## **GENETIC PROPERTY GOVERNANCE**

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The law governing an "individual genome" (the genetic material and information extracted from a single person) in the United States has two key shortcomings. First, it adopts an absolute conception of ownership, permitting only one entity to claim ownership over an individual genome—either the person from whom it was extracted or someone else, such as researchers and law enforcement officials. Consequently, the law fails to represent and protect the legitimate concurrent ownership interests of multiple entities stemming from, e.g., personhood, labor, and possession. Instead, it prioritizes one interest at the expense of another. Second, the law fails to accommodate the multifaceted and relational nature of an individual genome. An individual genome consists of both genetic material and genetic information; involves personal, familial, and collective aspects; and has varying degrees of excludability and subtractability. The law, however, does not consider these characteristics together.

This Article offers a new legal framework, "Genetic Property Governance," which is a form of collective ownership over an individual genome that balances the generation of social and economic benefits with the need to prevent severe individual and social harms. This framework embraces the idea of an individual genome as a commons, incorporating a liberal account of property and reconciling conflicting interests via two principles, proportionality and reasonableness. Overall, under Genetic Property Governance, an individual genome is a shared enterprise

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that reflects multiple interests and characteristics to yield just and productive outcomes.

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"It is more than likely that *joint ownership*, and not *separate ownership*, is the really archaic institution, and that the forms of property that will afford us instruction will be those that are associated with the rights of families and of groups of kindred."

-Henry Sumner Maine, 1906<sup>1</sup>

#### INTRODUCTION

Henrietta Lacks died from cervical cancer in 1951, at the age of 31.<sup>2</sup> It was only in 1973 that Henrietta's family learned that doctors at the Johns Hopkins Hospital had taken samples of her cancerous cells and given them, without her knowledge, to Dr. George Gey, a prominent cancer researcher.<sup>3</sup> In Dr. Gey's lab, the cells, which came to be known as the "HeLa cells," were discovered to have an extraordinary capacity to survive and reproduce. For that reason, these cells have had a significant role in scientific research and, over the years, have contributed to enormous scientific breakthroughs, including the development of the polio vaccine and the study of cancer and the AIDS virus.<sup>4</sup>

Thus far, the family of Henrietta Lacks has not sued anyone for ownership of the HeLa cells and the genetic information retrieved from them.<sup>5</sup> However, at a news conference on October 4, 2021, seventy years after Henrietta's death, the Lacks family announced that they are suing a biotechnology company, Thermo Fisher Scientific, which has been accused of profiting from Henrietta's "stolen" cells<sup>6</sup> and "making a conscious choice to sell and mass produce the living tissue of Henrietta Lacks."<sup>7</sup>

<sup>&</sup>lt;sup>1</sup> SIR HENRY SUMNER MAINE, ANCIENT LAW: ITS CONNECTION WITH THE EARLY HISTORY OF SOCIETY, AND ITS RELATION TO MODERN IDEAS 271 (10th ed. 1906) (emphasis added).

<sup>&</sup>lt;sup>2</sup> REBECCA SKLOOT, THE IMMORTAL LIFE OF HENRIETTA LACKS 65–66, 85– 86 (2010).

<sup>&</sup>lt;sup>3</sup> *Id.* at 32–33, 179–90.

<sup>&</sup>lt;sup>4</sup> *Id.* at 93–97, 214–16.

<sup>&</sup>lt;sup>5</sup> *Id.* at 328. In the past, the Lacks family raised concerns regarding use of the HeLa cells and the genetic information retrieved from them. In 2013, the National Institutes of Health (NIH) announced an agreement with the Lacks family. According to this agreement, scientists are required to seek permission to use the HeLa cells or Henrietta's genetic information in NIH-funded research. Moreover, the committee determining who can use the cells or the genetic information must include two members of the Lacks family. *See* Ewen Callaway, *Deal Done over HeLa Cell Line*, 500 NATURE 132 (2013) (describing the circumstances that led to the agreement).

<sup>&</sup>lt;sup>6</sup> Associated Press, *Henrietta Lacks' Estate Sued a Company Saying It Used Her "Stolen" Cells for Research*, NPR (Oct. 4, 2021, 9:32 PM), https://www.npr.org/2021/10/04/1043219867/henrietta-lacks-estate-sued-stolencells [https://perma.cc/V8UX-VUCD].

<sup>&</sup>lt;sup>7</sup> Maria Cramer, Henrietta Lacks, Whose Cells Were Taken Without Her

The Lacks' lawsuit reflects an urgent and timely topic: the ownership of what I term an "individual genome"—genetic material and information extracted from a single person. It incites a burning question to which the law has yet to provide a clear answer: Who can claim to have ownership over an individual genome—is it the person from whom an individual genome was extracted or someone else?

By ownership, I mean *authority*—the normative power to determine to some degree what others may do with a resource—that is enforceable against the "whole world."<sup>8</sup> According to this definition, the institution of property offers different "configurations of entitlements that constitute the contents of an owner's rights visà-vis others, or a certain type of others, with respect to a given resource."<sup>9</sup>

Before going any further, two points of clarification are appropriate. First, when I refer to "genetic material" and "genetic information," I mean a variety of genetic materials and forms of genetic information. These include specimen (e.g., hair and saliva), DNA sample (e.g., extracted and purified DNA and an isolated gene), manipulated genetic material (e.g., cell line and synthetic

*Consent, Is Honored by W.H.O.*, N.Y. TIMES (Oct. 15, 2021), https://www.nytimes.com/2021/10/13/science/henrietta-lacks-cells-who.html [https://perma.cc/M3N4-5WWQ].

<sup>&</sup>lt;sup>8</sup> Hanoch Dagan, *Autonomy and Property, in* RESEARCH HANDBOOK ON PRIVATE LAW THEORY 185, 187 (Hanoch Dagan & Benjamin Zipursky eds., 2020); Morris R. Cohen, *Property and Sovereignty*, 13 CORNELL L.Q. 8, 11–14 (1927). I should clarify that I am aware of the differences between the authority of private entities and that of public entities. *See* Avihay Dorfman, *Private Ownership and the Standing to Say So*, 64 U. TORONTO L.J. 402, 423–24 (2014) ("[B]oth private owners and some public officials occupy a position of discretionary authority over others. . . . But this resemblance is too shallow to support the inference that the standing of private owners is either continuous with, or an instance of, the sovereign power of public officials."). Nonetheless, for the purposes of this Article, I focus on the similarities between private entities and public entities—both have discretionary authority over others.

<sup>&</sup>lt;sup>9</sup> HANOCH DAGAN, A LIBERAL THEORY OF PROPERTY 20 (2021). To be sure, my argument is not that the institution of property is a relation between an owner and a resource. Rather, it is a relation between an owner and other individuals in reference to a resource. See Cohen, supra note 8, at 12 ("[W]e must recognize that a property right is a relation not between an owner and a thing, but between the owner and other individuals in reference to things."); JOSEPH W. SINGER ET AL., PROPERTY LAW: RULES, POLICIES, AND PRACTICES XXXIII-XXXV (7th ed. 2017) ("Property rights concern relations among people regarding control of valued resources. Property law gives owners the power to control things, and it does this by placing duties on non-owners."). Moreover, I adopt the view that property should be understood as "an umbrella for a limited and standardized set of property institutions," and not as "a 'laundry list' of substantive rights with limitless permutations." See, respectively, Hanoch Dagan, Property's Structural Pluralism: On Autonomy, the Rule of Law, and the Role of Blackstonian Ownership, 3 BRIGHAM-KANNER PROP. RTS. CONF. J. 27, 29 (2014), and DAGAN, supra, at 33.

DNA), and any information that can be derived or inferred from these genetic materials (e.g., information on single nucleotide polymorphism and chromosomes).<sup>10</sup>

Second, genetic material and genetic information are frequently inseparable; when someone collects the genetic material of another individual, they are also able to obtain the individual's genetic information from that material. That being the case, there are situations in which the physical form and the information embedded in it should not be treated as distinct matters. Therefore, for the purposes of this Article, I consider genetic material and genetic information to be a single resource and refer to them collectively as an "individual genome."

The question of ownership of an individual genome has been the subject of much debate and theorizing in the academic literature and beyond. By and large, the existing approaches to this question can be divided into two streams holding fundamentally different normative conceptions of genetic material and information and advancing competing legal interests.<sup>11</sup>

The first approach calls for legal recognition of the ownership interests of *the person from whom an individual genome was extracted*.<sup>12</sup> This approach has diverse theoretical underpinnings. Some scholars use property law to "assuage anxieties about misuse and exploitation."<sup>13</sup> Under property law, they claim, a person holds a "right to possession and use of his DNA, free from the interference of others."<sup>14</sup> Hence, a person has a monopoly

<sup>&</sup>lt;sup>10</sup> See discussion infra Section III.B.e.

<sup>&</sup>lt;sup>11</sup> Another perspective, which I do not discuss in this Article, contends that the concept of ownership is utterly inapplicable when it comes to genetic material and genetic information. In other words, according to this perspective, no one can claim ownership of these resources. *See, e.g.*, David Hersenov, *Self-Ownership, Relational Dignity, and Organ Sales*, 32 BIOETHICS 430 (2018) (claiming that a person cannot own their organs); James Toomey, *Property's Boundaries*, 109 VA. L. REV. 131, 185 (2023) (arguing that "[n]o one can own genetic information not the individuals in whom the information was first found, and not the scientists who found it."); Ass'n for Molecular Pathology v. Myriad Genetics, Inc., 569 U.S. 576 (2013) (in this case the U.S. Supreme Court ruled that a DNA segment is a "product of nature" and cannot be patented).

<sup>&</sup>lt;sup>12</sup> See, e.g., Catherine M. Valerio Barrad, Genetic Information and Property Theory, 87 Nw. U.L. REV. 1037 (1993); Radhika Rao, Genes and Spleens: Property, Contract, or Privacy Rights in the Human Body?, 35 J.L. MED. & ETHICS 371 (2007); Natalie Ram, Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research, 23 HARV. J.L. & TECH. 119 (2009); Meredith M. Render, The Law of the Body, 62 EMORY L.J. 549 (2013); MUIREANN QUIGLEY, SELF-OWNERSHIP, PROPERTY RIGHTS, AND THE HUMAN BODY: A LEGAL AND PHILOSOPHICAL ANALYSIS (2018); Jessica L. Roberts, Progressive Genetic Ownership, 93 NOTRE DAME L. REV. 1105 (2018).

<sup>&</sup>lt;sup>13</sup> Roberts, *supra* note 12, at 1163.

<sup>&</sup>lt;sup>14</sup> Barrad, *supra* note 12, at 1058.

over their individual genome, and other entities are excluded "from taking, using, receiving, selling, or otherwise misusing" it.<sup>15</sup> Other scholars reflect on the importance of self-ownership,<sup>16</sup> while pointing out that property law mirrors the sentiments society attaches to a specific thing; things deemed "ours" or recognized as personal and meaningful should therefore receive special protection.<sup>17</sup> Finally, several scholars touch on the connection to identity,<sup>18</sup> asserting that "no other individual or entity has a clearer or more justifiable claim over the [genetic] information than the person to whom it pertains."<sup>19</sup> An individual genome plays "a role in self-identity and may contain indications about one's present and future self. . . . Like a right to control the use of one's likeness, a right to control the use of one's genetic material . . . arises without the specific intent or perhaps innovation of the rights holder."<sup>20</sup>

This approach is not merely theoretical; it has permeated state and federal laws and court decisions in the United States in the last 30 years.<sup>21</sup> Various states recognize genetic material and/or genetic information as a person's private property.<sup>22</sup> Alaska's Genetic Privacy Act, for instance, recognizes a DNA sample and the results of DNA analyses as "the exclusive property of the person

<sup>&</sup>lt;sup>15</sup> Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611, 616 (2006).

<sup>&</sup>lt;sup>16</sup> QUIGLEY, *supra* note 12, ch. 8; Barrad, *supra* note 12, at 1070–72; Peter Halewood, *On Commodification and Self-Ownership*, 20 YALE J.L. & HUMAN. 131 (2008).

<sup>&</sup>lt;sup>17</sup> Robin Feldman describes the following scenario, which nicely illustrates the point on self-ownership: "suppose a man severs his finger while sawing wood in his backyard. One would expect that he has the right to ask that the finger be reattached, as opposed to any other potential uses or modes of disposition, including use for research. The man's priority right to those cells cannot possibly be connected to rights of privacy, nondisclosure, or informed consent. The man would claim the finger, not because it contains information that should be kept private or because he did not properly obtain his own consent before slicing off his finger. He would claim the finger because it is *his*." Robin Feldman, *Whose Body Is It Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law*, 63 STAN. L. REV. 1377, 1383 (2011).

<sup>&</sup>lt;sup>18</sup> See, e.g., Leigh M. Harlan, When Privacy Fails: Invoking a Property Paradigm to Mandate the Destruction of DNA Samples, 54 DUKE L.J. 179 (2004); Tufik Y. Shayeb, You Are What You Own: Reopening the Discussion on Universally Recognizing a Property Right in Genetic Information and Material, 38 WHITTIER L. REV. 181 (2017); Yaniv Heled & Liza Vertinsky, Genetic Paparazzi: Beyond Genetic Privacy, 82 OHIO ST. L.J. 409 (2021); Steven A. Fisher, Protecting Genetic Identity with the Right of Publicity: Applying California's Common Law Right of Publicity to Direct-to-Consumer Genetic Testing, 70 AM. U.L. REV. 1217 (2021).

<sup>&</sup>lt;sup>19</sup> Weeden, *supra* note 15, at 617.

<sup>&</sup>lt;sup>20</sup> Ram, *supra* note 12, at 145.

<sup>&</sup>lt;sup>21</sup> See discussion infra Section I.A.

<sup>&</sup>lt;sup>22</sup> See discussion infra Section I.A.a.

sampled or analyzed."<sup>23</sup> Courts have adopted a similar perspective. In one case, a person was sued for conspiring to take and test the genetic material of another.<sup>24</sup> The court found that the person from whom the genetic material was extracted had property rights over his genetic information (and not over his genetic material). In another case, a person sued a direct-to-consumer (DTC) genetic testing company for making his DNA ancestry tests available online.<sup>25</sup> The court acknowledged that he had property rights over his genetic information.

The second approach implies that the ownership interests of other entities—but not those of the person from whom an individual genome was extracted—should be legally recognized.<sup>26</sup> Similar to the first approach, scholars use different theoretical grounds to justify their views. Different scholars raise the importance of innovation and scientific research and emphasize on researchers' crucial role in advancing scientific knowledge.<sup>27</sup> They assert that we must minimize roadblocks to research and have simple and inexpensive access to an individual genome. In "the new era of biomedical technology," they insist, "it is critically important for the law to facilitate tissue transactions efficiently."<sup>28</sup> Several scholars argue for the valuelessness of an individual genome in its natural state (i.e., its unaltered form), noting that this resource becomes valuable only after we have done something with it; people themselves only inhabit their bodies and have not done anything to create an individual genome.<sup>29</sup> Other scholars explain that an

<sup>&</sup>lt;sup>23</sup> Alaska Stat. § 18.13.010(a)(2) (2021).

<sup>&</sup>lt;sup>24</sup> Order granting in part and denying in part the counter-defendants' motion to dismiss the counterclaim and dismissing the counterclaim in part, Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957 (Fla. 15th Cir. Ct. Jan. 23, 2017).

<sup>&</sup>lt;sup>25</sup> Order re motion to dismiss, Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761 (D. Alaska June 30, 2017).

<sup>&</sup>lt;sup>26</sup> See, e.g., Rina Hakimian & David Korn, Ownership and Use of Tissue Specimens for Research, 292 JAMA 2500 (2004); Pilar N. Ossorio, The Human Genome as Common Heritage: Common Sense or Legal Nonsense?, 35 J.L. MED. & ETHICS 425 (2007); Matthew W. Coryell, Patent Law as an Incentive to Innovate Not Donate: The Role of the U.S. Patent System in Regulating Ownership of Human Tissue, 36 IOWA J. CORP. L. 449 (2011); Albert E. Scherr, Genetic Privacy & the Fourth Amendment: Unregulated Surreptitious DNA Harvesting, 47 GA. L. REV. 445 (2013); Mark A. Hayden, The Burgeoning "Biorights Movement": Its Legal Basis, What's at Stake, and How to Respond, 59 B.C. L. REV. 1755 (2019); Thomas D. Holland, Novel Features of Considerable Biologic Interest: The Fourth Amendment and the Admissibility of Abandoned DNA Evidence, 20 COLUM. SCI. & TECH. L. REV. 271 (2019).

<sup>&</sup>lt;sup>27</sup> Jorge L. Contreras, *Genetic Property*, 105 GEO. L.J. 1, 7, 10, 20–28, 36 (2016).

<sup>&</sup>lt;sup>28</sup> Russell Korobkin, "No Compensation" or "Pro Compensation": Moore v. Regents and Default Rules for Human Tissue Donations, 40 J. HEALTH L. 1, 27 (2007) (on file with the author).

<sup>&</sup>lt;sup>29</sup> Jeff Gamber, Who Owns My Donated Tissue? The Public's Prostate

individual genome does not have value in isolation; its value comes "from being part of the larger collection."<sup>30</sup>

This second approach has also been heavily utilized across legislative and judicial institutions in the United States.<sup>31</sup> For many years, courts and legislatures have refused to assign property rights to the person from whom an individual genome was extracted while simultaneously legally recognizing—explicitly or implicitly—the ownership interests of other entities. For example, a de facto property regime has emerged through laws that enable different entities to exert extensive control over genetic material and/or information.<sup>32</sup> In addition, in several cases, the courts deemed—again explicitly or implicitly—that genetic material and/or information could be the property of other entities, such as researchers and law enforcement officials.<sup>33</sup>

The existing approaches have notable features in common. First, both protect rights that are proprietary in nature,<sup>34</sup> and situate an individual genome in a "zone" of liberty-rights and exclusivity.<sup>35</sup> Such rights boil down to the notion of exclusive rights, implying that third parties must "keep their hands off" an individual genome. Second, these approaches advocate "sole ownership" over an individual genome.<sup>36</sup> That is, they advance the perception of a single

- <sup>32</sup> See discussion infra Section I.B.b.
- <sup>33</sup> See discussion infra Section I.B.

<sup>34</sup> There is a difference between property (*in rem*) and personal (*in personam*) rights. Personal rights only bind the parties who have created them and are incapable of binding third parties. With property rights, no prior contract or other legal relationship is required to create a duty on the part of third parties to respect them. *See* J.E. PENNER, THE IDEA OF PROPERTY IN LAW 23, 27–29 (2000) (explaining that while rights in rem bind "all the world" and must be respected by all of the subjects of the legal system, rights in personam bind only specific individuals). *See generally* Wesley Newcomb Hohfeld, *Fundamental Legal Conceptions as Applied in Judicial Reasoning*, 26 YALE L.J. 710 (1917) (discussing the distinction between *in personam* and *in rem* rights).

<sup>35</sup> Hohfeld distinguished between claim-rights and liberty-rights. He stressed that claim-rights entail duties, that is, a claim-right is a claim against third parties for the performance of a duty. In contrast, liberty-rights do not impose obligations on others; they merely grant the right-holder freedom or permission. *See* Wesley Newcomb Hohfeld, *Some Fundamental Legal Conceptions as Applied in Judicial Reasoning*, 23 YALE L.J. 16 (1913) (elaborating on the reciprocal relationship of rights and duties).

<sup>36</sup> On the traditional sole-ownership model, *see* Michael A. Heller, *The Boundaries of Private Property*, 108 YALE L.J. 1163, 1167–68 (1999); Frank I.

*Inflammation: A Casenote on Washington University v. Catalona*, 26 ST. LOUIS U. PUB. L. REV. 357, 386 (2007); Kare Berg, *The Ethics of Benefit Sharing*, 59 CLINICAL GENETICS 240, 242 (2001).

<sup>&</sup>lt;sup>30</sup> Robert D. Truog et al., *Paying Tissue Donors: The Legacy of Henrietta Lacks* 3 (Dec. 4, 2014) (unpublished manuscript), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4256075/pdf/nihms511441.pdf [https://perma.cc/BQR7-N4J7].

<sup>&</sup>lt;sup>31</sup> See discussion infra Section I.B.

owner with unqualified dominion over an individual genome<sup>37</sup> and assume that multiple stakeholders cannot hold property rights over it. These approaches differ, however, in terms of the locus of decision-making authority over what happens with an individual genome. While the first approach designates *the person from whom an individual genome was extracted* as the locus of authority; the second designates *someone else*.

This Article's core argument is that the existing approaches get genome conceptualization and governance wrong. Not only do they understand legal interests primarily as individualist claims, but they also accentuate a commitment to an absolute conception of ownership<sup>38</sup> and assume that property law is primarily about exclusion.<sup>39</sup> An individual genome is therefore governed by Blackstone's conception of property as "sole and despotic dominion."<sup>40</sup> Accordingly, we are trapped in a tragic choice—we must determine whether an individual genome is owned by the person from whom it was extracted, or someone else.

Overall, the existing approaches view property as an individual entitlement and allow its exclusive and extensive use by only one entity, without paying attention to that relationship's effect on other individuals and society at large. Consequently, these approaches (to which I hereafter refer as the "current genome conceptualization and governance") fail to adequately address the challenges presented by the complexity of an individual genome.

Several scholars have so far proposed expanding the scope of ownership over an individual genome, suggesting that what is "mine" can *also* be "yours." For example, Natalie Ram has used the law of tenancy by the entirety as a possible lens through which we could protect *family members*.<sup>41</sup> As Ram has explained, because family is the core feature of the law of tenancy by the entirety, it helps "policymakers take proper account of the shared nature of

Michelman, *Ethics, Economics, and the Law of Property, in* NOMOS XXIV: ETHICS, ECONOMICS, AND THE LAW 3, 5 (1982).

<sup>&</sup>lt;sup>37</sup> See Dagan, supra note 9.

<sup>&</sup>lt;sup>38</sup> See generally MICHAEL A. HELLER & JAMES SALZMAN, MINE!: HOW THE HIDDEN RULES OF OWNERSHIP CONTROL OUR LIVES 13–14, 171–77 (2021) (describing the absolute view of ownership as "a light switch that goes on or off.").

<sup>&</sup>lt;sup>39</sup> Compare Thomas W. Merrill, Property and the Right to Exclude, 77 NEB. L. REV. 730 (1998) (arguing that the right to exclude is an essential condition of property), with Hanoch Dagan & Michael A. Heller, Conflicts in Property, 6 THEORETICAL INQUIRIES L. 37, 40–41 (2005) (stating that the focus on "exclusion, independence, and competition" in property law is overstated).

<sup>&</sup>lt;sup>40</sup> Compare Robert P. Burns, *Blackstone's Theory of the "Absolute" Rights of Property*, 54 U. CIN. L. REV. 67 (1985) (discussing Blackstone's theory of property as an absolute right), *with* DAGAN, *supra* note 9, at 79–81 (opposing the Blackstonian concept of property and arguing that there are various limitations to exclusion).

<sup>&</sup>lt;sup>41</sup> Natalie Ram, DNA by the Entirety, 115 COLUM. L. REV. 873 (2015).

identifying genetic information."<sup>42</sup> Jessica Roberts has taken one step further and also recognized the interests of *researchers*, asserting that they "will not always lose out."<sup>43</sup> She has used the progressive theory of property, which offers "a value[-]pluralist, communitarian, and redistributive theoretical approach" for resolving "genetic ownership" disputes.<sup>44</sup> Roberts has also maintained that progressive theory of property captures the fact that "genetic data is unique and replete with familial and intergenerational meaning."<sup>45</sup>

While these interesting and important proposals call into question assumptions about the scope of ownership over an individual genome, they do not fully address how to divide up the various ownership interests at stake, which extend beyond the interests of family members and researchers. More importantly, they lack a systematic *framework* for dividing ownership interests among multiple stakeholders. Lastly, these proposals do not move far enough toward perceiving an individual genome as a commons.<sup>46</sup> Consequently, they leave some legitimate interests unrepresented, including those of adversaries, employers, DTC genetic testing companies, and law enforcement officials.

This Article picks up where these proposals leave off, filling an important gap in the literature surrounding property rights over an individual genome. It establishes a new legal framework—what I call "Genetic Property Governance"—that does not rigorously vindicate a single owner's authority and provides a governance structure for recognizing and managing different ownership interests.<sup>47</sup> Consequently, Genetic Property Governance places equal emphasis on an individual genome's *relational* effects in addition to its individual effects.

<sup>47</sup> See generally JOSEPH WILLIAM SINGER, ENTITLEMENT: THE PARADOXES OF PROPERTY 6, 82–83 (2000) (arguing that property rights can be distributed among different stakeholders).

<sup>&</sup>lt;sup>42</sup> *Id.* at 877.

<sup>&</sup>lt;sup>43</sup> Roberts, *supra* note 12, at 1160.

<sup>&</sup>lt;sup>44</sup> *Id.* at 1121.

<sup>&</sup>lt;sup>45</sup> *Id.* at 1170.

<sup>&</sup>lt;sup>46</sup> Although a number of other scholars have similarly advanced the idea of commons in relation to genetic resources, their focus has been on resources such as biobanks or aggregate data. *See, e.g.*, Michael J. Madison, *Biobanks as Knowledge Institutions, in* GLOBAL GENES, LOCAL CONCERNS: LEGAL, ETHICAL, AND SCIENTIFIC CHALLENGES IN INTERNATIONAL BIOBANKING 22 (Timo Minssen et al. eds., 2019); Barbara J. Evans, *Genomic Data Commons, in* GOVERNING MEDICAL KNOWLEDGE COMMONS 74 (Brett M. Frischmann et al. eds., 2017); Nicola Lucchi, *Understanding Genetic Information as a Commons: From Bioprospecting to Personalized Medicine*, 7 INT'L J. COMMONS 313 (2013). To be more precise, to the best of my knowledge, no scholar has proposed treating genetic material and information extracted from a single individual as a commons.

Specifically, Genetic Property Governance conceptualizes an individual genome as a commons and implements a common property regime, including analytical tools for reconciling competing interests. It is also guided by a liberal conception of property, which promotes autonomy, structural pluralism, and relational justice.<sup>48</sup> On the whole, Genetic Property Governance is a "property type" that manages potential conflicts of property entitlements over an individual genome. It reflects a fundamentally relational approach toward genome conceptualization and governance, facilitating cooperation between many stakeholders and helping to build confidence and trust among them.

Genetic Property Governance is a more appropriate legal framework for two main reasons. First, it captures the effect that an individual genome has on oneself and others; it touches on the obligations that people have to one another, based on their relations, and considers how to distribute benefits and risks in a just way, thus avoiding the harm of exploitation. Second, this framework advances a "public health" approach to genome conceptualization and governance and adopts a non-absolute conception of ownership. This means that through systemic balancing and boundary-setting, Genetic Property Governance recognizes the interests of multiple stakeholders, together with the benefits and harms of using an individual genome.

The Article consists of three parts. Part I maps the current legal landscape (i.e., court decisions and legislation) in the United States and explores how an individual genome is conceptualized and governed in practice. Despite the paucity of relevant legislation and court decisions, those that do exist can still shed light on the values and ideologies adhered to by courts and legislatures. This part shows that the current genome conceptualization and governance is rooted in sole ownership (i.e., a resource is owned by only *one* entity) and a libertarian ethos. Consequently, an individual genome is conceptualized and governed either as a resource capable of supporting property rights for the person from whom it was extracted, or as a resource available for appropriation by other entities.

Part II discusses the flaws of the current genome conceptualization and governance. First, it does not recognize the relationality of an individual genome. In other words, it does not account for personal, familial, and collective interests altogether; it bestows exclusive and extensive property entitlements upon only one entity. I argue that this way of conceptualizing and governing an individual genome confers too much control to a single individual, ignores negative and positive externalities, and leads to significant power asymmetries between the person from whom an

<sup>&</sup>lt;sup>48</sup> DAGAN, *supra* note 9.

individual genome was extracted and other entities, among them DTC genetic testing companies, biotech companies, research institutions, and law enforcement officials.

Second, the current genome conceptualization and governance does not consider the attributes of an individual genome. I analyze the "economic features" of an individual genome, showing that it is difficult to characterize it along the dimensions of excludability and subtractability<sup>49</sup> and that there is a gap between its *de facto* and *de jure* status. I argue that an individual genome is not always a private good, as might be expected.

Third, the current genome conceptualization and governance lacks explanatory power. At present, an individual genome is deemed property only for some entities and only in some contexts. Moreover, genetic material and information are treated differently despite being often bound up together. I assert that no satisfactory explanations are presented for why an individual genome is conceptualized and governed in this way.

Part III supports a more relational approach to genome conceptualization and governance and presents Genetic Property Governance as an alternative legal framework. I argue that an individualistic approach for genome conceptualization and governance is not inevitable and show that it is possible to account for personal, familial, and collective interests altogether and to also investigate benefits and harms for multiple stakeholders. Building on Elinor Ostrom's commons theory<sup>50</sup> and the knowledge commons framework (which is inspired by and builds in part on Ostrom's theory),<sup>51</sup> this part establishes the institutional responses necessary to represent the various stakeholders and interests involved. It suggests treating an individual genome as a commons<sup>52</sup> governed by a common property regime. It should be noted that although Ostrom focuses on common-pool resources, which are different from an individual genome,<sup>53</sup> her work teaches us several important

<sup>&</sup>lt;sup>49</sup> Vincent Ostrom & Elinor Ostrom, *Public Goods and Public Choices: The Emergence of Public Economies and Industry Structures, in VINCENT OSTROM,* THE MEANING OF AMERICAN FEDERALISM: CONSTITUTING A SELF-GOVERNING SOCIETY 163, 165–68 (1991).

<sup>&</sup>lt;sup>50</sup> Charlotte Hess & Elinor Ostrom, *Ideas, Artifacts, and Facilities: Information as a Common-Pool Resource*, 66 LAW & CONTEMP. PROBS. 111, 121–23 (2003). *See generally* ELINOR OSTROM, GOVERNING THE COMMONS: THE EVOLUTION OF INSTITUTIONS FOR COLLECTIVE ACTION (2015) (developing a theory of institutional arrangements for the governance of common-pool resources).

<sup>&</sup>lt;sup>51</sup> Katherine J. Strandburg et al., *The Knowledge Commons Framework*, *in* GOVERNING MEDICAL KNOWLEDGE COMMONS 9–18 (Brett M. Frischmann et al. eds., 2017).

<sup>&</sup>lt;sup>52</sup> By "commons" I mean "institutional arrangements for managing shared access to a pooled or collected resource." *See* Madison, *supra* note 46, at 28.

<sup>&</sup>lt;sup>53</sup> *Id*. at 30–31.

lessons.<sup>54</sup> For instance, under a common property regime, multiple stakeholders could have protected ownership interests in an individual genome but within a hierarchy of power—not all commoners must exercise equal control or enjoy similar privileges.<sup>55</sup> In other words, different stakeholders could hold different property entitlements.

Part III also stresses that Genetic Property Governance should be guided by a liberal conception of property, which draws on Ostrom's insights as well. This conception of property is founded on three key pillars: private authority, structural pluralism, and relational justice.<sup>56</sup> According to Hanoch Dagan, the liberal conception postulates that property should be considered an "empowering device in the service of people's self-determination," enabling them to pursue their conception of the good.<sup>57</sup> At the same time, property must address interpersonal relationships and abide by the maxim of reciprocal respect for one another.58 The liberal conception insists, in effect, that private authority must be structured to augment opportunities for both individual and collective selfdetermination; no authority can claim more than what is required for self-determination, and the authority of one entity must be consistent with the self-determination of others.<sup>59</sup> Moreover, the institution of property should include "a structurally pluralist inventory of property types"<sup>60</sup> and serve a variety of commitments, among them those "to personhood, desert, . . . social responsibility, and distributive justice."61 According to the liberal conception of property, property types that do not meet the requirements of private authority, structural pluralism, and relational justice, should be abolished or modified.

Part III then argues that implementing a liberal conception of property in the context of an individual genome entails two

<sup>&</sup>lt;sup>54</sup> Katherine J. Strandburg et al., *Governing Knowledge Commons, in* GOVERNING KNOWLEDGE COMMONS 2, 12–19 (Brett M. Frischmann et al. eds., 2014).

<sup>&</sup>lt;sup>55</sup> Hess & Ostrom, *supra* note 50, at 124–26; Edella Schlager & Elinor Ostrom, *Property-Rights Regimes and Natural Resources: A Conceptual Analysis*, 68 LAND ECON. 249, 249–54 (1992). *See also* Gregory S. Alexander, *Governance Property*, 160 U. PA. L. REV. 1853, 1865–66 (2012) (explaining that in governance property institutions some interest holders may hold greater control than others).

<sup>&</sup>lt;sup>56</sup> DAGAN, *supra* note 9, at 1–9.

<sup>&</sup>lt;sup>57</sup> *Id.* at 3.

<sup>&</sup>lt;sup>58</sup> Id. at 4.

<sup>&</sup>lt;sup>59</sup> Irit Samet & Hanoch Dagan, *The Beneficiary's Ownership Rights in the Trust Res in A Liberal Property Regime*, 86 MODERN L. REV. 599, 707 (2023).

<sup>&</sup>lt;sup>60</sup> Dagan, *supra* note 8, at 186.

<sup>&</sup>lt;sup>61</sup> Hanoch Dagan, *Private Law Pluralism and the Rule of Law, in* PRIVATE LAW AND THE RULE OF LAW 158, 163 (Lisa M. Austin & Dennis Klimchuk eds., 2014). *See also* DAGAN, *supra* note 9, at 50–58 (describing personhood, community, and utility as important values in property law).

important steps. First, we must assess if the property interest at issue is *legitimate*, that is, we must determine whether the entity has a legal claim over an individual genome. This investigation comprises examining the property interest in question and ensuring that it protects autonomy and self-determination as the ultimate values of property. After determining whether the entity has a legitimate property interest, we proceed to the second step of determining whether a specific use by one of the legitimate owners reflects *appropriate control*. In order to do so, two analytical tools proportionality and reasonableness—are utilized.<sup>62</sup>

Proportionality assesses the rationality and necessity of a given means in pursuit of an aim and strives to adopt the least restrictive solution.<sup>63</sup> Reasonableness requires weighing all the relevant considerations.<sup>64</sup> Proportionality and reasonableness are, in essence, principles that can help set boundaries to ownership over an individual genome and ensure that the property system is just and consistent with its underlying values. These principles are particularly helpful because they are attentive to property's externalities—they ask us to consider the effects of people's actions on others while accounting multiple interests and evaluating different uses.

When applying proportionality and reasonableness, I suggest considering two criteria: the type of genetic component and the purpose of the stakeholder's use. As I explained, an individual genome encompasses a variety of genetic materials and forms of genetic information, including specimen, DNA sample, manipulated material, and information (there are also different types of information). In addition, an individual genome may be used for different purposes, such as not-for-profit scientific research, the gathering of valuable information, or the promotion of economic interests. By assigning different weights to each component and purpose, we can better locate disproportionate and unreasonable uses.

<sup>&</sup>lt;sup>62</sup> Unlike the reasonableness principle, which is frequently used in private law, the proportionality principle has been mostly used in the domains of constitutional and administrative law. In this Article, I suggest that *both* principles should be used in the domain of private law. On the emerging use of proportionality in private law, *see*, *e.g.*, Pnina Alon-Shenker & Guy Davidov, *Applying the Principle of Proportionality in Employment and Labour Law Contexts*, 59 MCGILL L.J. 375 (2013); Zhong Xing Tan, *The Proportionality Puzzle in Contract Law: A Challenge for Private Law Theory*?, 33 CAN. J.L. JURIS. 215 (2020).

<sup>&</sup>lt;sup>63</sup> Aharon Barak, *Foreword: A Judge on Judging: The Role of a Supreme Court in a Democracy*, 116 HARV. L. REV. 19, 147–48 (2002). *See generally* AHARON BARAK, PROPORTIONALITY: CONSTITUTIONAL RIGHTS AND THEIR LIMITATIONS (2012).

<sup>&</sup>lt;sup>64</sup> Barak, *supra* note 63, at 145–47.

Finally, Part III concludes by addressing the implications of Genetic Property Governance for real-world cases. It demonstrates how two cases—the Lacks family's lawsuit, with which I began this Article, and *Cole v. Gene by Gene*, which I will cover later on<sup>65</sup>— may come out differently if Genetic Property Governance would be implemented. I hope that by the end of this Article, it will be clear that Genetic Property Governance has considerable advantages and enormous promise over the existing governance structure. The latter is plagued by an absolutist, all-or-nothing approach that we must reject.

#### I. CURRENT GENOME CONCEPTUALIZATION AND GOVERNANCE

This part describes how an individual genome is currently conceptualized and governed in the United States. It demonstrates how law-making institutions (i.e., courts and legislatures) presently conceptualize and govern an individual genome. Although there is relatively little relevant legislation and only a small number of court decisions, it is still possible to learn about the conceptions of an individual genome held by judges and legislatures and their ways of approaching governance of this resource.

Mapping the current legal landscape reveals that an individual genome is considered either a unique identifier and a person's "book of life"<sup>66</sup> or a means of knowledge production. Notably, an individual genome is conceptualized and governed either as a resource capable of supporting property rights for the person from whom it was extracted, or a resource available for appropriation by other entities, among them researchers who extract and cultivate it or entities who find and possess it. This absolute conception of ownership results in only *one* entity having decision-making authority over an individual genome.

Interestingly, as I demonstrate, not all legislation and court decisions are explicitly framed in property terms. However, even if they do not use the property language, I claim that the legislation and court decisions have implicitly established a property regime. Thus far, many courts and legislators have refrained from using the property language with regard to the human body; they do not want to state who "owns," for example, a corpse or fertilized embryos.<sup>67</sup> However, I believe that we have a property regime over the human body whether the property language is employed or not. At the end

<sup>&</sup>lt;sup>65</sup> Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761 (D. Alaska June 30, 2017). *See* discussion *infra* Section I.A.a.

<sup>&</sup>lt;sup>66</sup> Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCIENCES 1, 2 (2019).

<sup>&</sup>lt;sup>67</sup> Toomey, *supra* note 11.

of the day, legislation and court decisions assign *control* over the human body and normative authority to determine what others may do with it. And that is, in fact, what constitutes property.

It is worth emphasizing that while this part focuses on how genome conceptualization and governance is reflected in *practice*, similar conceptions and governance approaches can be found in the academic literature. As I briefly discussed in the Introduction, while some scholars support the establishment of property rights for the person from whom an individual genome was extracted,<sup>68</sup> other scholars touch on the importance of recognizing the property interests of other entities.<sup>69</sup> Another point to emphasize is that the current genome conceptualization and governance frequently treats genetic material and genetic information as distinct resources (which is in contrast to what I propose in this Article). Therefore, throughout the remainder of this part, I will stick to the terminology used in the legislation and the court decisions, referring to the terms "genetic material" or "genetic information" depending on the context.

# A. A Resource Supporting Property Rights of the Person from Whom It Was Extracted

The conceptualization and governance of an individual genome as a resource capable of supporting property rights for the person from whom it was extracted is manifested both in legislation and court decisions. As I demonstrate, some court decisions and legislation *explicitly* determine that genetic material and/or genetic information are a person's private property, whereas others create a *de facto* property regime by bestowing control rights that can be binding or enforceable against third parties. The outcome is nonetheless the same—the proprietary nature of the person's right is affirmed.

## a. An Explicit Property Regime

To this day, several legislatures and courts have explicitly determined that genetic material and/or genetic information are owned solely by the person from whom they were extracted. This person has affirmative exercise of power over them—they have the power to determine what third parties may or may not do with their genetic material and/or genetic information.

Five states—Colorado, Georgia, Alaska, Florida, and Louisiana—decree that genetic material and/or genetic information are the property of the person from whom they were extracted.

<sup>&</sup>lt;sup>68</sup> See sources cited supra notes 12–20.

<sup>&</sup>lt;sup>69</sup> See sources cited supra notes 26–30.

Alaska recognizes a DNA sample and the results of a DNA analysis performed on it as being "the exclusive property of the person sampled or analyzed."<sup>70</sup> In the respective Judiciary Letter of Intent, it is written that "current laws regarding collection, retention or disclosure of DNA information are inadequate[,] and steps should be taken to protect genetic privacy, property interests and information derived from samples."71 At the Senate Judiciary Standing Committee, Senator Donny Olson, the bill's sponsor, declared that "at this point, all I want to do is make sure that we have some type of protection for our genetic code, which is establishing a privacy or property right so that we have some control as to who gets that information and that's it."72 Florida likewise recognizes that the results of DNA analysis, "whether held by a public or private entity, are the [person's] exclusive property."<sup>73</sup> Notice that the law in Florida recognizes only genetic information as the exclusive property of a person, precluding genetic material. Colorado, Georgia, and Louisiana determine the same.<sup>74</sup>

In recent years, several bills identifying genetic material and genetic information as private property have been proposed in other states. For instance, in New Jersey, a new bill states that the "sample and the genetic information resulting from a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed."<sup>75</sup> Worth noting is that New Jersey had previously attempted to confer property rights for genetic material. However, after pharmaceutical companies intervened, the idea was abandoned. The companies argued that property rights would allow "a person to demand royalties from a new product resulting from a clinical study involving the patient's genetic material."<sup>76</sup>

<sup>73</sup> FLA. STAT. ANN. § 760.40 (West 2021).

<sup>&</sup>lt;sup>70</sup> Alaska Stat. § 18.13.010(a)(2) (2021).

<sup>&</sup>lt;sup>71</sup> S. JOURNAL, 23rd Leg., 2nd Sess., at 2404-05 (Alaska 2004), https://www.akleg.gov/pdf/23/J/S2004-03-04.PDF [https://perma.cc/Y48W-JS6E].

<sup>&</sup>lt;sup>72</sup> An Act Relating to Genetic Privacy: Hearing on S. 217 Before S. Judiciary Standing Comm., 23rd Leg., at 7 (Alaska 2004) (statement of Rep. Donny Olson, Witness Register, S. Judiciary Standing Comm.).

<sup>&</sup>lt;sup>74</sup> COLO. REV. STAT. ANN. § 10-3-1104.7 (West 2021); GA. CODE ANN. § 33-54-1 (West 2021); LA. STAT. ANN. § 22:1023 (2021). However, compared to Alaska and Florida, the laws in these states are narrower in terms of their scope they are aimed at preventing genetic information from being used by insurers and other payers to deny access.

<sup>&</sup>lt;sup>75</sup> Gen. Assemb. 525, 220th Leg., Reg. Sess. (N.J. 2022).

<sup>&</sup>lt;sup>76</sup> Jonathan Weems, *A Proposal for a Federal Genetic Privacy Act*, 24 J. LEGAL MED. 109, 124 (2003).

Similar bills were introduced but failed in states like Alabama,<sup>77</sup> Texas,<sup>78</sup> North Dakota,<sup>79</sup> New Hampshire,<sup>80</sup> Massachusetts,<sup>81</sup> Arizona,<sup>82</sup> and Vermont.<sup>83</sup> In the past, Oregon declared that genetic information was the person's property. However, in this case, the scientific community "complained that the assignment of a proprietary right to each individual's genetic information (including their genetic code) would be a major obstacle to genetic research."<sup>84</sup> Consequently, in 2001, Oregon modified its law, and now it only states that a person's genetic information is "uniquely private."<sup>85</sup>

Courts have adopted a similar perspective in two relatively recent cases. In both cases, the courts agreed to accord property rights over genetic information (but not genetic material) to the person from whom it was extracted. Because these cases are less known and discussed in the literature, I describe them at length.

The first case, *Peerenboom v. Perlmutter*, involved two businessmen, Harold Peerenboom and Isaac Perlmutter, who had a dispute over a tennis court.<sup>86</sup> Peerenboom started receiving defamatory letters at a certain point, and he believed that Isaac and Laura Perlmutter were responsible for them.<sup>87</sup> In an attempt to prove the Perlmutters' involvement in the "defamatory campaign," Peerenboom used a lawsuit in which the Perlmutters had tangential involvement to obtain their genetic material, test it, and compare it with DNA collected from the defamatory letters. Peerenboom provided the Perlmutters with documents made from a material that enabled the collection of their genetic material, and during the deposition, he also collected bottles of water that the Perlmutters had left behind.<sup>88</sup> Although the test results exculpated the Perlmutters from any involvement in the defamatory campaign, Peerenboom distorted them to cast a negative light on the Perlmutters. He also

<sup>84</sup> Richard A. Spinello, *Property Rights in Genetic Information*, 6 ETHICS & INFO. TECH. 29, 33 (2004).

<sup>85</sup> Or. Rev. Stat. § 192.533 (2021).

<sup>&</sup>lt;sup>77</sup> H.R. 78, 2012 Leg., Reg. Sess. (Ala. 2012).

<sup>&</sup>lt;sup>78</sup> S. 475, 84th Leg., Reg. Sess. (Tex. 2015).

<sup>&</sup>lt;sup>79</sup> H.R. 1314, 63rd Leg. Assemb., Reg. Sess. (N.D. 2013).

<sup>&</sup>lt;sup>80</sup> S. 262, 2019 Gen. Ct., Reg. Sess. (N.H. 2019).

<sup>&</sup>lt;sup>81</sup> S. 1080, 187th Gen. Ct., Reg. Sess. (Mass. 2011).

<sup>&</sup>lt;sup>82</sup> H.R. 2069, 55th Leg., 1st Reg. Sess. (Ariz. 2021).

<sup>&</sup>lt;sup>83</sup> H.R. 370, 2019 Gen. Assemb., Reg. Sess. (Vt. 2019).

<sup>&</sup>lt;sup>86</sup> Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957 (Fla. 15th Cir. Ct. Jan. 23, 2017). For more details on this case, *see* Mark Gollom, *Judge Dismisses Toronto Businessman's Hate-Mail Lawsuit Against Former Marvel CEO*, CBC (Sep. 28, 2021), https://www.cbc.ca/news/world/harold-peerenboom-isaac-perlmutter-hate-maillawsuit-1.6192473 [https://perma.cc/YE7R-BCMJ].

<sup>&</sup>lt;sup>87</sup> *Peerenboom*, 2017 Fla. Cir. LEXIS 14957, at \*2.

<sup>&</sup>lt;sup>88</sup> *Id.* at \*3.

disseminated the results to law enforcement officials, prosecutors, and the press.<sup>89</sup>

The Perlmutters filed a lawsuit against Peerenboom, arguing that Peerenboom was "involved in a civil conspiracy to steal" their genetic information.<sup>90</sup> Two of the legal claims they raised were conversion and civil theft. The Perlmutters argued that they have "an exclusive right of possession and ownership of the genetic information encoded in their genetic material" and that by collecting and analyzing their genetic material, Peerenboom "exercised an act of dominion and authority that deprived" them "of their rights of ownership, possession, control, and privacy."<sup>91</sup>

In response, Peerenboom argued that "the Perlmutters had no expectation of privacy nor continuing property rights in the water bottles, papers, or other items voluntarily left behind. . . . Any DNA left on the items was collected after the abandonment, which means collecting the DNA itself from these items is not actionable as conversion."<sup>92</sup> Peerenboom further argued that "it is conceptually impossible to deprive another person of his/her DNA," and thus, there was no "reasonable inference" that had occurred.<sup>93</sup>

The Circuit Court of the Fifteenth Judicial Circuit of Florida emphasized that this case concerns "the question of whether genetic information . . . constitutes 'property'" and declared that "no binding authority has definitively answered this question."<sup>94</sup> The court found that the Perlmutters had a sufficient property interest in their genetic information to sustain conversion and civil theft claims.<sup>95</sup> It held that the couple "plainly retain important intangible rights to their genetic information" and that "the wrongful dominion of this interest is an intrusion."<sup>96</sup> The court concluded that the definition of property should be expanded to include one's intangible rights over genetic information.<sup>97</sup>

In the second case, *Cole v. Gene by Gene*, a person named Michael Cole took a DNA ancestry test from a commercial DTC genetic testing company, Gene by Gene. Cole also signed up to participate in nine "projects" (i.e., websites run by volunteer administrators that allow customers to connect to individuals with

<sup>93</sup> *Id.* at 12.

<sup>&</sup>lt;sup>89</sup> *Id.* at \*4.

<sup>&</sup>lt;sup>90</sup> Id.

<sup>&</sup>lt;sup>91</sup> Counterclaim at 19, *Peerenboom*, 2017 Fla. Cir. LEXIS 14957 (on file with the author).

<sup>&</sup>lt;sup>92</sup> Plaintiff's Motion to Dismiss Counterclaim at 12, *Peerenboom*, 2017 Fla. Cir. LEXIS 14957 (on file with the author).

 $<sup>^{94}</sup>$  Id. at \*12–13.

 $<sup>^{95}</sup>$  *Id.* at \*13–14.

<sup>&</sup>lt;sup>96</sup> *Id.* at \*14.

 $<sup>^{97}</sup>$  Id. at \*14–15.

similar surnames, genetic characteristics, or regional histories).<sup>98</sup> At a certain point, Cole discovered that his name and email address were published on Rootsweb's website (a company unrelated to Gene by Gene) and that the DNA test results were published on the website of Family Tree (one of Gene by Gene's companies).<sup>99</sup>

Cole filed a lawsuit against Gene by Gene and claimed that he never "gave permission—written or otherwise—to Family Tree to make the results of his DNA tests publicly available or to disclose them to any unrelated third-party."<sup>100</sup> He maintained that releasing information without permission "carries serious and irreversible privacy risks" and that the "disclosures also violate Alaska's Genetic Privacy Act... which makes it unlawful for companies that collect consumers' genetic data to disclose such information without prior consent."<sup>101</sup>

Cole argued that when he signed up for the projects, he was not informed that the DNA test results would be publicly disclosed.<sup>102</sup> He explained that due to Gene by Gene's unlawful and wrongful conduct, he suffered significant harm.<sup>103</sup> Cole concluded that "Family Tree's past and ongoing disclosure of its customers' genetic information was perpetrated without their permission—let alone their informed written consent as mandated by the Genetic Privacy Act. As a result, Family Tree places its customers at risk of current and future exploitation of their genetic code."<sup>104</sup>

Gene by Gene denied the allegations against it. It claimed that Cole understood that by joining to a surname project group (in this case, the "Taylor project"), his name and email address will be shared with the group administrator. In this case, the administrator of the Taylor project posted Cole's name, email address, test kit number, and grandmother's maiden name "Taylor" on Rootsweb's website.<sup>105</sup> The company emphasized, however, that no *genetic* information was posted on Rootsweb's website.

Gene by Gene also pointed out that the information provided on Family Tree's website consisted solely of summaries of "junk DNA" listed by kit number.<sup>106</sup> The company added that "the tests are processed from 'junk DNA,' which is devoid of exons. Exons

<sup>&</sup>lt;sup>98</sup> Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761, at \*2 (D. Alaska June 30, 2017).

<sup>&</sup>lt;sup>99</sup> Id. at \*3.

<sup>&</sup>lt;sup>100</sup> Class Action Complaint and Demand for Jury Trial at 9, *Cole*, 2017 U.S. Dist. LEXIS 101761 (on file with the author).

<sup>&</sup>lt;sup>101</sup> *Id.* at 2.

<sup>&</sup>lt;sup>102</sup> *Id.* at 8.

<sup>&</sup>lt;sup>103</sup> *Id.* at 12.

<sup>&</sup>lt;sup>104</sup> *Id.* at 8–9.

<sup>&</sup>lt;sup>105</sup> Request for Relief at 2–5, *Cole*, 2017 U.S. Dist. LEXIS 101761 (on file with the author).

<sup>&</sup>lt;sup>106</sup> *Id.* at 5–6.

are the fabric of genetic information . . . . Because junk DNA does not contain exons, it does not contain genetic information."<sup>107</sup> The company further emphasized that "there is nothing in the Y-DNA . . . that can lead to any health-related information. The Y-DNA test is a purely genealogy and ancestry test."<sup>108</sup>

In addition, Gene by Gene argued that the Release Form that Cole signed contained the company's privacy policy and terms related to the participation in projects,<sup>109</sup> and that Cole had the option of not signing the form.<sup>110</sup> Cole, the company asserted, "signed the Release Form which clearly states what information will be released and refers to the Privacy Policy."<sup>111</sup> Moreover, the company noted that Cole "had the ability to change his settings to remove his information from the FTDNA [FamilyTreeDNA] website upon discovering the 'disclosure' of his personal information.... [but] [i]nstead, he chose to leave his FTDNA results online."<sup>112</sup>

The United States District Court for the District of Alaska ruled that Cole had property rights over his genetic information. The law in Alaska, the court held, "recognizes an exclusive property interest in one's DNA, and prohibits the unauthorized disclosure of DNA information. These statutory entitlements bear a close relationship to the common law torts of conversion of property and invasion of privacy."<sup>113</sup> The court emphasized that the legislature "created a substantive right" and that "the unauthorized disclosure of an individual's DNA . . . constitutes a concrete harm."<sup>114</sup>

### b. An Implicit Property Regime

In this sub-section, I demonstrate that some legislation and court decisions could be interpreted as a de facto property regime. Such legislation and court decisions are motivated by promoting the intrinsic value of genetic material and information and casting them as the sources of a person's individuality. They consequently grant that person exclusive and extensive control over genetic material and/or genetic information.

<sup>&</sup>lt;sup>107</sup> *Id.* at 2. On the difference between exon and introns, *see Exon*, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/genetics-glossary/Exon [https://perma.cc/VHM2-BCLQ] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>108</sup> Answer at 12, *Cole*, 2017 U.S. Dist. LEXIS 101761 (on file with the author).

 $<sup>^{109}</sup>$  *Id.* at 2.

 $<sup>^{110}</sup>$  *Id.* at 6.

 $<sup>^{111}</sup>$  *Id.* at 8.

<sup>&</sup>lt;sup>112</sup> Request for Relief at 8, *Cole*, 2017 U.S. Dist. LEXIS 101761.

<sup>&</sup>lt;sup>113</sup> Cole, 2017 U.S. Dist. LEXIS 101761, at \*8.

<sup>&</sup>lt;sup>114</sup> *Id.* at \*9.

As previously explained, even if the property language is not utilized, we could nonetheless have a property regime. There is no need to use the terms "property" or "ownership" or any other term of a similar nature to establish a property regime. Property law encompasses any legal rule that allocates control and power over a valuable resource, whether tangible or intangible, through the use, access, transfer, division, or destruction of that resource.

The Genetic Information Nondiscrimination Act of 2008 (GINA) is one of the laws that installs a de facto property regime.<sup>115</sup> Although GINA was enacted to deal with the issue of discrimination in health insurance and employment, it is still relevant for our discussion as it touches on the question of access and the use of genetic information by third parties. GINA prohibits insurers and employers from collecting genetic information from any person, including any request or requirement to undergo genetic testing or to provide genetic information.<sup>116</sup> By prohibiting the access and use of genetic information, GINA practically grants the person from whom the genetic information was extracted rights that are proprietary in nature (i.e., rights that are capable of binding third parties).

Similarly, some states grant individuals control over genetic material and/or information, even though they do not explicitly determine that these resources are the person's property. Those states in fact provide specific control rights, such as the right to notification about what is done with genetic information extracted from the person, the right to access that information, and the right to request destruction of genetic material and information.<sup>117</sup> Other states require consent for the disclosure or use of genetic

<sup>&</sup>lt;sup>115</sup> Genetic Information Nondiscrimination Act, Pub. L. No. 110-233, 122 Stat. 881 (2008) (codified as amended in scattered sections of 26 U.S.C., 29 U.S.C., and 42 U.S.C.).

<sup>&</sup>lt;sup>116</sup> 29 U.S.C § 1182; 42 U.S.C § 300gg–53.

<sup>&</sup>lt;sup>117</sup> Leslie E. Wolf et al., *The Web of Legal Protections for Participants in Genomic Research*, 29 HEALTH MATRIX 1, 63, 69–74 (2019). *See, e.g.*, N.J. STAT. ANN. § 10:5–48(a) (West 2021) ("A person who requires or requests that genetic testing be done or receives records, results or findings of genetic testing shall provide the person tested with notice that the test was performed and that the records, results or findings were received."); DEL. CODE ANN. tit. 16, § 1204 (West 2021) ("An individual promptly upon request, may inspect, request correction of and obtain genetic information from the records of that individual."); NEV. REV. STAT. ANN. § 629.141 (West 2021) ("A person who takes a genetic test may inspect or obtain any genetic information included in the records of the test."); OR. REV. STAT. § 192.537(5) (2021) ("A DNA sample from an individual that is the subject of a research project, other than an anonymous research project, shall be destroyed promptly upon completion of the project or withdrawal of the individual from the project . . . unless the individual or the individual's representative directs otherwise by informed consent.").

information by *any* person,<sup>118</sup> thereby creating rights that are enforceable against all other entities.

An implicit property regime has been established by courts as well. For example, in Lowe v. Atlas Logistics Group Retail Services (Atlanta), the first case that had gone to trial due to a violation of GINA, the United States District Court for the Northern District of Georgia held that it was unlawful for a company to have required its employees to undergo genetic testing to find a "devious defecator" (as termed by the court) in the company's warehouse.<sup>119</sup> This case dealt with a company named Atlas, which operates warehouses for products sold at grocery stores. At one point, a mystery employee of the company began "habitually defecating in one of its warehouses."<sup>120</sup> As a consequence, the company requested some of its employees, among them Jack Lowe and Dennis Reynold, to submit a cheek-swab sample so it could compare their cheek cell DNA to DNA from the "offending fecal matter" left in the warehouse.<sup>121</sup> Lowe and Reynold sued Atlas for violating GINA, and the court found that the "unambiguous language of GINA covers Atlas's request for Lowe's and Reynold's genetic information and thus compels judgment in favor of Lowe and Reynolds."<sup>122</sup> The company was henceforth found liable, and Lowe and Reynold were awarded \$ 2.2 million in damages.<sup>123</sup>

If we consider the discussion in this and the previous subsections, it is quite evident that several legislative acts and court decisions in the United States have created—explicitly or implicitly—property rights for the person from whom an individual genome was extracted, rights that are subject to relatively few limitations. These acts and decisions assume that exclusive and extensive control over genetic material and/or genetic information

<sup>&</sup>lt;sup>118</sup> Wolf et al., *supra* note 117, at 25, 40–42, 45–46. *See, e.g.*, DEL. CODE ANN. Tit. 16, §§ 1202(a) and 1203(a) ("No person shall obtain genetic information about an individual without first obtaining informed consent from the individual"; "No person shall retain an individual."); N.J. STAT. ANN. § 10:5–45 ("No person shall obtain genetic information from an individual, or from an individual's DNA sample, without first obtaining informed consent from the individual" ("[N] o person shall obtain genetic information or samples for genetic analysis from a person without first obtaining informed and written consent from the person or the person's authorized representative.").

<sup>&</sup>lt;sup>119</sup> Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC, 102 F. Supp. 3d 1360 (N.D. Ga. 2015).

<sup>&</sup>lt;sup>120</sup> Id. at 1361.

<sup>&</sup>lt;sup>121</sup> Id.

<sup>&</sup>lt;sup>122</sup> *Id.* at 1364.

<sup>&</sup>lt;sup>123</sup> Gina Kolata, *Georgia: \$ 2.2 Million Penalty for Illegal DNA Testing*, N.Y. TIMES (June 22, 2015), https://www.nytimes.com/2015/06/23/us/georgia-dollar2-2-million-penalty-for-illegal-dna-testing.html?\_r\_0 [https://perma.cc/AY5C-W6DT].

is central to a person's identity; hence, the significance of invoking "the framing of property, and its core right to exclude."<sup>124</sup> Consequently, there seems to be no real possibility of "interference," with the concept of "fair use" viewed as a barely tolerable infringement on a person's rights. In the end, this way of conceptualizing and governing an individual genome allows imposition of myriad restrictions on its use by other entities, often without considering whether the use yields social and economic benefits for others.

### **B.** A Resource Available for Appropriation by Other Entities

Other law-making institutions in the United States conceptualize and govern genetic material and information differently; they perceive them as resources available for appropriation by other entities, among them researchers who extract and cultivate them, or law enforcement officials who find and possess them in the course of a crime. Courts and legislatures recognize that these entities have ownership interests over genetic material and/or genetic information, whereas they do not recognize similar interests by the person from whom they were extracted. In some cases, it has been explicitly determined that genetic material and/or genetic information are someone else's property, yet in others, this determination is implicit. As I will discuss later, this state of affairs may have worrying implications: Due to the significant power asymmetries between those who generate and those who benefit from genetic material and information, this situation often introduces social and economic inequalities as well as opportunities for exploitation.

#### a. An Explicit Property Regime

In this sub-section, I discuss three court decisions that supported the idea that genetic material and/or genetic information should be available for appropriation by researchers or research institutions. In all of the cases, the courts found that a researcher or research institution—and not the person who contributed the genetic material and information—had property rights over them.<sup>125</sup> The ownership interests of those entities were justified by the instrumental value of genetic material and information and the consequences of their availability for use by third parties.

Ironically, although the courts were driven mainly by the public interest and by the significant implications of genetic material

<sup>&</sup>lt;sup>124</sup> Ram, *supra* note 41, at 893.

<sup>&</sup>lt;sup>125</sup> Radhika Rao, *Informed Consent, Body Property, and Self-Sovereignty*, 44 J.L. MED. & ETHICS 437, 440–41 (2016).

and information for fostering innovation and knowledge production, they eventually granted the researcher or the research institution exclusive property rights over these resources. This approach does not necessarily coincide with the public interest and efforts to advance scientific progress).

In Moore v. Regents of the University of California, which is one of the most debated and studied cases related to the question of ownership of a genetic material used in research, the Supreme Court of California held that Moore did not have continuing rights to control the use of his excised cells.<sup>126</sup> The court rested on the proposition that people do not possess property rights over "Blood and Bodily Substances" that have been removed from their bodies and that they cannot have property rights over "the genetic code for chemicals that regulate the functions of every human being's immune system."<sup>127</sup> The court posited that the goal of the researcher, David Golde, was to "manufacture lymphokines [, which] unlike a name or a face, have the same molecular structure in every human being."<sup>128</sup> In the end, the court recognized Golde's property rights over the excised cells, the cell line (which had been created from Moore's spleen cells), and the products derived from the cells. Furthermore, the court contended that the cell line and the products are patentable because they are products of invention.<sup>129</sup>

In the second case, *Greenberg v. Miami Children's Hospital Research Institute*, the United States District Court for the Southern District of Florida held that the families of children with Canavan disease did not have property rights over their body tissues and information.<sup>130</sup> It emphasized that there were no "contemporaneous

<sup>&</sup>lt;sup>126</sup> Moore v. Regents of the Univ. of Cal., 51 Cal. 3d 120 (1990). This case concerned John Moore, a person who had hairy-cell leukemia and underwent surgery to remove his spleen at the UCLA Medical Center. Moore's physician, David Golde, had arranged for parts of the removed spleen to be utilized for research without Moore's consent. In addition, after the spleen removal, Moore visited the UCLA Medical Center several times, and during those visits, Golde withdrew more genetic samples. Seven years later, Moore discovered that his cells were used to create an extremely valuable cell line and that it was patented.

<sup>&</sup>lt;sup>127</sup> *Id.* at 135.

<sup>&</sup>lt;sup>128</sup> Id. at 138–39.

<sup>&</sup>lt;sup>129</sup> *Id.* at 142.

<sup>&</sup>lt;sup>130</sup> Greenberg v. Miami Children's Hosp. Rsch. Inst., 264 F. Supp. 2d 1064 (S.D. Fla. 2003). In this case, families of children with Canavan disease approached Reuben Matalon and asked him to investigate the gene mutations responsible for Canavan disease. The goal of these families was to develop genetic carrier screening and prenatal testing for Canavan disease and that such testing would be affordable and accessible. The families provided Matalon with tissue and blood samples, familial pedigree information, and financial support. A Canavan registry was created, which stored the information about the families. After several years, Matalon successfully isolated the gene responsible for Canavan disease. He patented the genetic sequence he identified and the related inventions, without the families' consent.

expectations of return" when they donated tissues and information to research.<sup>131</sup> Moreover, in response to one of the families' claims, the court seemed to imply that, in fact, there might be "more support for property rights inherent" in the research performed by the researcher, Reuben Matalon, rather than in the donations of the tissues and the information.<sup>132</sup> Referring to *Moore*, the court concluded that using tissues and information in a way that is inconsistent with the wishes of donors is not conversion; donors do not have property rights after a donation is made.<sup>133</sup> The court also maintained that researchers do not have a duty to inform research subjects about their economic interests and that imposing such a duty would chill medical research and "would give rise to a type of dead-hand control."<sup>134</sup>

In the third case, *Washington University v. Catalona*, the United States Court of Appeals for the Eighth Circuit held that research participants who contributed biological materials to a project did not retain the property rights that allow them to authorize the transfer of such materials to another entity.<sup>135</sup> Rather, the court held that the research institution, Washington University, had property rights over the biological materials. Exclusive possession and control, the court announced, are prima facie evidence of ownership.<sup>136</sup>

Let me make an essential clarification at this point. When courts and legislators safeguard the ownership interests of other entities in genetic material and information, the person from whom these resources were extracted retains some control over them. After all, as I will further explain in Part II, there is a lot of genetic material in a person's body and the use of genetic information by one entity does not necessarily make it unavailable to others. These facts

<sup>136</sup> Wash. Univ. v. Catalona, 437 F. Supp. 2d 985, 994 (E.D. Mo. 2006) ("It is well-settled that exclusive possession and control of personal property is prima facie evidence of ownership, and anyone else claiming such property bears the burden of proof.").

<sup>&</sup>lt;sup>131</sup> Id. at 1074.

<sup>&</sup>lt;sup>132</sup> Id. at 1073.

<sup>&</sup>lt;sup>133</sup> *Id.* at 1070–71, 1074–75.

<sup>&</sup>lt;sup>134</sup> *Id.* at 1071.

<sup>&</sup>lt;sup>135</sup> Wash. Univ. v. Catalona, 490 F.3d 667 (8th Cir. 2007). In this case, William Catalona, a researcher whom Washington University employed, began collecting samples of biological materials for genetic cancer research. The materials were stored in the GU Biorepository. Most of the funding necessary to support the maintenance and operation of the Biorepository were provided by Washington University. In 2003, Catalona decided to leave Washington University for a new position at Northwestern University. He had begun to write to the research participants, asking them to indicate whether they were willing to transfer their samples to Northwestern University. Following Catalona's actions, Washington University sought to establish its ownership over the biological materials stored in the Biorepository.

therefore do not preclude the person from using their genetic material and information for other purposes as well.

In spite of this, I still stand by my assertion that the current genome conceptualization and governance has adopted an absolute conception of ownership. First, in a given interaction, only one entity has the de jure authority to make decisions regarding the same genetic material and information. Second, the law often provides no redress if a third party obtains access to genetic material and information. As the court decisions in *Moore*, *Greenberg*, and *Washington University* demonstrated, an individual's control over genetic material and information is frequently unsupported by the law, making it exceedingly tenuous.

### b. An Implicit Property Regime

In this sub-section, I show that a de facto property regime has emerged following the decisions and choices of some legislatures and courts. These legislatures and courts have essentially permitted the appropriation of genetic material and/or genetic information by others, primarily because they were actively trying to promote research and scientific development. By allowing third parties to use genetic material and/or genetic information without consent or any notification to the individual and barely setting limitations on their use, legislatures and courts have recognized the ownership interests of those entities in that genetic material and/or genetic information.

Two examples of relevant laws related to this property regime are the Common Rule<sup>137</sup> and the Privacy Rule.<sup>138</sup> The Common Rule was first promulgated in 1991 and it has been amended several times since then. This law aims to enhance the protection of human subjects by setting the conditions in which biospecimens and private information can be used in research conducted or supported by any Federal department or agency. It is important to emphasize that the Common Rule does *not* apply to non-federally funded research. The Privacy Rule was issued in 2002 and it sets standards and requirements related to the disclosure and use of identifiable health information by "covered entities." The term "covered entity" refers to any health plan, healthcare clearinghouse, or healthcare provider who sends health information

<sup>&</sup>lt;sup>137</sup> Codified at Subpart A of 45 C.F.R. pt. 46 (2021). As explained by Wolf et al., state laws largely follow the Common Rule. Some states, such as California, Maryland, New York, and Virginia, expand the scope of the Common Rule by applying the regulatory requirements to non-federally funded research. Other states, such as Texas and Wisconsin, apply broader legal protections to research in specific contexts. *See* Wolf et al., *supra* note 117, at 27–29.

<sup>&</sup>lt;sup>138</sup> Codified at 45 C.F.R. pt. 160 & pt. 164, sub pts. A & E.

in electronic form. Covered entities are also responsible for ensuring that their business associates comply with the Privacy Rule.

I contend that these laws install a de facto property regime by recognizing the property interests of other entities in an individual genome. Both the Common Rule and Privacy Rule practically authorize the appropriation of genetic material and information by other entities, among them researchers and law The Common Rule offers several enforcement officials. mechanisms that facilitate research and enable the performance of research without a person's consent. The Privacy Rule also permits the use of genetic information without authorization of the person from whom it was extracted in various of situations, including those of law enforcement and public health. By allowing different entities to use genetic material and information without consent and barely setting restrictions on how they can be used, the Common Rule and Privacy Rule essentially recognize the ownership interests that those entities have in them.

Let me start with the Common Rule. Under certain conditions, the Common Rule permits an institutional review board (IRB) to waive or alter consent.<sup>139</sup> Waiver or alteration of consent are permitted when: (1) the research involves public benefits or service programs;<sup>140</sup> or (2) the research poses minimal risk, the consent waiver would not adversely affect the rights and welfare of the individual, and the research could not practicably be carried out without the waiver of consent.<sup>141</sup> The Common Rule also determines when consent is not required, e.g., for certain kinds of secondary research using identifiable biospecimens and information.<sup>142</sup> This means that IRB approval and informed consent are required only if the research involves *identifiable* biospecimens and information.<sup>143</sup> Therefore, if the biospecimens and information are nonidentifiable-namely, the researcher has striped the identifiers or received biospecimens and information without identifiersinformed consent, IRB approval, and oversight are not mandatory.144

Similarly, the Privacy Rule holds that in some contexts, including public health activities, judicial and administrative proceedings, law enforcement actions, and research, a covered entity can disclose or use health information without authorization.<sup>145</sup> With respect to research, the Privacy Rule stipulates that the following points should be considered: the use and

<sup>&</sup>lt;sup>139</sup> §§ 46.116(e)–(f).

<sup>&</sup>lt;sup>140</sup> § 46.116(e)(3).

<sup>&</sup>lt;sup>141</sup> § 46.116(f)(3).

<sup>&</sup>lt;sup>142</sup> § 46.104(d)(4).

<sup>&</sup>lt;sup>143</sup> § 46.102(e).

<sup>&</sup>lt;sup>144</sup> Wolf et al., *supra* note 117, at 82.

<sup>&</sup>lt;sup>145</sup> § 164.512.

disclosure of genetic information do not involve more than minimal risk to privacy, the research could not be conducted without the waiver of consent, and the research could not be conducted without access to and use of the information.<sup>146</sup> In addition, health information that does not identify a person is not protected under the Privacy Rule.<sup>147</sup> According to this Rule, information becomes non-identifiable by removing eighteen specific types of identifiers, removing another 16 identifiers from a dataset for research purposes, or having a statistician certify that the risk of re-identification is minimal.<sup>148</sup>

It is worth noting that under both the Common Rule and the Privacy Rule, entities are typically required to obtain consent to use genetic material and information. Moreover, as one of the elements of informed consent, researchers are required to disclose their commercial interests in biospecimens and inform individuals that their biospecimens could have commercial value.<sup>149</sup> However, the consent mechanism set by the Common Rule and the Privacy Rule provides extremely limited protection to the person from whom that material and information were extracted. First and foremost, a person's interests can be protected only against use by a specific entity (researcher, healthcare provider, health plan, healthcare clearinghouse, and business associate) and generally not by other entities.<sup>150</sup> Moreover, the consent mechanism is a one-time exercise of individual choice and not a dynamic, ongoing process. Consent is, therefore, not continuously maintained. In addition, this mechanism provides only minimal control over what is done with the genetic material and information. People usually cannot bargain, for example, for compensation in exchange for participation in research.<sup>151</sup> Finally, the consent mechanism does not provide people

<sup>&</sup>lt;sup>146</sup> § 164.512(i)(2)(ii).

<sup>&</sup>lt;sup>147</sup> Jennifer Kulynych & Henry T. Greely, *Clinical Genomics, Big Data, and Electronic Medical Records: Reconciling Patient Rights with Research When Privacy and Science Collide*, 4 J.L. & BIOSCIENCES 94, 111, 115–16 (2017).

<sup>&</sup>lt;sup>148</sup> Id. See also James Scheibner et al., Data Protection and Ethics Requirements for Multisite Research with Health Data: A Comparative Examination of Legislative Governance Frameworks and the Role of Data Protection Technologies, 7 J.L. & BIOSCIENCES 1, 9 (2020).

<sup>&</sup>lt;sup>149</sup> § 46.116(c)(7). See also Jessica L. Roberts, Negotiating Commercial Interests in Biospecimens, 45 J.L. MED. & ETHICS 138 (2017).

 $<sup>^{150}</sup>$  The Common Rule only applies to human subject research; this means that it does not apply if biospecimens and information were not collected through interaction with a living individual specifically for the proposed research. *See* § 46.101. The Privacy Rule only applies to "covered entities" (i.e., healthcare providers, health plans, healthcare clearinghouses, and business associates). *See* § 164.104.

<sup>&</sup>lt;sup>151</sup> It is important to clarify that in other contexts, some entities do offer compensation. *See* Jessica L. Roberts et al., *Should You Profit from Your Genome?*, 35 NATURE BIOTECHNOLOGY 18, 18 (2017) (explaining that some biotech and pharmaceutical companies compensate individuals for licensing their

who have been harmed with a private right of action or legal remedies.<sup>152</sup>

This implicit property regime was not established through legislation alone—courts have also played a role in its emergence. In several cases concerning law enforcement, the courts held that if genetic material was left in a public space, then the person from whom it was extracted does not have any expectations of privacy.<sup>153</sup> Therefore, the genetic material and the information embedded in it are considered abandoned property and the person from whom they were extracted lacks ownership rights over them. In such cases, the courts did not impose meaningful restrictions on the use by law enforcement officials, implying that leaving genetic material in public exposes it to appropriation by other entities.

For example, in *King v. State*, the Superior Court of Delaware determined that Jeffrey King did not have reasonable expectations of privacy regarding the genetic material and information collected from a Wawa iced tea bottle placed in a public trashcan at Walmart.<sup>154</sup> The court maintained that by "throwing away trash in a public trash container," king threw away any "subjective expectation of privacy in it that society accepts as reasonably acceptable."<sup>155</sup> In addition, the court ruled that by testing King's DNA for identification purposes, the State did not violate his expectation of privacy.<sup>156</sup>

Similarly, in *Lovchik v. Commonwealth*, the Court of Appeals of Virginia clarified that trash and recyclables placed on a public street are abandoned property, objects devoid of the original owner's privacy expectations.<sup>157</sup> Accordingly, the court held that Jude Joseph David Lovchik had no "objectively reasonable

genetic information).

<sup>&</sup>lt;sup>152</sup> Wolf et al., *supra* note 117, at 99; Jessica L. Roberts & Valerie Gutmann Koch, *Law vs. Regulations in the Common Rule*, YALE J.L. & TECH. BLOG (Jan. 6, 2016), https://yjolt.org/blog/law-vs-regulations-common-rule [https://perma.cc/8VDK-3YLB].

<sup>&</sup>lt;sup>153</sup> See, e.g., People v. Gallego, 190 Cal. App. 4th 388 (Cal. Ct. App. Nov. 22, 2010) (holding that the defendant abandoned the cigarette butt in a public place and had no reasonable expectation of privacy concerning its DNA testing aimed at identifying him as a suspect in a criminal investigation); Guy v. State, No. 03-12-00466-CR, 2014 Tex. App. LEXIS 11577 (Tex. Ct. App. Oct. 22, 2014) (holding that the defendant had no legitimate expectation of privacy in a drinking straw that he had left behind in a police car); People v. Moore, No. 7292/2017, 2018 NYLJ LEXIS 3520 (N.Y. Sup. Ct. Oct. 26, 2018) (holding that the defendant voluntarily abandoned a cigarette and waived a legitimate expectation of privacy).

<sup>&</sup>lt;sup>154</sup> State v. King, No. 1909016237, 2021 Del. Super. LEXIS 48 (Del. Super. Ct. Jan. 21, 2021).

<sup>&</sup>lt;sup>155</sup> *Id.* at \*15.

<sup>&</sup>lt;sup>156</sup> *Id.* at \*16.

<sup>&</sup>lt;sup>157</sup> Lovchik v. Commonwealth, No. 1094-19-4, 2020 Va. App. LEXIS 249 (Va. Ct. App. Oct. 20, 2020).

expectation of privacy in his DNA identification profile as developed from DNA found on objects he had abandoned."<sup>158</sup>

A case from another domain is *Peerenboom*.<sup>159</sup> To recall, the court in this case found that the Perlmutters had property rights over their genetic information. The court also held that there is a significant distinction between genetic material and genetic information.<sup>160</sup> It stated that the previous court decisions on whether genetic material constitutes property (i.e., *Moore* and *Greenberg*) are inapplicable to the question of whether genetic information constitutes property.<sup>161</sup> The court decision, in this case, implies that while a person has property rights over their genetic information, they do not have property rights over genetic material. Because the court did not recognize that these rights are, in principle, capable of binding other entities to the genetic material, it set an important precedent, according to which anyone can collect genetic material as long as they do not use the information.

Considering the discussion in this sub-section and the previous one, it is clear that legislatures and courts have fundamentally perpetuated two narratives regarding ownership interests in an individual genome—"productive appropriation"<sup>162</sup> and abandonment.

According to the first narrative, *productive appropriation*, certain uses require some degree of additional effort. Thus, the entities who invest efforts to acquire access to genetic material and information should be the only ones to enjoy the benefits of their labors.<sup>163</sup> By legitimating this narrative and focusing on incentives

<sup>163</sup> The narrative of productive appropriation has long been reflected in the view taken by the U.S. Patent and Trademark Office. For many years, the Office assumed that DNA segments (i.e., genes) in isolated form were not considered to be "natural." Therefore, by virtue of their isolation from the rest of the genome, they were patent-eligible under 35 U.S.C. § 101. *See* Utility Examination Guidelines, 66 Fed. Reg. 1092, 1093 (Jan. 5, 2001). However, in 2013, the U.S. Supreme Court ruled that a DNA segment is a "product of nature" and cannot be patented. *See* Ass'n for Molecular Pathology v. Myriad Genetics, Inc., 569 U.S. 576 (2013). The Court held that discovering a DNA segment creates nothing new, and thus, there is no intellectual property to protect. The Court did, however, allow patents over complementary DNA (cDNA)—DNA synthesized from a single-stranded ribonucleic acid—because it was not "naturally occurring."

<sup>&</sup>lt;sup>158</sup> *Id.* at \*11.

<sup>&</sup>lt;sup>159</sup> Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957 (Fla. 15th Cir. Ct. Jan. 23, 2017).

 $<sup>^{160}</sup>$  Id. at \*15–16.

<sup>&</sup>lt;sup>161</sup> Id.

<sup>&</sup>lt;sup>162</sup> On the concept of "productive appropriation," *see* JULIE E. COHEN, BETWEEN TRUTH AND POWER: THE LEGAL CONSTRUCTIONS OF INFORMATIONAL CAPITALISM 59, 72 (2019). Cohen explains that there is a new type of public domain—she calls it the "biopolitical public domain"—where raw materials are available for taking and are framed as inputs to types of productive activity.

to production, legislatures and courts have cleared the way for recognition of the property interests of other entities.

According to the second narrative, *abandonment*, no property interests exist regarding resources not in an individual's possession and left by them in public spaces.<sup>164</sup> Therefore, leaving genetic material in public enables their appropriation by other entities and prevents possible protections. This narrative, widely utilized by the courts, reflects the "rule of 'finders keepers' . . . [which] stems from the doctrine of abandonment, in which the former title-holder surrenders all rights . . . and title is assigned to the first person who takes possession."<sup>165</sup>

# II. WHAT'S WRONG WITH THE CURRENT GENOME CONCEPTUALIZATION AND GOVERNANCE?

Part I discussed the two dominant approaches comprising the current genome conceptualization and governance. One approach treats an individual genome as a resource capable of supporting property rights for the person from whom it was extracted; the second treats it as a resource available for appropriation by other entities. These approaches, despite their differences, have one critical thing in common: they adopt an absolute conception of ownership over an individual genome, reducing interests in an individual genome to individualist claims.

What is wrong with a legal framework that assumes absolute ownership of an individual genome? In this part, I explore the key underlying problems of the current genome conceptualization and governance. Overall, I aim to demonstrate that these problems originate from the fact that courts and legislatures do not address the appropriate questions regarding the competing interests over an individual genome and they do not consider the repercussions of giving absolute ownership to one entity or another.

In the first section, I maintain that the current genome conceptualization and governance is motivated by a dominium perception of a single owner endowed with extensive control. Consequently, it disregards the relational dimension of an individual genome. In the second section, I argue that the current genome conceptualization and governance overlooks the features of an individual genome. It treats an individual genome as a private good (i.e., excludable and subtractable) although it is, de facto, certainly not always the case. In the last section, I claim that the current genome conceptualization and governance lacks explanatory power.

<sup>&</sup>lt;sup>164</sup> Elizabeth E. Joh, *Reclaiming "Abandoned" DNA: The Fourth Amendment and Genetic Privacy*, 100 Nw. U.L. REV. 857, 863–64 (2006).

<sup>&</sup>lt;sup>165</sup> Ram, *supra* note 41, at 905–06.

## A. Failure to Consider the Relationality of an Individual Genome

The current genome conceptualization and governance adopts an individualistic approach and ignores the inherent relationality of an individual genome. It does so in two different ways. First, it ignores an individual genome's familial and collective aspects. Second, it reflects an individualistic ideology and an absolute conception of ownership, recognizing only one "winner" and making everyone else "losers." In other words, it assumes control of an individual genome by one owner. Consequently, one entity is conferred with too much control, creating significant power asymmetries and inequalities.

### a. Familial and Collective Aspects of an Individual Genome

Human DNA is 99.9 percent identical among all individuals. Although 0.1 percent may not seem like much, it represents millions of distinct locations (6 million to be precise) in a person's genome where variation may exist.<sup>166</sup> That 0.1 percent is the reason why some people have an increased likelihood of developing a disease or possess specific physical and mental characteristics, such as hair color or tendencies for depression.<sup>167</sup> Not to be ignored are the epigenetic changes (i.e., chemical modifications that control the activity of genes without changing the DNA sequence) that impact on the behavior of affected genes.<sup>168</sup> Scientists believe that these changes produce unique epigenetic signatures.<sup>169</sup> In the near future, the distinctive nature of an individual genome may allow us to develop medical care tailored to specific genetic characteristics.<sup>170</sup>

<sup>&</sup>lt;sup>166</sup> Human Genomic Variation, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/dna-day/15-ways/human-genomic-variation

<sup>[</sup>https://perma.cc/7LR6-ENX9] (last visited Nov. 15, 2022). *See also* HENRY T. GREELY, THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION 10, 20–21 (2016). As Greely explains, each persons has two genomes, one from each parent. Therefore, the complete genome sequence of a person is about 6.4 billion bases long. When two people compare their genomes, they will vary about six million times.

<sup>&</sup>lt;sup>167</sup> Although many differences between individuals are because of differences in their genes, the interplay between genes and the environment also influences the expression of conditions or traits. On the interaction between genes and the environment, *see* Ingrid Lobo, *Environmental Influences on Gene Expression*, 1 NATURE EDUC. 39 (2008).

<sup>&</sup>lt;sup>168</sup> Epigenomics Fact Sheet, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/about-genomics/fact-sheets/Epigenomics-Fact-Sheet [https://perma.cc/43X4-SS2F] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>169</sup> Riya R. Kanherkar et al., *Epigenetics Across the Human Lifespan*, 2 FRONTIERS IN CELL & DEV. BIOLOGY 49 (2014).

<sup>&</sup>lt;sup>170</sup> Euan A. Ashley, *Towards Precision Medicine*, 17 NATURE REV. GENETICS 507 (2016).

Knowledge of a person's genetic profile may turn current medicine's "one size fits all" approach into a more personalized approach, one supporting selection of the best treatment for each individual.

However, an important fact about an individual genome is that beyond its *personal* aspects, it also has *familial* and *collective* features. As I noted at the beginning of this section, a person shares about 99.9 percent of their DNA with other individuals. Among the 3 million genetic differences that exist between individuals, we share some of those with family members, such as mother/father, siblings, grandfather/grandmother, uncle/aunt, and niece/nephew.

Surprisingly, these familial and collective features are rarely considered by today's genome conceptualization and governance. For instance, the laws of Colorado, Georgia, Alaska, Florida, and Louisiana stipulate that genetic material and/or genetic information are the exclusive property of the person from whom they were extracted.<sup>171</sup> Nowhere in these laws is it stated that genetic information is shared with other individuals, including family members and complete strangers. In a similar vein, the courts in *Peerenboom* and *Cole* ignored the familial and collective features when deciding that Isaac and Laura Perlmutter and Michael Cole possessed an exclusive property right in their genetic information.<sup>172</sup>

I am convinced that when determining how an individual genome should be treated, it is essential to consider these three aspects—personal, familial, and collective—altogether. When debating interests in an individual genome, consideration of its multiple aspects is important because it directs us to the stakeholders involved and how their claims interact. Considering the various aspects also prevents the harmful outcomes resulting when not bearing all the relevant interests in mind.

1. Familial Aspects

Offspring inherit 50 percent of their DNA from each genetic parent.<sup>173</sup> DNA is grouped in chromosomes, and parents pass DNA on to their offspring by transferring entire chromosomes to the embryo (there are a total of 46 chromosomes, and each parent provides 23 chromosomes).<sup>174</sup> This means that offspring also share some parts of their sequence with siblings and other genetic relatives. For example, offspring share 50 percent with siblings, 25

<sup>&</sup>lt;sup>171</sup> See discussion supra Section I.A.a.

<sup>&</sup>lt;sup>172</sup> Id.

<sup>&</sup>lt;sup>173</sup> Alan McHughen, DNA Demystified: Unravelling the Double Helix 201 (2020).

<sup>&</sup>lt;sup>174</sup> Chromosomes Fact Sheet, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/about-genomics/fact-sheets/Chromosomes-Fact-Sheet [https://perma.cc/N3XB-XN5X] (last visited Nov. 15, 2022).

percent with grandparents or uncles and aunts, and 12.5 percent with great-grandparents or first cousins.<sup>175</sup>

Also worth noting that the Y chromosome (i.e., the sexdetermining chromosome) is passed down in one piece from father to son and that the mitochondrial DNA (i.e., a chromosome found outside the nucleus, in the mitochondria) is inherited exclusively from the mother.<sup>176</sup> Therefore, it is possible to identify Ychromosome and mitochondrial DNA profiles that are shared among genetic relatives.<sup>177</sup>

Because genetically related relatives have fewer genetic differences (compared to random people), an individual genome can be used to identify and learn about them as well. Hence, when an individual genome of a particular person is collected and analyzed, some information on that person's genetic relatives is also revealed.<sup>178</sup>

### 2. Collective Aspects

All the world's people are about 99.9 percent identical in terms of their genetic sequence.<sup>179</sup> In addition, the genes that one person possesses are part of the "human gene pool," namely, the set of genes of the human species.<sup>180</sup>

In the early years of the 21<sup>st</sup> century, the "human genome" was recognized as an element of humanity's "common heritage" by the Universal Declaration on the Human Genome and Human Rights.<sup>181</sup> The Declaration reads as follows: "The Human Genome underlies the fundamental unity of all members of the human family,

<sup>&</sup>lt;sup>175</sup> BRUCE R. KORF, HUMAN GENETICS AND GENOMICS 36 (2007); Ram, *supra* note 41, at 901–02.

<sup>&</sup>lt;sup>176</sup> *Id.* at 878.

<sup>&</sup>lt;sup>177</sup> Id.

<sup>&</sup>lt;sup>178</sup> Id. at 876. See also Shanni Davidowitz, 23andEveryone: Privacy Concerns with Law Enforcement's Use of Genealogy Databases to Implicate Relatives in Criminal Investigations, 85 BROOK. L. REV. 185 (2019) (describing the increasing use of genealogy databases by law enforcement agencies against family relatives); Robert I. Field et al., Am I My Cousin's Keeper? A Proposal to Protect Relatives of Genetic Database Subjects, 18 IND. HEALTH L. REV. 1 (2021) (proposing a new concept of privacy that would protect genetic relatives).

<sup>&</sup>lt;sup>179</sup> Whole Genome Association Studies, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/17516714/2006-release-about-whole-genome-

association-studies [https://perma.cc/5ABQ-CAAT] (last visited Nov. 15, 2022). <sup>180</sup> The human gene pool is made up of every variant form of a gene (called allele). *See The Collective Set of Alleles in a Population Is Its Gene Pool*, NATURE

EDUC., https://www.nature.com/scitable/topicpage/the-collective-set-of-allelesin-a-6385985/ [https://perma.cc/HLV2-75UJ] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>181</sup> UNESCO Res. 29C/17, Universal Declaration on the Human Genome and Human Rights (Nov. 11, 1997).

as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity."<sup>182</sup>

It is worth noting that this position is unfounded and overly reductionist; it assumes that there is an "archetype genome" and treats an individual genome as a representative of the genome of humanity. In reality, no such archetype exists. As explained by Hank Greely, the human genome does not have determinate boundaries it "has changed, is changing, and will continue to change inevitably from generation to generation."<sup>183</sup>

That said, the fact that there is no archetypical genome should not negate the collective interest in how an individual genome is used.<sup>184</sup> Given the fact that some genetic components are found in almost all humans and the importance that an individual genome has for our understanding of biological processes, there is a unique public interest in this resource. It seems that all people have some stake in what becomes of the human gene pool. For instance, all individuals have a stake in the genetic variants that may be introduced to the human gene pool as a result of the use of gene editing technology, once the technology will be safe and effective.

In addition, all people have an interest in the benefits derived from the use of an individual genome. More profound knowledge of human genetics and a better understanding of human genetic diversity is of utmost importance because they "can be used to bring about scientific and medical developments that benefit all of humankind."<sup>185</sup> Put simply, the research of an individual genome holds the promise of revolutionizing medicine and improving the health of all people in every society.

# b. Individualistic Ideology and Absolute Conception of Ownership

The current genome conceptualization and governance centers around the inviolability and separateness of people. It focuses on the premise of individual control and maximization of personal gain, positioning "the sovereign individual as the ultimate

<sup>&</sup>lt;sup>182</sup> *Id.* at art. 1. On the view that the human genome is the heritage of humanity, *see* Matthieu Queloz, *The Double Nature of DNA: Reevaluating the Common Heritage Idea*, 24 J. POLIT. PHILOS. 47–48 (2016) ("[T]he human genome is best thought of as a repository of information: a record of biological history and a source of future innovation that is best compared to the cultural and natural heritage."); Ossorio, *supra* note 26 (supporting the designation of the human genome as part of the common heritage of humanity).

<sup>&</sup>lt;sup>183</sup> HENRY T. GREELY, CRISPR PEOPLE: THE SCIENCE AND ETHICS OF EDITING HUMANS 209 (2021).

<sup>&</sup>lt;sup>184</sup> See Michelle J. Bayefsky, *The Human Genome as Public: Justifications and Implications*, 31 BIOETHICS 209 (2017).

<sup>&</sup>lt;sup>185</sup> *Id.* at 215.

source of political authority . . . [and] self-interested rationality as the origin[al] point for social ordering."<sup>186</sup>

Moreover, the current genome conceptualization and governance incorporates an absolute conception of ownership, allowing the choice of only one "winner." As previously illustrated, courts and legislatures have protected the ownership interests of the person from whom an individual genome was extracted, or of some other entity. Several laws (e.g., legislated in Alaska and Florida)<sup>187</sup> and court decisions (e.g., handed down in *Peerenboom* and *Cole*)<sup>188</sup> have designated the person from whom an individual genome was extracted as the locus of authority. In contrast, other laws (e.g., the Common Rule and Privacy Rule)<sup>189</sup> and court decisions (e.g., *Moore, Greenberg*, and *Washington University*)<sup>190</sup> have identified other entities as the locus of authority.

The individualistic ideology and the absolute conception of ownership reflected in the current genome conceptualization and governance are worrisome. They cannot represent and address multiple concurrent interests in an individual genome (e.g., interests of the person from whom an individual genome was extracted, family members, researchers, law enforcement officials, adversaries, employers, and DTC genetic testing companies) and the broader effects on this resource.

Furthermore, by incorporating Blackstone's vision of absolute and extensive property entitlements, the individualistic ideology and the absolute conception of ownership reflect a distorted conception of property.<sup>191</sup> As other scholars have argued, and as I urge in this Article, property rights over a resource may be distributed among several different entities, and one individual does not necessarily have to have absolute power over it.<sup>192</sup> The institution of property should, similarly, incorporate a more relational approach and be guided by more egalitarian and communitarian values.<sup>193</sup>

Carrying this line of argument further, we should be concerned about protecting the ownership interests of one entity exclusively. A legal regime that recognizes solely the property rights

<sup>&</sup>lt;sup>186</sup> COHEN, *supra* note 162, at 7.

<sup>&</sup>lt;sup>187</sup> See supra text accompanying notes 70–74, 115–18.

<sup>&</sup>lt;sup>188</sup> See supra text accompanying notes 86–114, 119–23.

<sup>&</sup>lt;sup>189</sup> See supra text accompanying notes 137–52.

<sup>&</sup>lt;sup>190</sup> See supra text accompanying notes 126–36, 153–61.

<sup>&</sup>lt;sup>191</sup> See generally DAGAN, supra note 9, at 79–81.

<sup>&</sup>lt;sup>192</sup> See Dagan, supra note 9; SINGER, supra note 47; Heller, supra note 36, at 1182–83; Kristen A. Carpenter et al., *In Defense of Property*, 118 YALE L.J. 1022, 1066–67 (2009).

<sup>&</sup>lt;sup>193</sup> See Gregory S. Alexander, *The Social-Obligation Norm in American Property Law*, 94 CORNELL L. REV. 745 (2009); Eduardo M. Peñalver, *Land Virtues*, 94 CORNELL L. REV. 821 (2009).

of the person from whom an individual genome was extracted creates exclusive rights, unlimited in duration and subject to relatively few limitations. This regime grants the respective person too much control—there is no understanding of "fair use" or possibility of intervention. Such a regime also neglects familial and collective aspects, depriving family members of legal protection and failing to address population-level problems and socially and economically beneficial activities, such as the development of new medical advancements as well as valuable insights regarding changes in genotypes over the course of time, both within and between populations.

At the same time, we should be reluctant to adopt a regime that recognizes other entities' ownership interests while denying property rights from the person from whom an individual genome was extracted. Such a regime particularly neglects personal and familial aspects, implying that the person from whom an individual genome was extracted and their genetic relatives do not have ownership interests.

This regime, moreover, does not recognize fairness as a fundamental value in the distribution of burdens and benefits resulting from the use of an individual genome.<sup>194</sup> There are, to be sure, many benefits to be derived, including monetary ones. At present, researchers and DTC genetic testing companies are the only ones who can reap profits from an individual genome, denying a fair share of any monetary benefits from the person who contributed an individual genome together with their genetically related relatives.

To conclude, the current genome conceptualization and governance contains an epistemic deficiency by paying little to no attention to relationality. Law-making institutions do not deeply understand the various aspects of an individual genome and have not thought through how a resource with all these features should be conceptualized and governed. Hence, the current genome conceptualization and governance fails to provide adequate tools for identifying and addressing all of the different effects—personal, familial, and collective. It is also narrow and reductionist. It supports an individualistic ideology that enshrines personal liberty as its core value. The ensuing regime therefore fails to respect the ownership interests of multiple stakeholders and allows selected harms and benefits to go unrepresented and unaddressed.

# B. Exclusion of the "Economic" Features of an Individual Genome

<sup>&</sup>lt;sup>194</sup> See Roberts, *supra* note 12, at 1123–28.

We have reached to point where we can ask: What are the attributes of an individual genome? What do we need to know about it to develop a sensible and fair legal ownership regime?

Under the current genome conceptualization and governance, these questions remain largely unexplored, with the attributes of an individual genome left imprecise. As will be shown, an individual genome operates at different levels simultaneously, a fact causing normative analyses to fail if focusing on only one or another attribute. Therefore, it is essential for law-making institutions to first inquiry into the attributes of an individual genome, and only then, to determine the legal mechanisms appropriate for its governance.<sup>195</sup>

In the economics and the legal literatures, a distinction is often made between four types of goods—public, private, club, and common-pool resources<sup>196</sup>—that are characterized along two dimensions: excludability and subtractability (see Figure 1). Excludability refers to whether it is possible to exclude other people from using the good.<sup>197</sup> Subtractability refers to whether one person's use makes the good unavailable to other people.<sup>198</sup> While I follow Elinor Ostrom's usage of the term "subtractability," some scholars use "rivalry" as an alternative term.<sup>199</sup>

It should be highlighted that the different categories offered in the economics and the legal literatures may be useful in developing ownership regimes, but they are certainly not a set of "truths" about property. They are also undoubtedly not the only set of categories with which one might think about property. Ultimately, they are simply theoretical constructs created to divide up resources in the world.

Indeed, as I demonstrate in this section, these categories may not be the best categorization system for thinking about an individual genome and its relationship to property as a legal institution. My analysis shows that it is difficult to determine how an individual genome fits simply on one dimension, and this suggests that the categories were designed with other types of resources in mind. Nevertheless, these categories are still useful for

<sup>&</sup>lt;sup>195</sup> As Henry Smith claims, "[a]lthough property is not a thing, the nature of the thing in the world helps determine what kind of legal thing it can correspond to." *See* Henry E. Smith, *The Thing About Exclusion*, 3 BRIGHAM-KANNER PROP. RTS. CONF. J. 95, 118 (2014).

<sup>&</sup>lt;sup>196</sup> Hess & Ostrom, *supra* note 50, at 119–20; Lawrence B. Solum, *Questioning Cultural Commons*, 95 CORNELL L. REV. 817, 821–24 (2010).

<sup>&</sup>lt;sup>197</sup> Ostrom & Ostrom, *supra* note 49, at 165.

<sup>&</sup>lt;sup>198</sup> *Id.* at 165–66.

<sup>&</sup>lt;sup>199</sup> See generally Elinor Ostrom, Beyond Markets and States: Polycentric Governance of Complex Economic Systems, 100 AM. ECON. REV. 614, 644–45 (2010) (suggesting the use of "subtractability of use" in place of "rivalry of consumption.").

my purposes in this Article since they help highlight the distinctive features of an individual genome.

Subtractability						
		Low	High			
	Difficult	Public Goods	Common-Pool			
		Sunset	Resources			
Exclusion		Common Knowledge	Irrigation Systems			
			Libraries			
	Easy	Club Goods	Private Goods			
		Day-Care Centers	Doughnuts			
		Country Clubs	Personal Computers			

Figure	1-Types	of Goods <sup>200</sup>

How are these types of goods governed? As a rule, attempts are made to govern goods in correlation with their attributes. It is important to remember that the attributes of goods do not necessarily dictate any particular governance structure. However, in most cases we would prefer to avoid "tragicomic effects," such as granting exclusive entitlements over goods that cannot be exclusively held.<sup>201</sup> Therefore, goods like doughnuts and personal computers, which are in most cases excludable and subtractable, will be governed by a private property regime (because this regime creates efficient allocations).<sup>202</sup> In contrast, goods like sunsets and common knowledge, which are generally non-excludable and nonsubtractable, will be governed by an open-access regime (because private entities cannot efficiently provide them).<sup>203</sup>

<sup>&</sup>lt;sup>200</sup> Figure 1 was reproduced from Hess & Ostrom, *supra* note 50, at 120.

<sup>&</sup>lt;sup>201</sup> See Margaret A. McKean, Common Property: What Is It, What Is It Good For, and What Makes It Work?, in PEOPLE AND FORESTS: COMMUNITIES, INSTITUTIONS, AND GOVERNANCE 27, 31 (Clark C. Gibson et al. eds., 2000) ("[W]e... often attempt to create public rights in private goods and private rights in pure public goods or common-pool goods, with tragicomic effects (such as awarding an infinite number of rights to an inexhaustible resource or awarding exclusive rights to resources that cannot be exclusively held)."). See also James M. Acheson, Private Land and Common Oceans: Analysis of the Development of Property Regimes, 56 CURRENT ANTHROPOLOGY 28, 29–30 (2015) ("When the costs of defending boundaries are relatively low and the value of resources in an area is high, people have a strong incentive to generate a private property regime. When the costs of exclusion are high relative to the value of resources, the probability of a common property regime being developed or maintained is high. When the costs of exclusion are very high relative to the value of resources, open access will likely result.")

<sup>&</sup>lt;sup>202</sup> Solum, *supra* note 196, at 822.

<sup>&</sup>lt;sup>203</sup> *Id. See also* Yochai Benkler, *Open-Access and Information Commons, in* THE OXFORD HANDBOOK OF LAW AND ECONOMICS: PRIVATE AND COMMERCIAL LAW 256 (Francesco Parisi ed., 2017) (arguing that an open-access regime is most feasible in the case of resources that are either nonrivalrous or partially

As Part I of this Article revealed, the current genome conceptualization and governance is dominated by a sole-ownership model; dictating an individual genome to be governed by a private property regime (i.e., allowing one party to use genetic material or genetic information while preventing another party from using that *same* material or information). One could thus straightforwardly posit that an individual genome is de facto a private good, meaning excludable and subtractable. However, when considering an individual genome as an economic and legal good—namely, analyzing it in terms of excludability and subtractability—we can show that this is not always the case. Such an analysis reveals that there is often a gap between the *de facto* and the *de jure* status of an individual genome. That is, an individual genome is *made* a private good by technology, law, or social norms, whereas it is, de facto, another type of good.<sup>204</sup>

### a. Genetic Material

In terms of excludability, genetic material is challenging to characterize. On the one hand, most of a person's genetic material lies within their body. This genetic material is more excludable because it can be secured, and people can be prevented from accessing it. This material, furthermore, cannot be accessed except through an intervention, and it is typically believed that in order to intervene in someone else's body, a person should be authorized to do so. In other words, a person can restrict access to their body and so prevent others from collecting genetic material.

On the other hand, the body is, in fact, a "leaky vessel." Humans leave traces of their genetic material everywhere—on discarded tissues, bottles of water, and smoked cigarettes.<sup>205</sup> It is thus extremely difficult to exclude others from accessing genetic material found in this way. Theoretically, it is possible to prevent the shedding of genetic material, or to collect all material that has been shed. People can, for instance, wear gloves at all times, carry cleaning materials to wipe down every surface they touch, and burn the things that they want to throw into the trash.

To illustrate the excludability point, imagine yourself walking around with a heavy backpack that contains dozens and dozens of copies of a pocket-sized book. The backpack has a hole at the bottom, and sometimes a book falls out. It is relatively easy for

congestible).

<sup>&</sup>lt;sup>204</sup> See Amy Kapczynski & Talha Syed, *The Continuum of Excludability and the Limits of Patents*, 122 YALE L.J. 1900, 1916–21 (2013) (claiming that excludability is affected by legal entitlements, technologies, and social norms).

<sup>&</sup>lt;sup>205</sup> Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. REV. 665, 666–67 (2011).

you to prevent other people from using the copies that are in your backpack, but unless you are vigilant and pick up every book that falls out—a Herculean task when it comes to genetic material—it will be easy for someone to pick up a fallen copy.

In terms of subtractability, genetic material is similarly challenging to characterize. On the one hand, when a researcher or an adversary collects genetic material, the material collected has high subtractability. Its use by these entities prevents the person from whom the material was extracted from using that *same* genetic material.

Yet, a tiny amount of genetic material can become a lot of material and thus has low subtractability. Under certain circumstances, an almost unlimited amount of genetic material can be generated from just a few cells. Cell lines, for example, can provide an unlimited supply of material—they are propagated in vitro from tissue or body fluid and become immortalized.<sup>206</sup> The HeLa cell line taken from Henrietta Lacks, became the first immortalized cell line and was "capable of renewing itself in artificial culture indefinitely."<sup>207</sup> Moreover, there is so much genetic material in the 37 trillion cells contained in a typical body,<sup>208</sup> the total amount of genetic material that one person has can effectively be treated as an "infinite" resource. This possibility can be likened to filling a jar with water from the ocean.

To illustrate the subtractability point, consider the sourdough starter in the fridge of your favorite master baker. Any particular spoonful of starter is subtractable. Once it is used to make a loaf of bread, it cannot be used to make another loaf. However, with the addition of water and flour to even the tiniest bit of starter, the baker has enough starter to distribute to all of the "sous bakers" in the area within a few hours.

### b. Genetic Information

In terms of excludability, genetic information is, again, difficult to categorize. On the one hand, like most types of information,<sup>209</sup> genetic information can be freely copied given its

<sup>&</sup>lt;sup>206</sup> Gurvinder Kaur & Jannette M. Dufour, *Cell Lines: Valuable Tools or Useless Artifacts*, 2 SPERMATOGENESIS 1 (2012). *See also* SKLOOT, *supra* note 2, at 99–100 (clarifying that even if cells are extracted from the *same* sample, they may behave differently).

<sup>&</sup>lt;sup>207</sup> Alan Dove, *The Art of Culture: Developing Cell Lines*, SCIENCE (Nov. 21, 2014), https://www.science.org/content/article/art-culture-developing-cell-lines [https://perma.cc/7JLW-PXGJ].

<sup>&</sup>lt;sup>208</sup> Ananda L. Roy & Richard S. Conroy, *Toward Mapping the Human Body at a Cellular Resolution*, 29 MBoC 1779, 1779 (2018).

<sup>&</sup>lt;sup>209</sup> Robert A. Heverly, *The Information Semicommons*, 18 BERKELEY TECH. L.J. 1127, 1157–58 (2003) (discussing the non-excludable nature of information).

digital format. Therefore, it is difficult to exclude people from accessing it. Genetic information can be distributed in various ways and the person from whom it was taken may not even notice what has transpired. Once the genetic information is "out there," it is difficult to prevent its use. Excluding people from accessing genetic information is arduous because people leave their genetic material behind everywhere, so genetic information is everywhere as well.

On the other hand, genetic information is more excludable to the degree that it is possible to limit access. The power to prevent others from using genetic information depends on a range of factors: the state of information technology (e.g., encryption), informal rules that govern people's behavior, and legal requirements. Concretely, if an entity stores genetic information as securely as they would store any other information, it becomes more excludable.

The same holds true for the subtractability of genetic information. On the one hand, because it can be copied, multiple stakeholders can use that information simultaneously. On the other, some uses of DNA make unalterable changes to genetic information, as in the case of gene-editing technologies.<sup>210</sup> To the extent that the new information overwrites the old information and makes it unavailable, or otherwise changes the nature of that information (either in the person or in the gene pool more broadly), its use renders the genetic information highly subtractable. We can compare this to using a program that sometimes alters its own source code.

To make the discussion on the economic features of an individual genome more concrete, it would be helpful to analyze some of the cases described previously. *Peerenboom* and *Cole* are instructive examples to start with. In these cases, the courts held that only the person from whom an individual genome was extracted had property rights over the genetic information. One may be inclined to think that this institutional arrangement (i.e., a private property regime) is justified by the nature of genetic information as a private good (i.e., excludable and subtractable). However, analyzing the cases from an economic perspective reveals that under the circumstances of these cases, the genetic information was de facto a public good given that it was non-excludable and non-subtractable.

In *Peerenboom*, the genetic information of Isaac and Laura Perlmutter was obtained from bottles of water and paper that were placed in publicly accessible places. Therefore, the information was less excludable. The information also had low subtractability. Although Harold Peerenboom processed and used the genetic

<sup>&</sup>lt;sup>210</sup> For more information on gene-editing technologies, such as CRISPR-Cas9, and their implications, *see* NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, HUMAN GENOME EDITING: SCIENCE, ETHICS, AND GOVERNANCE 15–25 (2017).

information, Isaac and Laura Perlmutter were not prevented from using it. The situation in *Cole* is quite similar. When Michael Cole took a DNA ancestry test and handed over the genetic material to Gene by Gene, the genetic information was no longer excludable, and it had low subtractability because the use by Gene by Gene did not prevent Cole from using that same information.

Another fascinating example is *Moore*. The court held in this case that only Golde had property rights over the genetic material that was extracted from Moore. One may presume that the recognition of property rights in this case were justified by the nature of the genetic material as a private good. Nevertheless, the circumstances of the case indicate that the genetic material was a club good de facto (i.e., excludable and non-subtractable). To be clear, Golde was able to exclude others from using the genetic material—it was securely stored, and he was able to deny access to it. Concerning subtractability, Golde was able to create unlimited copies of Moore's genetic material using cell culture techniques; the genetic material thus had low subtractability.

To conclude, this analysis demonstrates that in the cases mentioned, an individual genome was not governed in correlation with its attributes. In circumstances where an individual genome was perceived as having the characteristics of a public or club good, it was treated as a private good. In other words, because only one entity was granted exclusive entitlements, the use of genetic material or information by one party precluded the use of the same material or information by another party.

As I clarified at the beginning of this section, we may choose to use various institutional arrangements, and thus, the decision to govern public or club goods by a private property regime is not alarming in and of itself. The concern in the cases mentioned above arises because the decision to govern an individual genome with a private property regime led to tragicomic effects. First, the benefits of an individual genome were allotted to a single owner, so that no one else could benefit from its social and economic value. Second, important negative externalities arose. There were multiple stakeholders with ownership interests in an individual genome and the private property regime was structurally incapable of representing and protecting all of them.

## C. Lack of Explanatory Power

In moral philosophy, explanatory power is a key criterion for theory assessment.<sup>211</sup> Explanatory power is evaluated by the theory's capacity to provide explanations at a high level of

 $<sup>^{211}</sup>$  Mark Timmons, Moral Theory: An Introduction 14–15 (2nd ed. 2013).

specificity.<sup>212</sup> This criterion, I believe, is equally applicable in law, because like a moral theory, the law should also attend to details and include satisfactory explanations. Maximizing the explanatory power of the law can ultimately help achieving consistency, stability, clarity, and predictability—all central components of the rule of law.<sup>213</sup>

The current genome conceptualization and governance lacks explanatory power for three main reasons. *First*, it quite often protects the interests of some entities (e.g., researchers and law enforcement agencies) yet denies the legitimate interests of the person from whom it was extracted, who we may call its "proximate originator," and their family members. As I will explain in Part III, I believe that the interests of the person from whom an individual genome was extracted and their family members are legitimate and deserve legal recognition. The pursuit of such interests is intrinsically tied to the value of personhood, and it is fundamental to one's self-development and fulfillment as a human being.

To illustrate, in *Moore*, the court found that the genetic material was Golde's property and rejected Moore's claim of ownership over this material.<sup>214</sup> The court emphasized that it cannot be argued that Moore has property rights over excised cells and the genetic code embedded in them. It appears, then, that while the court refused to protect the interests of the person from whom an individual genome was extracted, it did confer property rights to another person whose interests lay in capitalizing on the genome.

This way of conceptualizing and governing an individual genome is not accompanied by clear and constructive explanations. It is not clear why Golde's ownership interests should be protected while Moore's should not. Ownership is not an absolute concept; it is a fluid legal construct that can assume many variations. Therefore, it is not the case that the genetic material and information have to "belong" to either Golde or Moore—both can have legitimate ownership interests in them.

Moreover, the court declared that there is a "natural limit" embedded in an individual genome that prevents us from recognizing property rights for the person from whom it was extracted. The court held that "the particular genetic material which is responsible for the natural production of lymphokines . . . is also the same in every person; it is no more unique to Moore than the number of vertebrae in the spine or the chemical formula of

<sup>&</sup>lt;sup>212</sup> *Id.* at 15.

<sup>&</sup>lt;sup>213</sup> See Jeremy Waldron, *The Rule of Law and the Importance of Procedure*, *in* GETTING TO THE RULE OF LAW: NOMOS L 3, 5–6 (James E. Fleming ed., 2011).

<sup>&</sup>lt;sup>214</sup> See supra text accompanying notes 126–29.

hemoglobin."<sup>215</sup> It underlined that Moore effectively urged the court to recognize his "ownership of the results of socially important medical research, including the genetic code for chemicals that regulate the functions of every human being's immune system."<sup>216</sup>

However, the court's assumption that there is a natural limit embedded in an individual genome that prevents us from recognizing property rights for the person from whom it was extracted is fallacious, first as a factual matter and second as a normative matter. Such a natural limit does not exist—the way we conceptualize and govern resources results from our *choices*. Indeed, resources have the potential to *shape* patterns of behavior. Their physical characteristics may impact on what people can or cannot do with them. Yet, they are to a large extent *subject to shaping*.<sup>217</sup> They can "be made to reflect any set of values."<sup>218</sup> They are what we make of them, and it is in our power to govern them based on our needs and values.<sup>219</sup>

Second, in many cases, property interests are recognized only in genetic information but not in genetic material. The distinction between genetic material and genetic information is selfcontradictory. One significant characteristic of an individual genome is that it has both tangible and intangible components. Although these components are distinct from one another, they are bound up together in many cases. When someone collects another person's genetic material from a drinking cup, they can analyze it and receive genetic information. And, as I previously argued, this distinction may set an important-but not desirable-precedent. One of the possible implications of this distinction is that anyone can collect material from a person's cup of coffee or bottle of water and store it as long as they do not derive information from the material. Therefore, it is important to take seriously the ontology of an individual genome and acknowledge that it is comprised of *both* genetic material and information.

To illustrate, several state laws verily provide protection only for genetic information while excluding genetic material.<sup>220</sup> In

<sup>&</sup>lt;sup>215</sup> Moore v. Regents of the Univ. of Cal., 51 Cal. 3d 120, 139 (1990).

<sup>&</sup>lt;sup>216</sup> *Id.* at 135.

<sup>&</sup>lt;sup>217</sup> See Yochai Benkler, *The Role of Technology in Political Economy: Part* 3, THE LAW AND POLITICAL ECONOMY PROJECT (July 27, 2018), https://lpeproject.org/blog/the-role-of-technology-in-political-economy-part-3/ [https://perma.cc/XM6N-WVPR]. Benkler refers to "technology," which is defined as "congealed practical knowledge embedded in material culture." In this Article, I extend Benkler's argument and reasoning to "resources" more broadly.

<sup>&</sup>lt;sup>218</sup> LAWRENCE LESSIG, CODE: VERSION 2.0 32 (2006).

<sup>&</sup>lt;sup>219</sup> See Langdon Winner, *Do Artifacts Have Politics?*, 109 DAEDALUS 121 (1980). Winner refers to "technology," which is defined as "all of modern practical artifice . . . smaller or larger pieces or systems of hardware of a specific kind." *Id.* at 123. I broaden Winner's argument to "resources" in this Article.

<sup>&</sup>lt;sup>220</sup> See supra text accompanying notes 73–74, 117–18.

Peerenboom, the court clarified the distinction between the two.<sup>221</sup> It held that Peerenboom relied "on cases regarding genetic materials for the proposition that the Perlmutters lack a property interest in their genetic information," and emphasized that "[t]hese cases are inapplicable to the question of whether genetic information constitutes property."222 Interestingly, the Perlmutters themselves suggested that genetic material can be distinguished from genetic information. The couple argued that "the counterclaim does not allege a conversion claim that is based on the incidental retention of raw genetic material. Rather, the counterclaim alleges a conversion claim [that] arises from Conspirators' intentional theft of the Perlmutters' confidential genetic information."223 Nevertheless, it appears that the couple made this argument for strategic reasons; they knew that a conversion claim over genetic material was previously rejected by different courts and therefore they are less likely to win.

These examples clearly show that legislatures and courts define the scope of ownership of an individual genome through categories; once a category has been chosen, a set of legal rules automatically apply. I believe their positions stem from the premise that because genetic material is *internal* to the body, it cannot be the property of the person from whom it was extracted.<sup>224</sup> In contrast, because genetic information is *external* to the body, it can become that person's property. By doing so, legislatures and courts do not pay sufficient attention to the fact that an individual genome incorporates both genetic material and information. They also assume that a person's interest in genetic information is distinct from any interest in genetic material.

*Third*, the person from whom an individual genome was extracted sometimes has property rights over genetic information, and sometimes does not, even under similar conditions. For example, in different law enforcement cases, courts refused to grant defendants any property rights over genetic information that was collected and analyzed from so-called "evidence" found in public

<sup>&</sup>lt;sup>221</sup> Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957, at \*15–16 (Fla. 15th Cir. Ct. Jan. 23, 2017).

<sup>&</sup>lt;sup>222</sup> *Id.* at \*15.

<sup>&</sup>lt;sup>223</sup> Isaac and Laura Perlmutter's Response in Opposition to the Motions to Dismiss Filed by Counterclaim Defendants at 2, *Peerenboom*, 2017 Fla. Cir. LEXIS 14957 (on file with the author).

<sup>&</sup>lt;sup>224</sup> It is worth highlighting that one of the things that holds courts and legislatures back in recognizing property rights over genetic material could be slavery. For example, in his dissent in *Moore*, Justice Mosk stated that one of the factors that should guide in this case is the "prohibition against indirect abuse of the body by its economic exploitation for the sole benefit of another person. The most abhorrent form of such exploitation, of course, was the institution of slavery." *See* Moore v. Regents of the Univ. of Cal., 51 Cal. 3d 120, 173–74 (1990).

spaces. They have ruled that the defendants did not have reasonable expectations of privacy in such circumstances.<sup>225</sup> In Peerenboom, where the conditions were quite similar (i.e., genetic material that was collected from a public space), the court granted the Perlmutters property rights over genetic information, emphasizing the possession of important privacy interests in that information.<sup>226</sup> In Greenberg, the court argued that once genetic information is voluntarily transmitted to someone else, the person from whom it was extracted no longer has property rights over the respective information.<sup>227</sup> In contrast, in Cole, despite the fact that Cole likewise voluntarily transmitted his genetic (material and) information to Gene by Gene, the court determined that he had property rights over the genetic information.<sup>228</sup> Once again, in all of these case, no satisfactory explanations are provided and it seems that the way in which an individual genome is governed is highly intuitive.

To conclude, legislatures and courts engage in boundary work: the process of identifying what falls inside the boundaries of a certain domain and what does not.<sup>229</sup> Under the current genome conceptualization and governance, an individual genome is deemed property for some entities but not others, genetic material and information are treated differently, and an individual genome is considered property only in some contexts. It appears, then, that legislatures and courts draw boundaries between different units of analysis while claiming that they are indeed analytically separable. The crucial issue is that in the case of an individual genome, that boundary work lacks adequate explanations. This state of affairs makes the current genome conceptualization and governance overly inconsistent with respect to the distinctions existing between entities, genetic components, and contexts.

<sup>&</sup>lt;sup>225</sup> See supra text accompanying notes 153–58.

<sup>&</sup>lt;sup>226</sup> Peerenboom, 2017 Fla. Čir. LEXIS 14957, at \*14.

<sup>&</sup>lt;sup>227</sup> Greenberg v. Miami Children's Hosp. Rsch. Inst., 264 F. Supp. 2d 1064 (S.D. Fla. 2003).

<sup>&</sup>lt;sup>228</sup> Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761, at \*2 (D. Alaska June 30, 2017).

<sup>&</sup>lt;sup>229</sup> Sheila S. Jasanoff, *Taking Life: Private Rights in Public Nature, in* LIVELY CAPITAL 155, 162 (Kaushik Sunder Rajan ed., 2020) ("Many controversies about the right way to draw the line between nature and culture illustrate the centrality of the law as a device for performing what I call 'ontological surgery' in modern political systems. Courts, legislatures, and regulatory agencies routinely grapple with conflicts about the nature and meaning of natural objects. How we define and characterize boundary-crossing objects, and how we choose to interact with the resulting things, are worked out as much through law as through scientific research and development. Such concepts as the environment, clean air, brain death, DNA fingerprint, or even 'natural mother' are located in webs of meaning crucially shaped by the law. The law constructs both life and capital and, more specifically, demarcates those aspects of life that can be owned from those that cannot.").

#### **III. GENETIC PROPERTY GOVERNANCE**

The previous parts provided a comprehensive analysis of the current genome conceptualization and governance, including the significant challenges it raises. Now, it is time to offer some insights as to how genome conceptualization and governance should operate in the future. As part of this forecast, I suggest Genetic Property Governance as an alternative framework.

This novel legal framework revises the prevailing yet outdated approaches in place and adopts a "public health" approach.<sup>230</sup> This means that the new framework focuses on the relational aspects of an individual genome and abandons the individualistic ideology and absolute conception of ownership that have so strongly colored the current genome conceptualization and governance. Moreover, it imposes substantive constraints on people's behavior with respect to others. Adopting a public health approach allows Genetic Property Governance to construct a model of property entitlements over an individual genome that better protects the legitimate interests of individuals, third parties, and the general public more broadly. It enables Genetic Property Governance to better respond to the different stakeholders involved given its capacity to weigh benefits and harms as well as to reconcile overlapping, and at times competing, interests.

One of the main challenges of this framework is that it represents a paradigm shift—it calls for a shift from a discourse that overwhelmingly privileges individual liberty to a discourse that also acknowledges that we live in an interdependent society in which people have obligations to one another. I therefore acknowledge that it might not be easy to move to a "public health era" when it comes to an individual genome.

Overall, in this part, I call to recognize multiple property interests and I offer initial guidelines for decision-making. Specifically, I suggest treating an individual genome as "ours"; instead of focusing on securing greater individual control and imposing a libertarian ethos, we should promote fundamental more egalitarian and communitarian values and recognize the multiple interests at stake and the values that those interests implicate. At the same time, we must prevent inefficiency and lack of productivity, avoid the harms of exploitation, and refrain from slipping into significant power asymmetries that promote strong inequalities.

<sup>&</sup>lt;sup>230</sup> See Jonathan Zittrain, *Three Eras of Digital Governance* 1–5 (Sept. 15, 2019) (unpublished manuscript), https://papers.csm?abstract\_id=3458435

<sup>[</sup>https://perma.cc/9X4Z-5X28] (describing the change in the frameworks we use to govern information technology). Zittrain explains that there is a move "from a discourse around rights . . . to one of public health, which naturally asks for a weighing of the systemic benefits or harms of a technology." *Id.* at 1.

Ultimately, Genetic Property Governance represents a relational approach than the one that is now in place.

## A. Genetic Property Governance – A Bird's Eye View

Genetic Property Governance has three main features. The first feature is the conceptualization and governance of an individual genome as *a commons*. That is, an individual genome is held and used in common, thus avoiding a situation of a single decision-maker.<sup>231</sup> Indeed, when a resource is held and used in common, outcomes are dependent on the actions of multiple stakeholders, making it possible to bring about what Garrett Hardin famously called the "Tragedy of the Commons" (i.e., the calamity of overuse),<sup>232</sup> as well as what Michael Heller termed the "Tragedy of the Anticommons" (i.e., the calamity of underuse).<sup>233</sup> Genetic Property Governance attempts to avoid these tragedies.

The second feature of Genetic Property Governance is the establishment of a *common property regime*. As Elinor Ostrom has shown, individuals can jointly use and manage a resource in an efficient way and that collective action problems can be solved without turning to government or private property institutions.<sup>234</sup> She has suggested that common property regimes, where group members have different property entitlements, can be designed.<sup>235</sup> Unlike other institutional arrangements, a common property regime adopts a non-absolute conception of ownership and promotes values that may be lost particularly in government or private property regimes. A common property regime accommodates different types of property interests by carefully restricting opportunities for domination. In other words, this regime accepts that ownership does not have to be wholly individualistic or collectivist; instead, it can represent a mix of property interests.

I wish to point out that another institutional arrangement for a commons—an open-access regime—could potentially be instituted. Under this regime, a resource is declared open to the public and people can use it without asking the permission of

<sup>&</sup>lt;sup>231</sup> Carol Rose, *The Comedy of the Commons: Custom, Commerce, and Inherently Public Property*, 53 U. CHI. L. REV. 711, 746–47 (1986). *See also* Charlotte Hess, *Mapping the New Commons* (July 1, 2008) (unpublished manuscript), https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1356835 [https://perma.cc/Y3V6-GLSX] (identifying other commons and collective-action communities).

<sup>&</sup>lt;sup>232</sup> Garrett Hardin, *The Tragedy of the Commons*, 162 SCIENCE 1243 (1968).

<sup>&</sup>lt;sup>233</sup> Michael A. Heller, *The Tragedy of the Anticommons: Property in the Transition from Marx to Markets*, 11 HARV. L. REV. 621 (1998).

<sup>&</sup>lt;sup>234</sup> OSTROM, *supra* note 50.

<sup>&</sup>lt;sup>235</sup> Schlager & Ostrom, *supra* note 55.

anyone.<sup>236</sup> Specifically, instead of providing asymmetric exclusive entitlements, an open-access regime provides a set of symmetric use privileges.<sup>237</sup> Take the Creative Commons as an example. The Creative Commons is a regime in which different license conditions are mixed and matched to create licenses attuned to different situations.<sup>238</sup> The various licenses allow the public to copy, distribute, and make selective use of a person's creative work. Although it might be worth considering in the future, I am skeptical if the American society is prepared to adopt an open-access regime in relation to an individual genome. As previously stated here, the individualistic ideology is firmly entrenched in the U.S. legal system; any commitment to collective sharing is almost unthinkable.

The third feature of Genetic Property Governance is the incorporation of a *liberal conception of property*, as developed by Hanoch Dagan.<sup>239</sup> This conception treats each person with equal concern and respect<sup>240</sup> and claims that authority expresses interpersonal power.<sup>241</sup> It respects a person's autonomy and conception of the good yet, at the same time, is attentive to the concerns of others.<sup>242</sup>

It would be helpful to consider the third feature of Genetic Property Governance as two steps that one needs to follow. The *first* step would be to determine whether the property interest at stake is legitimate. The legitimacy would be evaluated based on the likelihood of this interest to reflect and serve people's life plans; the property interest must act as a key source of autonomy and selfdetermination. In the case of an individual genome, there may be multiple stakeholders, including the person from whom an individual genome was extracted, family members, researchers, law enforcement officials, adversaries, employers, and DTC genetic testing companies, that have prima facie property entitlements over an individual genome. This group of stakeholders is not restricted; new entities may join as long as their interest is legitimate.

The *second* step is to ensure that a particular use by one of the legitimate owners reflects appropriate control over an individual genome. In other words, in this step, we guarantee that the particular

<sup>&</sup>lt;sup>236</sup> Benkler, *supra* note 203. Benkler argues that "[t]he defining characteristic of open-access commons, by comparison to property, whether individual or collective, is their utilization of (a) symmetric use privileges for (b) an open, undefined set of users in the general public." *Id.* at 256.

<sup>&</sup>lt;sup>237</sup> *Id.* at 272–73.

<sup>&</sup>lt;sup>238</sup> LAWRENCE LESSIG, FREE CULTURE: HOW BIG MEDIA USES TECHNOLOGY AND THE LAW TO LOCK DOWN CULTURE AND CONTROL CREATIVITY 283–86 (2004).

<sup>&</sup>lt;sup>239</sup> DAGAN, *supra* note 9.

<sup>&</sup>lt;sup>240</sup> *Id.* at 38.

<sup>&</sup>lt;sup>241</sup> Dagan defines authority as "the normative power" people have on others. *Id.* at 2.

 $<sup>^{242}</sup>$  Id. at 4.

use complies with the requirement of relational justice. For this purpose, Genetic Property Governance uses *reasonableness and proportionality* as analytical tools for coordinating competing property entitlements.<sup>243</sup> These principles would ensure appropriate control over an individual genome and demarcate what is "inside" and "outside" the boundaries of authority.<sup>244</sup> For instance, to examine whether particular uses are troublesome, Genetic Property Governance would consider the type of the genetic component in question and the purpose of the stakeholder's use.

Overall, the three features of Genetic Property Governance yield a legal framework that is pluralistic in nature; a framework that recognizes a group of entities as owners and facilitates arrangements for common governance over of an individual genome. This framework regards independence and community as essential components of the value of self-determination.

### **B.** Genetic Property Governance – A Closer Look

### a. Why a Property Regime?

Genetic Property Governance establishes a property regime with respect to an individual genome. Property is a powerful regime<sup>245</sup>—it has several advantages that can help address the myriad issues raised by an individual genome.

First, property forms the basic structure of entitlements and focuses on the ways in which they should be allocated.<sup>246</sup> It sets the rules for procuring, using, and protecting the resources we need to form relationships with other people and the entitlements we bring to the table when we negotiate with others. When it is implemented correctly, a property regime can produce realistic and equal opportunities to obtain the resources we need and deserve for each

<sup>&</sup>lt;sup>243</sup> Barak, *supra* note 63, at 145–48.

<sup>&</sup>lt;sup>244</sup> The idea of appropriate control over an individual genome is very much inspired by Helen Nissenbaum's framework of contextual integrity. *See* HELEN NISSENBAUM, PRIVACY IN CONTEXT: TECHNOLOGY, POLICY, AND THE INTEGRITY OF SOCIAL LIFE 127–45 (2009). Nissenbaum holds that the "right to privacy is neither a right to secrecy nor a right to control but a right to appropriate flow of personal information" and that the "norms, which rescribe the flow of personal information in a given context, are a function of the types of information in question; the respective roles of the subject, the sender (who may be the subject), and the recipient of this information, and the principles under which the information is sent or transmitted from the sender to the recipient." *Id.* 127.

<sup>&</sup>lt;sup>245</sup> See DAGAN, supra note 9, at 243–47; SINGER, supra note 47, at 13–15; GREGORY S. ALEXANDER & EDUARDO M. PEÑALVER, AN INTRODUCTION TO PROPERTY THEORY 1–6 (2012).

<sup>&</sup>lt;sup>246</sup> SINGER, *supra* note 47, at 13, 61.

person.<sup>247</sup> This type of regime can also ensure fair distribution of resources among members of society.<sup>248</sup>

Second, no prior contract or other legal relationship is required to create an obligation on the part of third parties.<sup>249</sup> Because property rights are *in rem*, they run with the resource and are universally enforceable.<sup>250</sup> As Hohfeld explained, property helps us to conceptualize rights as availing "against persons constituting a very large and indefinite class of people."<sup>251</sup>

Third, property is not unitary in nature; it aims to accommodate property interests of numerous entities.<sup>252</sup> Indeed, different arrangements that manage conflicts between property rights already exist. For example, trust law considers the rights of the settlor, the trustee, and the beneficiaries;<sup>253</sup> waste law considers the entity who holds the rights in the present (e.g., life tenant) and the entity with future rights (e.g., remainderman);<sup>254</sup> and tenancy by the entirety offers a mechanism that "is grounded on unity of identity and on family."<sup>255</sup>

Finally, a property regime positively affects the utilization of a resource and provides solutions to collective action issues.<sup>256</sup> As suggested by Ostrom and her followers, groups can solve collective problems through the design of common property regimes. When property entitlements are well defined and enforced, they hold people accountable.<sup>257</sup> After all, the value of a resource decreases when it is treated negligently or carelessly.<sup>258</sup> As a result, those having property rights over it have an incentive to manage it efficiently.

b. Common Property Regime

<sup>&</sup>lt;sup>247</sup> *Id.* at 141.

<sup>&</sup>lt;sup>248</sup> Id. at 144–45.

<sup>&</sup>lt;sup>249</sup> Robert P. Merges, *What Kind of Rights Are Intellectual Property Rights*?, *in* THE OXFORD HANDBOOK OF INTELLECTUAL PROPERTY LAW 57, 60 (Rochelle Dreyfuss & Justine Pila eds., 2018).

<sup>&</sup>lt;sup>250</sup> Thomas W. Merrill & Henry E. Smith, *The Property/Contract Interface*, 101 COLUM. L. REV. 773, 777 (2001); ALEXANDER & PEÑALVER, *supra* note 245, at 2.

<sup>&</sup>lt;sup>251</sup> Hohfeld, *supra* note 35, at 718.

<sup>&</sup>lt;sup>252</sup> SINGER, *supra* note 47, at 62, 88.

<sup>&</sup>lt;sup>253</sup> DAGAN, *supra* note 9, at 83.

<sup>&</sup>lt;sup>254</sup> *Id.* at 82–83.

<sup>&</sup>lt;sup>255</sup> Ram, *supra* note 41, at 877.

<sup>&</sup>lt;sup>256</sup> Elinor Ostrom, *How Types of Goods and Property Rights Jointly Affect Collective Action*, 15 J. THEORETICAL POL. 239 (2003).

<sup>&</sup>lt;sup>257</sup> RICHARD L. STROUP, ECO-NOMICS: WHAT EVERYONE SHOULD KNOW ABOUT ECONOMICS AND THE ENVIRONMENT 29–30 (2003).

<sup>&</sup>lt;sup>258</sup> Id.

Genetic Property Governance builds on Ostrom's commons theory and the knowledge commons framework—it protects multiple property interests and classifies the relationship between the different stakeholders as a type of shared ownership. I will first address Ostrom's commons theory, which serves as the foundation of the knowledge commons framework.

Thus far, Ostrom's theory has had significant real-world implications for the management of various resources. In *Governing the Commons*, Ostrom focused on a defined class of resources— common-pool resources (CPR)—and developed a theory that could facilitate their governance.<sup>259</sup> In terms of excludability and subtractability, it is difficult to exclude others from CPR use, and one person's use subtracts from another person's use of the same resource.<sup>260</sup> Irrigation, forestry, and fishery systems, for example, belong to this class of CPR. In addition, CPR are composed of resource systems that provide a flow of resource units or benefits from the larger systems.<sup>261</sup> The resource system itself generates a flow units or benefits over time, as illustrated by a lake.

Ostrom persuasively argues that if common property regimes are appropriately implemented (i.e., avoiding the tragedies of overuse and underuse), CPR will be governed more effectively and sustainably than under government and private property regimes. She defines property rights as "an enforceable authority to undertake particular actions in a specific domain" in relation to others interested in a resource.<sup>262</sup> She breaks rights into groups of operational-level entitlements and argues that there could be different types of property entitlements: 1) access ("[t]he right to enter a defined physical area and enjoy nonsubtractive benefits"); 2) extraction ("[t]he right to obtain resource units or products of a resource system"); 3) management ("[t]he right to regulate internal use patterns and transform the resource by making improvements"; 4) exclusion ("[t]he right to determine who will have access rights and withdrawal rights, and how those rights may be transferred"; and 5) alienation ("[t]he right to sell or lease management and exclusion rights").<sup>263</sup>

It is worth noting that these five entitlements "can be separately assigned to different individuals as well as being viewed as a cumulative scale."<sup>264</sup> Those who have entry and withdrawal

<sup>&</sup>lt;sup>259</sup> OSTROM, *supra* note 50, at 30–33; Hess & Ostrom, *supra* note 50, at 120–21.

<sup>&</sup>lt;sup>260</sup> Hess & Ostrom, *supra* note 50, at 120.

<sup>&</sup>lt;sup>261</sup> *Id.* at 121.

<sup>&</sup>lt;sup>262</sup> *Id.* at 124.

<sup>&</sup>lt;sup>263</sup> Id.

<sup>&</sup>lt;sup>264</sup> Elinor Ostrom & Charlotte Hess, *Private and Common Property Rights* 1 (Working Paper No. W07-25, 2007), https://surface.syr.edu/cgi/viewcontent.cgi?article=1024&context=sul

entitlements are called "Authorized Users." Entities who have access and withdrawal entitlements in addition to a collective choice entitlement to manage the resource are called "Claimants." Those who possess, in addition to the claimants' entitlements, the entitlement to determine who may access are called "Proprietors." Finally, those who hold the alienation entitlement, in addition to the entitlements held by the proprietors, are called "Full Owners."<sup>265</sup>

As an example, consider the governance of a fishery. Managing the fishery according to Ostrom's commons theory entails creating rules that demand, ban, or authorize behaviors for a group of fishermen. One set of rules may describe the standards that fishermen must meet in order to access the fishery (e.g., before entering the fishing area, fishermen should be required to reside in a specific jurisdiction and acquire a license). Another set of rules may define fishermen's entitlement to extract (e.g., fishermen will be allotted certain fishing areas by a lottery system). A third set of rules may concern the right to manage (e.g., there will be a group of fishermen who have the authority to decide how, when, and where fish could be harvested). A different set of rules may govern the right to exclude (e.g., fishermen will be able to restrict access to their fishing grounds to particular types of entities). Finally, there may be a set of rules governing the right to *alienate* (e.g., fishermen will be able to transfer their management and exclusion rights to others).<sup>266</sup>

Analyzing an individual genome under Ostrom's commons theory is not easy. In the traditional CPR, the boundaries are clear, the resource systems tend to be small and easy to observe,<sup>267</sup> and the group members are usually determined by geographical proximity to the CPR.<sup>268</sup> However, an individual genome is fundamentally different. It has tangible and intangible components that have created an entirely new type of "genetic artifact"—a resource whose boundaries are blurry and has a diverse community of potential users. Moreover, before proliferation of DNA sequencing and analysis tools, the "flow" of an individual genome (i.e., genetic information) was easy to follow because it was much more complex and expensive to derive information from genetic materials.

Irrespective of the differences between CPR and an individual genome, Ostrom's commons theory remains extremely useful because it demonstrates that groups are capable of managing their common resources provided that a certain set of conditions are met.<sup>269</sup> Her theory helps illustrate that an individual genome can be

<sup>[</sup>https://perma.cc/8L3Q-26LP].

<sup>&</sup>lt;sup>265</sup> Hess & Ostrom, *supra* note 50, at 125–26.

<sup>&</sup>lt;sup>266</sup> Schlager & Ostrom, *supra* note 55, at 249–54.

<sup>&</sup>lt;sup>267</sup> Hess & Ostrom, *supra* note 50, at 132.

<sup>&</sup>lt;sup>268</sup> Strandburg et al., *supra* note 51, at 14.

<sup>&</sup>lt;sup>269</sup> In the context of CPR, Ostrom identified eight design principles: 1) Clearly defined boundaries; 2) Congruence between appropriation and provision

reasonably treated as a commons if we design more just and effective institutions to govern it.

Going further, Ostrom's commons theory provides valuable insights as to how multiple stakeholders with property rights over one resource can find ways to cooperate and effectively organize themselves. First, there should be an understanding that organization of the commoners into a community creates a public good for those involved.<sup>270</sup> Anyone included in the community of users is endowed with the privilege to use it and therefore benefits from the resource. Second, rules that specify entitlements and obligations of multiple commoners must be devised because a hierarchy of relationship exists among the commoners-not all have the same privileges.<sup>271</sup> Third, to increase the likelihood that the commoners abide by the agreements made, it is necessary to invest in monitoring and sanctioning activities,<sup>272</sup> as well as build incentive structures that facilitate cooperation and trust.<sup>273</sup> Genetic Property Governance draws on these insights and expands them to the realm of an individual genome. What it suggests is that different stakeholders have legitimate property interests and that those stakeholders can benefit-though not equally-from the use of this resource.

After discussing Ostrom's commons theory and its implications to the governance of an individual genome, I now turn to discuss the knowledge commons framework. This framework, which has been developed by Katherine Strandburg, Brett Frischmann, and Michael Madison, aims to develop a systematic empirical approach for the study of knowledge commons governance.<sup>274</sup> Given the nature of an individual genome (i.e., a resource that is in the information and knowledge domains), the knowledge commons framework appears to be a more appropriate framework for its analysis than Ostrom's theory.

According to the knowledge commons framework, commons is defined as a form of community management or governance that seeks to promote sustainable collaboration and sharing. As I noted before, this framework is inspired by Ostrom's theory but includes a number of key adjustments. For the purposes of this Article, the most noteworthy adjustments are the following.

First, the knowledge commons framework applies to more than just natural resource commons. Compared to Ostrom's

rules and local conditions; 3) Collective-choice arrangements; 4) Monitoring; 5) Graduated sanctions; 6) Conflict-resolution mechanisms; 7) Minimal recognition of rights to organize; and 8) Nested enterprises. *See* OSTROM, *supra* note 50, at 90–102.

<sup>&</sup>lt;sup>270</sup> Hess & Ostrom, *supra* note 50, at 117.

<sup>&</sup>lt;sup>271</sup> Schlager & Ostrom, *supra* note 55, at 250–54.

<sup>&</sup>lt;sup>272</sup> Hess & Ostrom, *supra* note 50, at 117.

<sup>&</sup>lt;sup>273</sup> OSTROM, *supra* note 50, at 48; Ostrom, *supra* note 199, at 662–63.

<sup>&</sup>lt;sup>274</sup> Strandburg et al., *supra* note 51; Strandburg et al., *supra* note 54.

commons theory, this framework "investigate[s] the viability of . . . commons governance strategies with respect to knowledge, scientific, and cultural resources."<sup>275</sup> Second, the knowledge commons framework entails three key steps: an investigation of the background environments in which the commons operates, the identification of the basic attributes of the commons, and the establishment of "rules-of-use" that specify the level of openness with regard to the use of the commons.<sup>276</sup>

The preceding parts of this Article elaborated on the background environments of an individual genome (i.e., an individual genome is currently conceptualized and governed either as a resource capable of supporting property rights for the person from whom it was extracted, or a resource available for appropriation by other entities)<sup>277</sup> and its characteristics (i.e., an individual genome consists of both genetic material and genetic information; involves personal, familial, and collective aspects; and has varying degrees of excludability and subtractability).<sup>278</sup> The remainder of this part elaborates on the "rules-of-use" for an individual genome.

## c. A Liberal Conception of Property

Genetic Property Governance employs the liberal conception of property elaborated by Hanoch Dagan, which "draws on the insight of Elinor Ostrom that 'generalized institutional-choice and conflict-resolution' mechanisms, together with 'substantial local autonomy,' can enable and sustain commons property regimes."<sup>279</sup> It is worth noting that unlike Ostrom's commons theory, Dagan's liberal conception of property "recruits law in order to shore up the liberal right of exit without compromising the commons' success."<sup>280</sup> Due to space limitations, I discuss only the core features of the liberal conception of property—this conception treats each person with equal concern and respect,<sup>281</sup> while resting on three main pillars: private authority, structural pluralism, and relational justice.<sup>282</sup>

The first pillar, (precisely delineated) *private authority*, requires that property per se be committed to autonomy and self-

<sup>&</sup>lt;sup>275</sup> Madison, *supra* note 46, at 29.

<sup>&</sup>lt;sup>276</sup> Strandburg et al., *supra* note 54, at 21–36.

<sup>&</sup>lt;sup>277</sup> See discussion supra Part I.

<sup>&</sup>lt;sup>278</sup> See discussion supra Part II.

<sup>&</sup>lt;sup>279</sup> DAGAN, *supra* note 9, at 54.

<sup>&</sup>lt;sup>280</sup> Id.

 $<sup>^{281}</sup>$  As Dagan explains, property helps facilitate "self-authorship" for everyone. Id. at 3, 42–43.

 $<sup>^{282}</sup>$  Id. at 1–9.

determination.<sup>283</sup> That is, property should guarantee people's ability to write and rewrite their life stories and make long-term plans. A liberal conception thus recognizes that property plays "a distinctive and irreducible role in empowering people" as it "provides them temporally extended control over tangible and intangible resources, which they need in order to carry out their projects and advance their plans."<sup>284</sup>

The second pillar, *structural pluralism*, requires that property would be heterogeneous and capable of participation in different forms of interpersonal relationships.<sup>285</sup> This suggests that self-determination can be supported by different property types, including trust law and commons property, i.e., an institution that enables making decisions collectively among common-interest communities.<sup>286</sup>

The third pillar, *relational justice*, requires that property rely on mutual respect for self-determination (rather than independence), applied to owners and non-owners alike.<sup>287</sup> Such reciprocal respect establishes property types that delimit a person's authority and underly acceptable terms of interpersonal interactions.<sup>288</sup> It sets some limits on an owner's power on others while imposing diverse burdens and obligations on those same owners.<sup>289</sup> Relational justice is therefore "part of a certain vision of being *with others* in the world," that promises "a reasonably fair relational starting point from which parties can realize their respective freedoms."<sup>290</sup>

Taking the three pillars together, the institution of property with the liberal conception represents an *interpersonal* authority—it both empowers and deactivates people in their conduct of personal matters and interpersonal interactions.<sup>291</sup> Crucially, it does not center on a person's right to exclude but honors the interests of all the relevant stakeholders.<sup>292</sup>

Dagan explains that implementing the three pillars is complex and requires carefully following H. L. A. Hart's advice to distinguish "between the gravity of the different restrictions on different specific liberties and their importance for the conduct of a meaningful life."<sup>293</sup> Dagan suggests that one way of introducing the three pillars into a property regime is through modification of

- <sup>283</sup> *Id.* at 1–6.
- <sup>284</sup> *Id.* at 2.
- <sup>285</sup> *Id.* at 6–7.
- <sup>286</sup> *Id.* at 82–89.
- <sup>287</sup> *Id.* at 7–8, 114.
- <sup>288</sup> *Id.* at 130.
- <sup>289</sup> *Id.* at 8.
- <sup>290</sup> *Id.* at 126.
- <sup>291</sup> *Id.* at 60–61, 71–72.
- $^{292}$  Id. at 114, 141–42.
- <sup>293</sup> *Id.* at 46.

property entitlements so as to help address the different interests and concerns at play.<sup>294</sup> This means that instead of being guided by some idea of exclusive and extensive authority, a liberal property regime would promote interpersonal cooperation. Moreover, it would support different property types and be committed to promoting a variety of values that have an important role in people's autonomous pursuit of their life plans, among them personhood, community, and utility.<sup>295</sup>

Taking the liberal conception of property into consideration, how might a common property regime for governing an individual genome look like? I suggest that the following requirements are necessary for such a regime: a) the existence of *legitimate* property interests, namely interests that protect autonomy and selfdetermination as the ultimate values of property; and b) the implementation of *appropriate control* over an individual genome in order to comply with the commitment to relational justice.

#### d. Legitimate Property Interests

Different entities may be interested in using an individual genome and we need to make sure that only entities with legitimate property interests have a legal claim over an individual genome. It is thus important that the interest in question stems from values that enhance autonomy and self-determination.<sup>296</sup> To put it differently, the interest must empower the entity, allowing it to proceed with its plans and pursue its own goals. Below are examples of property interests that would be considered legitimate.

The first example is the interests of the person from whom an individual genome was extracted and their family members. The property interests of these entities stem from personhood and intelligible possession.

The value of *personhood* implies that legal protection should be granted over resources closely bound up with personhood.<sup>297</sup> Property as personhood maintains that having property rights over

<sup>&</sup>lt;sup>294</sup> Samet & Dagan, *supra* note 59, at 722–23.

<sup>&</sup>lt;sup>295</sup> DAGAN, *supra* note 9, at 49, 50–58; HANOCH DAGAN, PROPERTY: VALUES AND INSTITUTIONS xviii (2011). It should be made clear that although Dagan believes that values such as personhood, community, and utility have an important place in property law, he is adamant that autonomy and self-determination should not be subsumed beneath them. As he explains, "[a] genuinely liberal theory of property, then, does not imply that independence, personhood, community, and utility are irrelevant to property. Their significance, however, rather than fundamental or free-standing, is both derived from, and thus also circumscribed by, the role of these values in people's autonomous pursuit of their life plans." DAGAN, *supra* note 9, at 49.

<sup>&</sup>lt;sup>296</sup> DAGAN, *supra* note 9, at 59.

<sup>&</sup>lt;sup>297</sup> Margaret Jane Radin, *Property and Personhood*, 34 STAN. L. REV. 957 (1982).

resources is necessary to one's self-development and fulfillment as a human being. Property interests are thus protected in light of their deep connection to one's identity and sense of self.

The value of personhood rests mainly on the work of W.F. Hegel and Margaret Jane Radin. Hegel viewed property rights as essential to self-realization and believed that any meaningful account of freedom requires a presence in the physical world.<sup>298</sup> In Hegel's view, people can exercise their free will and manifest themselves by possessing, controlling, and owning resources.<sup>299</sup> Radin has built upon Hegel's work and similarly explains that "to achieve proper self-development—to be a *person*—an individual needs some control over resources in the external environment."<sup>300</sup> To Radin, those resources are precisely the items that people feel deeply connected to, such as wedding rings. In this regard she argues that "by virtue of this connection the person should be accorded broad liberty with respect to control over that 'thing."<sup>301</sup>

The interests of the person from whom an individual genome was extracted and their family members also stem from *intelligible possession*. According to this value, property interests should be recognized regardless of the resources' location in space.<sup>302</sup> Kant distinguished between sensible and intelligible possession.<sup>303</sup> The former refers to physical possession (the senses), the latter to the legal possession (mental, by means of reason) one has of a resource. Recognizing someone's intelligible possession of something means that a person should have a say about a resource and its use, even though they may not have sensible possession of it.

Returning to an individual genome, the person from whom it was extracted, together with their family members, are emotionally connected to it.<sup>304</sup> They understand an individual genome as being the constitutive medium of their self. They value this resource as their own, regardless of whether they have physical possession of it or if they personally contributed to its material contents. Building on personhood and intelligible possession, one could argue that these entities assume that they have ownership rights over an individual genome due to its personal and familial aspects. In light of this, the property interests of these entities enhance self-determination and the ability to plan and carry out meaningful life projects. As Aristotle once argued, "[w]hen

<sup>&</sup>lt;sup>298</sup> ALEXANDER & PEÑALVER, *supra* note 245, at 60–62.

<sup>&</sup>lt;sup>299</sup> Id. at 63–64.

<sup>&</sup>lt;sup>300</sup> Radin, *supra* note 297, at 957.

<sup>&</sup>lt;sup>301</sup> *Id.* at 960.

<sup>&</sup>lt;sup>302</sup> ALEXANDER & PEÑALVER, *supra* note 245, at 75–76.

<sup>&</sup>lt;sup>303</sup> Howard Williams, Kant's Concept of Property, 27 PHIL. Q. 32, 32 (1977);

B. Sharon Byrd & Joachim Hruschka, Kant on "Why Must I Keep My Promise?",

<sup>81</sup> CHI.-KENT L. REV. 47, 54-57 (2006).

<sup>&</sup>lt;sup>304</sup> See Roberts, *supra* note 12, at 1150–53.

everyone has his own separate sphere of interest . . . the amount of interest will increase, because each man will feel that he is applying himself to what is his own."<sup>305</sup>

A second example is the property interests of other stakeholders, such as researchers, law enforcement officials, adversaries, employers, and DTC genetic testing companies. The interests of these entities stem from possession, labor, and social welfare/utility. The significance of each of these values is derived from their function in people's autonomous pursuit of their life plans.

The value of *possession* implies that property rights are granted to a person who establishes possession.<sup>306</sup> Consistent with the maxims "finders keepers, losers weepers" or "first come, first served," whoever does something referred to as "possessing the resource" before anyone else, has property rights over that resource.<sup>307</sup> Certain entities, including law enforcement officials and adversaries, may appropriate an individual genome found in public spaces as they were the first entities to possess it. Please note that the collection of an individual genome in those cases must be subject to a warrant based upon probable cause or discovery in civil suits. I do not hold the view that an individual genome found in public spaces should be considered as an object that a person knowingly exposes to the public, and thus, loses their expectation of privacy.<sup>308</sup>

According to the value of *labor*, property rights are granted to those who combine their labor with the resource.<sup>309</sup> Based on the concept of dessert, a person enjoys an entitlement to the fruits of their labor. For example, the efforts and expenditures made by researchers and DTC genetic testing companies to reveal the scientific and social relevance embedded in an individual genome support recognition of their ownership interests in it.

According to the value of *social welfare/utility*, property rights are granted to those who produce the most social welfare or utility possible.<sup>310</sup> This value places an emphasis on the consequences of a certain action. More precisely, it focuses on the question of whether the action will maximize social welfare or

<sup>&</sup>lt;sup>305</sup> ALEXANDER & PEÑALVER, *supra* note 245, at 17.

<sup>&</sup>lt;sup>306</sup> Richard A. Epstein, *Possession as the Root of Title*, 13 GA. L. REV. 1221 (1979); Carol M. Rose, *Possession as the Origin of Property*, 52 U. CHI. L. REV. 73 (1985).

<sup>&</sup>lt;sup>307</sup> HELLER & SALZMAN, *supra* note 38, at 12–14.

<sup>&</sup>lt;sup>308</sup> So far, the Supreme Court has determined that the Fourth Amendment does not protect "what a person knowingly exposes to the public" and that a warrant is not required in such a situation. I believe that this view should be rejected. *See* Teneille R. Brown, *Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers*, 21 COLUM. SCI. & TECH. L. REV. 1 (2019).

<sup>&</sup>lt;sup>309</sup> ALEXANDER & PEÑALVER, *supra* note 245, at 37–46; Eric R. Claeys, *Labor, Exclusion, and Flourishing in Property Law*, 95 N.C.L. Rev. 415 (2017).

<sup>&</sup>lt;sup>310</sup> ALEXANDER & PEÑALVER, *supra* note 245, at 12.

utility, however those terms are defined. Some entities turn an individual genome into a more useful and beneficial resource. For entities like adversaries, employers, and law enforcement officials, their property interests help them to perform their duties to solve old civil and criminal cases and prevent new ones. For entities like researchers and DTC genetic testing companies, their property interests may motivate them to seek insights into important biological processes and ultimately improve the health of all individuals and illuminate human and family origins.

To help put this discussion in context, I identify the relevant stakeholders in some of the cases described in Part I and the justifications for considering their legitimate interests (see Figure 2).

Theory	Personhood	Intelligible Possession	Possession	Labor	Social Welfare/Utility
Peerenboom	Perlmutter	Perlmutter	Peerenboom	N/A	Peerenboom
Cole	Cole	Cole	Gene by	Gene by	Gene by Gene
			Gene	Gene	
Lowe	Lowe and	Lowe and	Atlas	N/A	Atlas
	Reynold	Reynold			
Moore	Moore	Moore	Golde	Golde	Golde
King	King	King	Law	Law	Law
			Enforcement	Enforcement	Enforcement

Figure 2—Stakeholders with Legitimate Property Interests

## e. Appropriate Control

The mission of Genetic Property Governance is not simply to legitimize the authority held by different stakeholders. Rather, its mission is also to "address qualitative judgments about social relationships and obligations"<sup>311</sup> and create dedicated structures to manage the use of an individual genome and assure *appropriate* control. Genetic Property Governance thus provides a mature approach to complying with our commitment to relational justice namely, mutual respect for self-determination—and resolving collisions between the varying legitimate property interests.

It is beyond the scope of this Article to delineate the set of legal principles and rules at the foundations of Genetic Property Governance or to specify the types of entitlements that each stakeholder may have. I leave this task for another time. However, I would like to offer some recommendations on where and how to start. Overall, these recommendations direct us toward a more

<sup>&</sup>lt;sup>311</sup> Joseph W. Singer, *Democratic Estates: Property Law in a Free and Democratic Society*, 94 CORNELL L. REV. 1009, 1045 (2009).

nuanced approach for genome conceptualization and governance, according to which parallel to property entitlements, entities also have obligations towards one another.

Genetic Property Governance applies two principles to determine if a particular use by one of the legitimate owners reflects appropriate control over an individual genome and to resolve conflicts between competing interests: proportionality and reasonableness. These principles identify relevant factors for the evaluation of uses.<sup>312</sup>

Generally speaking, proportionality and reasonableness consider the specific circumstances in question, evaluate possible uses, and impose limits accordingly. Proportionality examines if: (1) an action fits the goal behind performance of that action; (2) there are no other means appropriate for achieving the goal; and (3) the harm is not too drastic in relation to the benefits gained by achieving the goal.<sup>313</sup> Reasonableness asks to weigh the various considerations.<sup>314</sup> This principle is meant to prevent wholly unreasonable or arbitrary decisions and ensure that action do not violate the norms identified with a free and democratic society.<sup>315</sup>

Because we want to consider diverse issues, reconciling the different interests in the case of an individual genome tends to be complex. Therefore, when applying proportionality and reasonableness to the case of an individual genome, I propose two evaluative criteria that will affect the assignment of control over an individual genome: the types of genetic components and the purpose of the stakeholder's use.

## 1. Types of Genetic Components

The current genome conceptualization and governance reflects a fundamentally broad categorical approach that is insensitive to diverse "genetic components." To illustrate, in *Cole*, the court prohibited "the unauthorized disclosure of *DNA information*."<sup>316</sup> In *Peerenboom*, the court declared that "a property right exists in the Perlmutters' *genetic information*."<sup>317</sup> The law in

<sup>&</sup>lt;sup>312</sup> It should be clarified that Genetic Property Governance does not support radically ad hoc judgments. It employs the two principles as a means of establishing "more-or-less bright line rules" by legislators or courts. *See, e.g.*, Hanoch Dagan, *Reimagining Takings Law, in* PROPERTY AND COMMUNITY 39, 51 (Gregory S. Alexander & Eduardo M. Peñalver eds., 2010).

<sup>&</sup>lt;sup>313</sup> Barak, *supra* note 63, at 147–48.

<sup>&</sup>lt;sup>314</sup> *Id.* at 145.

<sup>&</sup>lt;sup>315</sup> Joseph William Singer, *The Rule of Reason in Property Law*, 46 U.C. DAVIS L. REV. 1369, 1421–23 (2013).

<sup>&</sup>lt;sup>316</sup> Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761, at \*8 (D. Alaska June 30, 2017) (emphasis added).

<sup>&</sup>lt;sup>317</sup> Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957, at \*14 (Fla. 15th Cir. Ct. Jan. 23, 2017) (emphasis added).

Florida determines that "[t]he results of . . . *DNA analysis*, whether held by a public or private entity, are the exclusive property of the person tested."<sup>318</sup> In *Greenberg*, the court ruled that the person from whom an individual genome was extracted had "no cognizable property interest in . . . *genetic matter*."<sup>319</sup>

Genetic material and information are unfortunately broad terms. For the purpose of evaluating uses, an individual genome should be perceived as a resource comprised of the following genetic components: specimen, DNA sample, manipulated material, and information.

A *genetic specimen* is the physical material comprising living organisms. Examples include hair, saliva, flakes of skin, and "touch DNA" (i.e., a sample obtained through physical contact between one person and an object or another person).<sup>320</sup> It is the basic source from which information is extracted or manipulated materials are produced. Unlike specimens, genetic information and manipulated materials require more effort in their creation.

A *DNA sample* is extracted and purified DNA (i.e., DNA isolated from the cell's nucleus)<sup>321</sup> or an isolated gene (i.e., a particular segment of DNA that was isolated from the rest of the genome).<sup>322</sup> It is worth noting that scientific and technological advances now make it possible to conduct genetic analyses with a relatively small quantity of extracted DNA.<sup>323</sup>

*Manipulated genetic material* is material, such as a cell line (i.e., cells that have been adapted to grow continuously)<sup>324</sup> or synthetic DNA (DNA strands that were rewritten),<sup>325</sup> that was adapted (i.e., manipulated) by means of laboratory methods. In some

<sup>&</sup>lt;sup>318</sup> FLA. STAT. ANN. § 760.40 (West 2021) (emphasis added).

<sup>&</sup>lt;sup>319</sup> Greenberg v. Miami Children's Hosp. Rsch. Inst., 264 F. Supp. 2d 1064, 1074 (S.D. Fla. 2003) (emphasis added).

<sup>&</sup>lt;sup>320</sup> Francesco Sessa et al., *Touch DNA: Impact of Handling Time on Touch Deposit and Evaluation of Different Recovery Techniques: An Experimental Study*, 9 SCIENTIFIC REP. 1 (2019).

<sup>&</sup>lt;sup>321</sup> Siun Chee Tan & Beow Chin Yiap, *DNA, RNA, and Protein Extraction: The Past and the Present*, 2009 J. BIOMEDICINE & BIOTECHNOLOGY 1 (2009).

<sup>&</sup>lt;sup>322</sup> Bruce Alberts et al., *Isolating, Cloning, and Sequencing DNA, in* MOLECULAR BIOLOGY OF THE CELL (4th ed. 2002), https://www.ncbi.nlm.nih.gov/books/NBK26837/ [https://perma.cc/DWS3-9XXG].

<sup>&</sup>lt;sup>323</sup> Karen Norrgard, Forensics, DNA Fingerprinting, and CODIS, 1 NATURE EDUC. 35 (2009); Katie E. Fowler et al., Novel Approach for Deriving Genome Wide SNP Analysis Data from Archived Blood Spots, 5 BMC RSCH. NOTES 503 (2012); Souvik Ghatak et al., A Simple Method of Genomic DNA Extraction from Human Samples for PCR-RFLP Analysis, 24 J. BIOMOLECULAR TECHNIQUES 224 (2013).

<sup>&</sup>lt;sup>324</sup> SKLOOT, *supra* note 2, at 100.

<sup>&</sup>lt;sup>325</sup> Synthetic Biology, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/about-genomics/policy-issues/Synthetic-Biology [https://perma.cc/A373-TPY4] (last visited Nov. 15, 2022).

cases, genetic material is manipulated to produce a significant difference in its substance, a unique chemical composition different from the ones existing in nature.

*Genetic information* is the order of nucleotides found in DNA.<sup>326</sup> There are four nucleotide bases: adenine (A), guanine (G), cytosine (C), and thymine (T). The nucleotide bases pair up with each other, A with T and C with G; one genome consists of a total of 3.2 billion nucleotide base pairs.<sup>327</sup> Once the DNA has been extracted, it is possible to sequence it to produce a data record that consists of the sequence of the nucleotide bases (e.g., ATTTGGGCAC).<sup>328</sup> Genetic information can be either identified or de-identified. Such being the case, many scholars though raise severe concerns regarding the re-identification of information and claim that genetic information cannot be truly anonymized.<sup>329</sup>

Genetic information can be divided into five types. One type is information on *single nucleotide polymorphism* (SNP). SNP refers to one location—a single base-pair—in the DNA sequence.<sup>330</sup> Most SNPs do not have substantial known effects.<sup>331</sup> Yet, some studies have shown that certain SNPs are associated with some phenotypes.<sup>332</sup> Most DTC genetic testing companies conduct analyses based on this type of genetic information.<sup>333</sup> The companies do not analyze the entire genetic sequence of a person they only check for the presence or absence of specific SNPs and provide risk assessments accordingly.

A second type is information on *short tandem repeats* (STRs). STRs are strands of DNA containing core repeat units of 2-7 nucleotides in length. Such stretches are repeated from approximately half a dozen to several dozen times.<sup>334</sup> One genome

<sup>&</sup>lt;sup>326</sup> Deoxyribonucleic Acid (DNA) Fact Sheet, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/about-genomics/fact-sheets/Deoxyribonucleic-Acid-Fact-Sheet [https://perma.cc/WBY5-WTA5] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>327</sup> GREELY, *supra* note 166, at 10.

<sup>&</sup>lt;sup>328</sup> Analysis of genetic information can reveal a person's genotype and phenotype. *See DNA Sequencing Fact Sheet*, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/about-genomics/fact-sheets/DNA-Sequencing-Fact-Sheet [https://perma.cc/NC3G-7J2S] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>329</sup> See, e.g., Melissa Gymrek et al., *Identifying Personal Genomes by* Surname Inference, 339 SCIENCE 321 (2013); Katherine Drabiak, Caveat Emptor: How the Intersection of Big Data and Consumer Genomics Exponentially Increases Informational Privacy Risks, 27 HEALTH MATRIX 143, 166–67 (2017).

<sup>&</sup>lt;sup>330</sup> *SNP*, NATURE EDUC., https://www.nature.com/scitable/definition/snp-295/ [https://perma.cc/4PMX-Y59R] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>331</sup> Id.; Holger Schwender et al., Testing SNPs and Sets of SNPs for Importance in Association Studies, 12 BIOSTATISTICS 18, 27 (2011).

<sup>&</sup>lt;sup>332</sup> BENJAMIN PIERCE, GENETICS ESSENTIALS: CONCEPTS AND CONNECTIONS 374 (2009).

<sup>&</sup>lt;sup>333</sup> Chelsea Weiermiller, *The Future of Direct-to-Consumer Genetic Testing: Regulation and Innovation*, 16 N.C. J.L. & TECH. 137, 138–39 (2015).

<sup>&</sup>lt;sup>334</sup> John M. Butler, Short Tandem Repeat Typing Technologies Used in

contains thousands upon thousands of STR markers that occur in both coding and noncoding genes.<sup>335</sup> Some think of STRs as similar to "a single, common currency in a financial sense" since they "permit equivalent genetic information to be shared and compared."<sup>336</sup>

A third type is information on *single genes*. Genes are specific segments of DNA,<sup>337</sup> and a single gene may contain different variations, called alleles.<sup>338</sup> In other words, an allele is a particular version of a gene and can result in different phenotypes. This type of information can help identify mutations that can lead to genetic diseases or other genetic conditions.<sup>339</sup>

A fourth type is information on *chromosomes*. DNA is organized into chromosomes, and each chromosome contains thousands of genes.<sup>340</sup> Information from chromosomes reveals the major genetic changes (e.g., an extra copy of a chromosome) that cause certain genetic conditions.<sup>341</sup>

The fifth and final type is information on the *whole genome*. That is, the complete sequence of a person's DNA.<sup>342</sup> At present, whole-genome sequencing is used mainly in healthcare and research; however, some DTC genetic testing companies have started offering whole-genome sequencing services to customers as well.<sup>343</sup>

Genetic Property Governance recognizes that the four types of genetic components (i.e., specimen, DNA sample, manipulated

Human Identity Testing, 42 BIOTECHNIQUES ii, ii (2007).

<sup>&</sup>lt;sup>335</sup> Some genes act as manuals for making proteins and are called proteincoding genes. *See What Is a Gene?*, U.S. NAT'L LIBRARY MED., https://medlineplus.gov/genetics/understanding/basics/gene/

<sup>[</sup>https://perma.cc/B9W5-DYLG] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>336</sup> Butler, *supra* note 334.

<sup>&</sup>lt;sup>337</sup> What Is a Gene?, supra note 335.

<sup>&</sup>lt;sup>338</sup> *Allele*, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/genetics-glossary/Allele [https://perma.cc/RFJ2-6L3D] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>339</sup> Heidi Chial, *Rare Genetic Disorders: Learning About Genetic Disease Through Gene Mapping, SNPs, and Microarray Data*, 1 NATURE EDUC. 192 (2008).

<sup>&</sup>lt;sup>340</sup> Gene, NAT'L HUM. GENOME RSCH. INST., https://www.genome.gov/genetics-glossary/Gene [https://perma.cc/44LD-N7DK] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>341</sup> S.G. Gregory et al., *The DNA Sequence and Biological Annotation of Human Chromosome 1*, 441 NATURE 315 (2006); Karen H. Miga et al., *Telomere-to-Telomere Assembly of a Complete Human X Chromosome*, 585 NATURE 79 (2020).

<sup>&</sup>lt;sup>342</sup> Since the Human Genome Project, "the holy grail of genomics was the ability to perform whole-genome sequencing quickly, accurately, and relatively inexpensively." Mark A. Rothstein, *Currents in Contemporary Bioethics: The Case Against Precipitous, Population-Wide, Whole-Genome Sequencing*, 40 J.L. MED. & ETHICS 682, 682 (2012).

<sup>&</sup>lt;sup>343</sup> Fisher, *supra* note 18, at 1241.

material, and information) can each receive a different weight. And yet, genetic material need not be separated from genetic information. As previously explained, the two are often bound together—when genetic material is collected, it can be analyzed to obtain information—so a distinction between these components in many circumstances is problematic. This does not, however, negate the possibility of assigning different *weights* to different genetic components, depending on purpose and the stakeholder's interests in doing so.

For example, we could impose more restrictions on the use of genetic specimens and DNA samples, contrary to the use of manipulated genetic materials. The person from whom an individual genome was extracted, and their family members, have a more remarkable "genetic contribution and proximity" to genetic specimens and DNA samples than to manipulated genetic materials. Therefore, they may have more say regarding the former rather than the latter. We could also decide to create a sharing mechanism,<sup>344</sup> which considers the relative contribution and proximity to the genetic component. If the genetic contribution and proximity are high, the entity could enjoy monetary benefits.

In addition, in contrast to information on the whole genome, we could impose fewer restrictions on the use of information on SNP (i.e., information on one location in the DNA sequence). Because information on SNP is less likely to be unique, its use by other stakeholders would not necessarily be inappropriate. More broadly, we could determine a minimum amount of information to be processed and analyzed without causing significant harm to the person from whom it was extracted and their family members.

2. Purpose of the Stakeholder's Use

The stakeholder's purpose for using an individual genome may also influence whether their use is proportionate and reasonable. We could decide that some purposes are less appropriate than others and impose more restrictions to their realization.

For instance, the use of an individual genome for not-forprofit scientific purposes may be viewed as more proportionate and reasonable than for-profit scientific purposes. Similarly, use for research projects or connecting different individuals may be more

<sup>&</sup>lt;sup>344</sup> See Mary T. Danforth, Cells, Sales, and Royalties: The Patient's Right to a Portion of the Profits, 6 YALE L. & POL'Y REV. 179 (1988); Gary E. Marchant, Property Rights and Benefit-Sharing for DNA Donors?, 45 JURIMETRICS J. 153 (2005); Rebecca A. Johnson & David Wendler, Challenging the Sanctity of Donorism: Patient Tissue Providers as Payment-Worthy Contributors, 25 KENNEDY INST. ETHICS J. 291 (2015).

proportionate and reasonable than the transfer of an individual genome to third parties for commercial purposes.

The transformation of an individual genome into a commodity and its use to produce economic value may be more disturbing although such a use should not be prohibited entirely. Some transformations aim at deriving individual economic benefits rather than producing population-level insights and benefits; hence these practices should be reviewed for their distributional effects (i.e., the uneven distribution of benefits and risks). Again, because research participants or consumers do not identify as groups with recognizable bargaining power, they may be utilized as "'treasure troves' to be mined for private economic gain."<sup>345</sup> Under such circumstances, an individual genome would be transformed into a "commons ripe for exploitation"<sup>346</sup> and the subject of a form of bioprospecting as researchers and DTC genetic testing companies "compete to discover new patterns and extract their marketplace value."<sup>347</sup>

The establishment of a sharing mechanism, as I suggested, would be a fair and just solution to issues of proportionality and reasonableness with respect to exploitation and inequality outcomes since all stakeholders making a large genetic contribution and enjoying close proximity would receive remuneration. Such a mechanism, for instance, could enable the production of social and economic benefits and reduce power asymmetries between those who generate an individual genome and those who profit from it. We might even consider allowing the person from whom an individual genome was generated and genetic relatives to bargain either separately or together over commercial interests.<sup>348</sup>

# C. What Difference Would Genetic Property Governance Make?

Genetic Property Governance is not only theoretical; it has practical implications. So, what difference would this new legal framework make in real cases? Consider the lawsuit brought by the Lacks family.<sup>349</sup> As a reminder, in this case, the Lacks family recently filed a lawsuit against Thermo Fisher Scientific, which has benefited from the use of the HeLa cells.

<sup>&</sup>lt;sup>345</sup> Brief for the International Center of Technology Assessment, the Indigenous Peoples Council on Biocolonialism, Greenpeace, Inc., Friends of the Earth, and the Council for Responsible Genetics as Amicus Curiae in Support of Plaintiff-Appellees at 14, Ass'n for Molecular Pathology v. USPTO, 702 F. Supp. 2d 181 (S.D.N.Y 2010) (No. 2010-1406).

<sup>&</sup>lt;sup>346</sup> COHEN, *supra* note 162, at 51.

<sup>&</sup>lt;sup>347</sup> *Id.* at 48.

<sup>&</sup>lt;sup>348</sup> See Roberts, *supra* note 12, at 1132–33.

<sup>&</sup>lt;sup>349</sup> See supra text accompanying notes 5–7.

How would this case turn out under Genetic Property Governance? One possible outcome involves identifying who has ownership claims over the genetic material and information extracted from Henrietta. Recall that Genetic Property Governance recognizes the ownership interests of multiple stakeholders—as long as they are legitimate—and implements a common property regime.<sup>350</sup> The legitimacy of a property interest is determined by whether the interest upholds autonomy and self-determination as property's ultimate values.

Therefore, under Genetic Property Governance, we would not need to choose between Henrietta, her family, and Thermo Fisher Scientific. All parties would have legitimate property interests over the genetic material and information in question.<sup>351</sup>

Henrietta and her family would have legitimate property interests based on personhood and intelligible possession. By virtue of the personal and familial aspects, the genetic material and information extracted from Henrietta are closely bound up with her identity and the identity of her family members. The fact that the genetic material and information are not in their possession should not negate their property claims over them. In the case of Henrietta Lacks, the ownership interests of Henrietta and her family dramatically affect the ability to make meaningful choices about the course of their lives and allow them to lead satisfying lives.

Concurrently, Thermo Fisher Scientific also has a legitimate property interest over the genetic material and information. Their property interest stems from possession and labor. The company, after establishing possession over the genetic material and information, has combined its labor with the original elements. The ownership interests of Thermo Fisher Scientific has driven the company to fulfill its goal and contribute to the improvement of the entire population's health. In light of the collective aspects of an individual genome, Thermo Fisher Scientific's research can provide fundamental insights into biological processes.

A second possible outcome concerns the remedy given by the court. Remember that Genetic Property Governance follows the maxim of reciprocal respect for autonomy and self-determination,<sup>352</sup> and it uses two principles to examine the appropriateness of uses and

<sup>&</sup>lt;sup>350</sup> See discussion supra Section III.B.d-e.

<sup>&</sup>lt;sup>351</sup> It is important to note that while all parties in this case have legitimate interests over the relevant genetic material, there are entities who do not. It would have been inappropriate, for instance, for the doctors who collected samples from Henrietta Lacks without her knowledge to join the lawsuit and assert that they, too, have legitimate interests over the genetic material. Recall that the doctors removed material from Henrietta's *body*, and many people, like myself, believe that consent is required before intruding in another's body.

<sup>&</sup>lt;sup>352</sup> See supra text accompanying notes 287–90.

resolve conflicts between different competing interests.<sup>353</sup> To guarantee that the use of genetic material and information reflects appropriate control, Genetic Property Governance would warrant applying the proportionality and reasonableness principles. The next step in this case would thus be to inquiry whether Thermo Fisher Scientific's use complies with the proportionality and reasonableness principles, including evaluation of the type of genetic component at stake and the purpose of the company's use.

This case revolves around the HeLa cell line and its embedded genetic information. Due to my lack of knowledge about the type of information the company has used, I focus only on the genetic material. As suggested earlier, we could consider the genetic contribution and proximity of the entity selected to the genetic component. Thinking about genetic contribution and proximity as a continuum, the contribution and proximity of the Lacks family are somewhere in the middle. On the one hand, the genetic material is not in its natural state-the company has manipulated it. On the other hand, it has not been substantially manipulated; it has only been adapted to grow continuously, while maintaining its strong connection to the Lacks family's DNA.354 Therefore, the interests of both parties should receive equal weight. In terms of the purpose of the company's use, this case concerns use for scientific and commercial purposes. With respect to the commercial uses of the HeLa cells, concerns are raised regarding the significant power asymmetries created between the two parties.

In this case, it seems that the company has pursued a legitimate goal (scientific use is considered legitimate and I personally I do not think that commercialization should be considered inherently illegitimate). There also appears to be a rational connection between the company's use and the achievement of the goal(s) (genetic material is necessary for research and commercialization). Nevertheless, the company's use seems to be disproportionate because there is a less restrictive but equally effective alternative to what the company has done, and the company's actions have caused too much harm. Moreover, it is clear that Thermo Fisher Scientific has not placed the Lacks family's concerns at the forefront of its priorities, as evidenced by the lack of respect with which the members of the Lacks family have been treated. The company has also treated the Lacks family unfairly and

<sup>&</sup>lt;sup>353</sup> See supra text accompanying notes 312–15.

<sup>&</sup>lt;sup>354</sup> SKLOOT, *supra* note 2, at 216. Although there is a strong connection between the HeLa cell and Henrietta's cell, they are not *identical*. As explained by Rebecca Skloot, "[c]ells change while growing in culture. . . . [T]his happened to Henrietta's cells once they were placed in culture. And they passed those changes on to their daughter cells, creating new families of HeLa cells that differed from one another in the same way that second, third, and fourth cousins differ, though they share a common ancestor." *Id.* at 215.

unjustly by refusing to distribute the profits made as a result of their use of the HeLa cells. To remedy proportionality and reasonableness issues, the company could distribute benefits to the family and notify family members about future uses.

To conclude, when attempting to solve the dispute between the Lacks family and Thermo Fisher Scientific, Genetic Property Governance would recognize that all parties have legitimate property interests that need to be reconciled in a way that would ensure appropriate control. The fairest solution would therefore be to rule that the company can continue to use the cell line as long as it shares its benefits with the Lacks family and does not silence the family's own voice.

Now let us turn to another case, *Cole*.<sup>355</sup> In this case, the United States District Court for the District of Alaska held that Cole had property rights over his genetic information. It stated that the law in Alaska recognizes an exclusive property interest in one's DNA sample and analysis and forbids disclosure of the DNA analysis results to third parties without authorization.

Much like it was in the case of the Lacks family, under Genetic Property Governance, both Cole and Gene by Gene would have legitimate property interests over the genetic material and information. The values of personhood and intelligible possession support Cole's property interest. The genetic material and information collected from him are intimately connected to his identity, and his property interest empowers him to pursue his conception of the good. Gene by Gene simultaneously has also a legitimate property interest over the genetic material and information. This interest stems from possession and labor. Following the receipt of Cole's DNA by the company, it immediately began conducting ancestry research and analyzing the DNA sample. This enabled Gene by Gene to achieve its mission of revealing the social importance that is encoded in people's genetic material and information.

After establishing that all of the property interests at stake are legitimate, the next step is to make sure that an appropriate level of control is maintained over the genetic material and information. This is assessed by the proportionality and reasonableness principles, which consider the type of genetic component and the purpose of the use. In this case, the relevant genetic components are genetic specimen (i.e., Cole's cheek swab), DNA sample (i.e., the extracted and purified DNA from Cole's cheek swab), and information on Y-STR<sup>356</sup> (i.e., short tandem repeat markers in Y

<sup>&</sup>lt;sup>355</sup> See supra text accompanying notes 98–114.

<sup>&</sup>lt;sup>356</sup> Request for Relief at 5–6, Cole v. Gene by Gene, Ltd., No. 1:14-cv-00004-SLG, 2017 U.S. Dist. LEXIS 101761 (D. Alaska June 30, 2017) (on file with the author).

chromosome).<sup>357</sup> Gene by Gene used these genetic components to conduct ancestry research so that Cole could find other individuals who share similar genetic information.

In terms of the genetic specimen and the DNA sample, Cole's genetic contribution and proximity to these components are high—the specimen was taken directly from Cole and the DNA sample was analyzed to provide Cole with results on his geographic origins and genetic connections. Therefore, there should be more restrictions on the use of these components by Gene by Gene. For instance, Gene by Gene should not transmit them to third parties without notifying Cole, should inform Cole of anything that happens with them, and should destroy them after performing the test.

In terms of the information on Y-STR, there should be fewer restrictions on the use of this type of information. Y-DNA is the DNA that males inherit from their fathers, and an important fact about this type of information is that it undergoes extremely little change from one generation to the next. This provides an explanation for why a man's Y-DNA will be the same as or extremely similar, to that of his father, grandfather, great grandfather, and so on.<sup>358</sup>

Considering the types of genetic components and the purpose of the use in this case, I do not believe that Gene by Gene's actions were completely disproportionate and unreasonable. After all, the company pursued a legitimate goal (performing ancestry research and finding matches with other costumers at Cole's request) and there is a rational connection between the company's use and the achievement of that goal. Although Gene by Gene could have avoided posting the list of Y-STR results on its website, or at least it could have notified Cole that these results are publicly available, I still believe that the harm was not too drastic. The type of information in question is not as sensitive and unique as Cole and the court claim it to be.

#### **IV. CONCLUSION**

The 20th and 21st Centuries were marked by important developments in molecular biology. One of the first occurred in 1953, when Rosalind Franklin, James Watson, and Francis Crick discovered that DNA molecules exist in the form of a double helix—

<sup>&</sup>lt;sup>357</sup> *Y-DNA Test*, FAMILYTREEDNA, https://help.familytreedna.com/hc/enus/articles/4408063356303-Y-STR-Results-Guide-#panel-1-1-12--0-0 [https://perma.cc/Y77E-NED2] (last visited Nov. 15, 2022).

<sup>&</sup>lt;sup>358</sup> YOUR DNA GUIDE, https://www.yourdnaguide.com/ydna [https://perma.cc/G9G3-NLK6] (last visited Nov. 15, 2022).

that is, a twisted-ladder structure.<sup>359</sup> Since then, the pace of scientific discoveries and technological breakthroughs has accelerated.

However, alongside the tremendous opportunities these events have created, they have also challenged our legal, social, and economic infrastructures with sometimes new yet fundamental dilemmas. Does an individual genome have unique features and, if so, how should these features be reflected in the law? Who could claim ownership over an individual genome? What can be done to protect both individual and collective interests in how an individual genome is used? What legal framework should be applied? This Article has attempted to address these pivotal dilemmas.

I have argued in this Article that scholars and lawmakers in the United States are currently struggling to find satisfying resolutions to the pressing questions arising from ownership of an individual genome. I have also argued these same entities hold a reductionist view of genome conceptualization and governance and apply traditional rules and approaches that are inadequate to deal with the complexities and distinctiveness of an individual genome.

In this Article, I have focused primarily on how genome conceptualization and governance is utilized in practice; I have sought to reveal how genetic material and information are conceptualized and governed by legislatures and courts. I have demonstrated that these same courts and legislatures tend to integrate an individual genome into the traditional property framework as if it were identical to the subjects traditionally treated within this framework. As a result, these bodies have largely ignored any consideration of an individual genome's ontology. I believe that there is something inherently wrong with conceptualizing and governing an individual genome without understanding its features. The study and analysis of the character of this resource can help us understand the effect of diverse institutional arrangements on the incentives and outcomes of the actions taken by the respective stakeholders.

Most notably, I have shown that courts and legislatures appear to adhere to the conviction that there is only one correct lens—the individualistic lens—through which everything is deducible and to which everything is relatable. This perspective underlines their commitment to an absolute conception of ownership, that of a single owner who has the right "to act as the exclusive gatekeeper of the owned thing."<sup>360</sup> It assumes that we could not, and indeed should not, legally recognize the ownership interests of multiple stakeholders regarding an individual genome.

<sup>&</sup>lt;sup>359</sup> Leslie A. Pray, *Discovery of DNA Structure and Function: Watson and Crick*, 1 NATURE EDUC. 100 (2008).

<sup>&</sup>lt;sup>360</sup> Thomas W. Merrill & Henry E. Smith, *The Morality of Property*, 48 WM. & MARY L. REV. 1849, 1850 (2007).

Hence, when seen through the individualistic lens, only one entity is at the locus of decision-making authority when it comes to what happens to an individual genome.

This Article joins recent efforts to expand the scope of ownership of an individual genome and proposes a new legal framework, Genetic Property Governance. Unlike the current genome conceptualization and governance, the new framework gives proper attention to the features of an individual genome and appreciates that this resource is comprised of both genetic material and genetic information, and that it has personal, familial, and collective aspects. Moreover, Genetic Property Governance treats an individual genome as a commons and implements a common property regime. It is also guided by a liberal conception of property, suggesting that the institution of property must address interpersonal relationships and abide by the maxim of reciprocal respect.

Overall, Genetic Property Governance provides more fitting directions for grappling with issues of individual genome ownership and offers new ways of thinking about genome conceptualization and governance. This legal framework perceives the different stakeholders as *dividuals*—rather than individuals—and adopts a broad relational perspective.

The Article has sowed the preliminary seeds for this alternative framework but there is still much work to be done and more dialogue to be fostered. Many critical and timely questions are still open and unexplored. For example, what types of property entitlements does each stakeholder have over an individual genome? What are the implications of Genetic Property Governance for different uses, such as genome editing or transferring (by sale, barter, or gift) an individual genome from one party to another? This Article will hopefully spark a continuing round of conversations about these and other questions. Most crucially, it will guide us in changing how an individual genome is conceptualized and governed.