesich v. New England Life Ins. Co., 50 S.E. 68, 69–70 (Ga. 1905).

[154] *See* Suter, *supra* note 138, at 767; *see also* J. Madison, *Property*, *in* THE PAPERS OF JAMES MADISON 14:266--68 (William T. Hutchinson, et al. eds., 1792) http://press-pubs.uchicago.edu/founders/documents/v1ch16s23.html, https://perma.cc/J8PH-SBBZ.

[155] *See* Suter, *supra* note 138, at 767.

[156] *See* Ambriscoe, *supra* note 73 at 1210–11.

[157] *See id.* at 1193–94.

However, a right to privacy *is*, at its core, a property interest, and always has been.[158]

[75] The need for a right to privacy–both originally and in this context–arises from the need for an interest that cannot be monetized in the way that traditional property can.[159] By owning our bodies and body products, we gain control over how and when our genetic information and material can be used, but in treating our individual parts as separate from each other, we inevitably detach ourselves from our identities as full, entire persons—the very thing we hope to protect.[160]

[76] If the goal here—and it is—is to preserve the dignity of the individual, then we must strive to keep the self whole, a goal best served by the right of privacy.[161]

[77] Ultimately, if we aim to create a framework through which Henrietta's dignity would have been preserved, and her children would have been able to benefit from the commercialization of her cells (if she had chosen to donate them), we must craft a legal structure that instills in individuals interests in both privacy and property when it comes to their genetic materials and information.

VI. A PROPOSAL

[78] To protect Henrietta, and those who find themselves in the position she was in, there needs to be basic, yet comprehensive, legislation at the federal level. That legislation must accomplish three main things: (1)

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[158] Agreement with such an assertion is not necessary to ultimately agree with the conclusion that privacy and property are the two pillars necessary to uphold and individual's right to exercise control over their own genetic information.

[159] *See* Suter, *supra* note 138, at 761–62.

[160] *See id.* at 763.

[161] *See* Dunn, *supra* note 4, at 640.

create a property interest in genetic information and materials for the individuals to whom that information pertains; (2) supplement the privacy rights of individuals in their genetic information; and (3) create both a civil remedy and a criminal penalty for those who infringe upon the interests that individuals have in their own genetic information and materials.

[79] To that end, the following is a brief outline of what such legislation might look like, modeled in part off the Alaska statute discussed previously:

1. Statement of Intent

> This statute shall be interpreted as affording to individuals a property interest in their own genetic material and information, with that interest possessing all the rights typically attached to an interest in property. This statute shall be applied to all instances of research conducted on human biological material, and shall not be construed as applying only in the doctor-patient context.

2. Definitions

> (a) "Genetic information" means both the biological human material (blood, tissue, et al.) and the results of any analysis, testing, or observation of that material.[162]
>
> (b) "Genetic testing" means laboratory tests of human biological material for medical or research purposes.[163]

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[162] *See generally* COLO. REV. STAT. § 10-3-1104.6 (2)(c)(I)(2016) (discussing genetic information and the limitations on disclosure of information, as well as liabilities and legislative components).

[163] *See* COLO. REV. STAT. § 10-3-1104.7 (2)(b) (2016).

(c) "Researcher" means any individual who performs genetic testing on the genetic information of another.

3. Genetic Information

(a) Genetic information is the unique property of the individual to whom the information pertains.

(b) A researcher may not collect genetic information from, perform genetic testing on, retain genetic testing results of, or disclose the genetic testing results of another person unless that researcher has first obtained the written, informed consent of the person, or that person's legal guardian or authorized representative.[164]

(c) Prohibitions of section (b) of this statute do not apply to genetic information collected or tested for law enforcement purposes, for the purpose of determining paternity, or for emergency medical treatment.

(d) **Civil Remedy.** A person may bring a civil action against a researcher who collects, tests, retains, or discloses his genetic information in violation of (a) of this section. In addition to actual damages, a researcher violating this section will be liable for damages in the amount of $10,000. If the violation resulted in monetary gain for the violator, he will be liable for damages in the amount of $200,000.[165]

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[164] See COLO. REV. STAT. § 10-3-1104.7 (10)(a) (2016); see *also* ALASKA STAT. § 18.13.010(a)(1) (2016).

[165] See COLO. REV. STAT. § 10-3-1104.6 (11)-(12) (2016); see *also* ALASKA STAT. § 18.13.020 (2016).

> (e) **Criminal Penalty.** An individual has committed the crime of unlawful genetic information collection, testing, retention, or disclosure when he collects, tests, retains, or discloses the genetic information of another in violation of (a) of this section. A person who has committed the crime of unlawful collection, testing, retention, or disclosure of genetic information is guilty of an infraction, punishable by a fine of no less than $1000 and no more than $100,000.[166]

[80] Statutory language may not be enough. As we learned from the Florida example, broad language can be interpreted narrowly. This proposal seeks to be specific enough to avoid that scenario, while remaining generally applicable enough to provide adequate coverage. Frustratingly, it is not even certain that a statute such as this would have helped Henrietta maintain control over her biological tissue.

[81] Had things not unfolded as they did—Henrietta's biopsy done without her knowledge, her cells kept with her none the wiser, and her name lost to the annals of history until an industrious young writer took the time to dig her up—she may still not have had the wherewithal to vindicate her rights, had they existed. How can a person seek relief for damages they are unaware have been done to them?

[82] That analysis ignores a crucial component of any modern statute—modern society. Societal values, ideas, and sensibilities have changed and evolved in the years since Henrietta first walked into Johns Hopkins complaining of a pain in her abdomen. This statute, or one like it, may not have saved the real Henrietta from the injustice done to her, but it could very well prevent the same from happening to a modern Henrietta Lacks.

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[166] *See* ALASKA STAT. § 18.13.030(a) (2016).