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# Progressive Genetic Ownership

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## PROGRESSIVE GENETIC OWNERSHIP

Jessica L. Roberts\*

Recently, property law scholars have challenged neoclassical economic theory as the primary lens for understanding ownership. As an alternative to the all-too-familiar concepts of welfarism, rational choice theory, and cost-benefit analysis, they offer “progressive property,” a school of thought grounded in value pluralism, communitarianism, and redistribution. To date, much of the progressive property literature has focused exclusively on land use. This Article tests the versatility of this new property school by applying it to a novel context: genetic ownership. As with real property, discussions surrounding genetic ownership have been entrenched in the language of neoclassical economics. Given the proliferation of deontological concerns related to genetic research—such as privacy, identity, autonomy, and social justice—neoclassical economic theory is woefully incomplete as a theory of genetic ownership. Progressive property promises a more complete approach. Yet this conclusion does not establish progressive property as universally appropriate. Certain unexpected similarities exist between land and genetic data. Thus, while progressive property is well-suited to situations dealing with unique objects of ownership that raise deontological and distributive concerns, it should not necessarily supplant neoclassical law and economics for resolving all legal disputes regarding the ownership.

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INTRODUCTION .....	1107
I. OWNERSHIP DEBATES .....	1112
A. <i>What Is Progressive Property?</i> .....	1112
1. Neoclassical Economic Theories of Property .....	1112
2. Progressive Property as an Alternative .....	1115
B. <i>What Is Genetic Ownership?</i> .....	1121
1. Genetic Ownership Controversies.....	1123
2. Genetic Ownership Entitlements .....	1128
a. Right to Exclude .....	1130
b. Right to Access.....	1131
c. Right to Commercialize .....	1132
II. HEGEMONY OF NEOCLASSICAL LAW AND ECONOMICS IN GENETIC OWNERSHIP.....	1133
A. <i>Genetic Comedies</i> .....	1133
1. Research Incentives .....	1134
2. Participation Incentives .....	1135
B. <i>Genetic Tragedies</i> .....	1138
1. Anticommons .....	1138
2. Collective Action Problems .....	1140
3. Perverse Incentives .....	1141
III. FAILURE OF NEOCLASSICAL ECONOMIC THEORY FOR GENETIC OWNERSHIP .....	1145
A. <i>Doctrinal Failures</i> .....	1145
1. Informed Consent .....	1145
2. Growing Genetic Ownership Rights.....	1148
B. <i>Intuitive Failures</i> .....	1149
1. Personal Ownership .....	1150
2. Commodification Anxieties.....	1153
3. Declining Research Altruism .....	1155
IV. PROGRESSIVE GENETIC OWNERSHIP .....	1156
A. <i>Progressive Model of Genetic Ownership</i> .....	1156
1. Plural Genetic Values .....	1156
2. Genetic Communities .....	1160
3. Genetic Distributive Justice .....	1163
B. <i>Applying the Model</i> .....	1164
1. Right to Exclude .....	1164
2. Right to Access .....	1165
3. Right to Commercialize .....	1166
CONCLUSION .....	1167

## INTRODUCTION

Neoclassical law and economics has been a dominant lens in property law for decades.<sup>1</sup> This view is such an integral part of the property law canon that law students typically encounter it during their very first weeks of study when discussing the costs of fox hunting or the efficiency of whaling customs.<sup>2</sup> Yet recently, a new school of thought—progressive property—has disrupted these traditional theoretical underpinnings of American property law.

The progressive property movement challenges the dominance of neoclassical law and economics, urging us to consider the lived human experience, not just costs and benefits, when considering normative theories of property.<sup>3</sup> The familiar concepts of social welfare, rational actors, and cost-benefit analysis are such popular—and largely unquestioned—tools for understanding the legal system that they may well escape notice.<sup>4</sup> However, progressive property scholars maintain that these analytical tools, which comprise the core approach of neoclassical law and economics, fail to capture all the concerns at stake within ownership disputes. Specifically, progressive property theorists favor plural and incommensurable values over a singular account of welfare, acknowledge that human beings are not purely self-interested rational actors, and support distributive justice over simply maximizing net welfare. Importantly, progressive property does not outright reject promoting welfare, rational choice theory, or cost-benefit analysis. Rather, it situates those concerns within a greater conversation about the meaning and purpose of property.

Advocates have billed progressive property as a new school of thought. Yet if this movement truly represents the future of property theory, it must apply across a number of different contexts. While a handful of progressive property scholars have written about intellectual property, the principal focus of progressive property since its inception has been land use. This Article interrogates whether progressive property might apply in other domains. In so doing, it seeks to answer a novel and important question: whether progressive property is a theory of property writ large or whether it is exclusive to land use.

These debates matter. While seemingly abstract, property theories serve a variety of real-world functions. They justify the recognition of property rights and articulate their boundaries.<sup>5</sup> Property theories also explain how

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1 See Gregory S. Alexander, *The Social-Obligation Norm in American Property Law*, 94 CORNELL L. REV. 745, 750 (2009); Eduardo M. Peñalver, *Land Virtues*, 94 CORNELL L. REV. 821, 822 (2009).

2 See *Ghen v. Rich*, 8 F. 159, 159 (D. Mass. 1881); *Pierson v. Post*, 3 Cai. 175, 177 (N.Y. Sup. Ct. 1805); see also JESSE DUKEMINIER ET AL., PROPERTY 39–55 (7th ed. 2010).

3 For a detailed explanation of the progressive property movement and its relationship to neoclassical law and economics, see *infra* Part I.

4 See I. Glenn Cohen, *The Right Not to Be a Genetic Parent?*, 81 S. CAL. L. REV. 1115, 1152 (2008) (explaining that “[m]any implicitly or explicitly think about legal-system design in consequentialist terms”).

5 See Margaret Jane Radin, *Property and Personhood*, 34 STAN. L. REV. 957, 958 (1982).

and why society distributes property interests among potential stakeholders.<sup>6</sup> In other words, theory informs the most foundational question of property law: who should own what. And finally, property theory legitimizes existing rights by explaining why allocating ownership interests in a particular way is appealing or fair.<sup>7</sup> Property theories are at once generative, descriptive, normative, and validating. Shifting how we think about property changes how we construe ownership and how we distribute its corresponding legal entitlements.

Along with this debate in property law scholarship, a contemporaneous ownership debate has been raging within bioethics. People historically have not had meaningful ownership rights in their genetic data.<sup>8</sup> During a 2016 White House forum, President Barack Obama opined: “I would like to think that if somebody does a test on me or my genes, that that’s mine, but that’s not always how we define these issues.”<sup>9</sup> He went on to tell participants in his Precision Medicine Initiative that the success of the program requires “understanding who owns the data.”<sup>10</sup> But why?

We must resolve questions of genetic ownership because biospecimens and the DNA they contain are highly valuable both scientifically and commercially.<sup>11</sup> Much of modern medical science hinges on access to human tissue,<sup>12</sup> leading to the creation of extensive private, public, and nonprofit-run biobanks around the globe.<sup>13</sup> By some estimates, biobanks in the United States alone house over 500 million biospecimens, with that number increasing by twenty million every year.<sup>14</sup> Many Americans are familiar with the \$43 billion per year biotech industry, much of which is built on enforcing exclusive patent rights.<sup>15</sup> However, recently the patent stranglehold that biotech has had on genetic information has weakened, as individuals are gaining what resemble de facto property interests in their DNA. People who contribute specimens for research are beginning to demand “biorights,” including rights to compensation, access, and continuing control.<sup>16</sup>

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6 See GREGORY S. ALEXANDER & EDUARDO M. PEÑALVER, AN INTRODUCTION TO PROPERTY THEORY 6–8 (2012).

7 See *id.* at 7.

8 See *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (Cal. 1990); see also *DUKEMINIER ET AL.*, *supra* note 2, at 70–83.

9 Julie Hirschfeld Davis, *Who Owns Your Genetic Data? Obama Says You Do*, SEATTLE TIMES (Feb. 25, 2016), <http://www.seattletimes.com/nation-world/who-owns-your-genetic-data-obama-says-you-do>.

10 *Id.*

11 See HARRIET A. WASHINGTON, DEADLY MONOPOLIES 234 (2011).

12 See *id.*

13 See Mark A. Rothstein et al., *Comparative Approaches to Biobanks and Privacy*, 44 J.L. MED. & ETHICS 161, 161 (2016).

14 Natalie Ram, *DNA by the Entirety*, 115 COLUM. L. REV. 873, 884 (2015).

15 See WASHINGTON, *supra* note 11, at 48.

16 Beth Daley & Ellen Cranley, *‘Biorights’ Rise: Donors Demand Control of Their Samples*, BOS. GLOBE (Oct. 10, 2016), <https://www.bostonglobe.com/metro/2016/10/09/the-rise-biorights-donors-are-demanding-control-and-sometimes-cash-exchange-for-genetic-samples>

For example, four patients, represented by the American Civil Liberties Union (ACLU), filed a complaint against the genetic testing company Myriad Genetics for denying them access to their genetic information.<sup>17</sup> They argue that Myriad violated the Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule, which creates a right to access the information contained within a person's health records.<sup>18</sup> The complainants underwent genetic testing with Myriad to assess their risks related to breast, ovarian, and other cancers. While Myriad provided them with a test report related to those risks, it refused to release the full set of their genetic results, maintaining that HIPAA only requires the company to release data that is "clinically actionable."<sup>19</sup>

What might not be apparent is that this latest controversy is, at bottom, a battle over genetic ownership. Myriad took a significant financial hit in 2013 when the Supreme Court invalidated its patents on isolated genes linked to breast and ovarian cancers.<sup>20</sup> Moreover, its corner on the genetic testing market will further decrease as many of its remaining patents expire.<sup>21</sup> With its patent monopoly in inescapable peril, Myriad's most valuable asset is now its extensive proprietary database of genetic information.<sup>22</sup> But whether Myriad can extract value from that database turns on how the law defines the ownership interests in the genetic information that the database contains. The way we understand genetic ownership and its underlying purpose will undoubtedly shape the outcome of this claim.

In addition to the most recent installment in the Myriad saga, courts have addressed the issue of property rights in genetic data head-on in two recent cases: *Peerenboom v. Perlmutter* and *Cole v. Gene by Gene, Ltd.* In *Peerenboom*, Isaac and Laura Perlmutter sued Harold Peerenboom for conversion, among other things. They alleged that Peerenboom conspired to obtain their genetic material as part of a scheme to retaliate against the Perlmutters in a neighborhood dispute.<sup>23</sup> The Perlmutters asserted that they "have an exclusive right of possession and ownership of the genetic information encoded in their genetic material" and that "[b]y collecting, analyzing, and testing their genetic material to obtain the Perlmutters' confidential genetic

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/jCbaQ2E5t6c0Qs1kcITMRM/story.html; see also Jessica L. Roberts, Biorights (work in progress).

17 Health Information Privacy Complaint, Zeughauer v. Myriad Genetics Lab., U.S. Dep't of Health & Human Servs., Office for Civil Rights (May 19, 2016), [https://www.aclu.org/sites/default/files/field\\_document/2016.5.19\\_hipaa\\_complaint.pdf](https://www.aclu.org/sites/default/files/field_document/2016.5.19_hipaa_complaint.pdf); see also Erika Check Hayden, *Myriad Genetics Caught in Data Fight*, 533 NATURE 449, 449 (2016).

18 45 C.F.R. § 164.524 (2014); see also Health Information Privacy Complaint, *supra* note 17, at 1.

19 Health Information Privacy Complaint, *supra* note 17, at 4.

20 See *infra* notes 253–61 and accompanying text.

21 See John M. Conley et al., *Myriad after Myriad: The Proprietary Data Dilemma*, 15 N.C. J.L. & TECH. 597, 599 (2014).

22 See *id.* at 599–600.

23 See Amended Counterclaim at 6–11, *Peerenboom v. Perlmutter*, No. 2013-CA-015257 (Fla. Cir. Ct. Apr. 7, 2017).

information, Conspirators exercised an act of dominion and authority that deprived the Perlmutter of their rights of ownership, possession, control, and privacy.”<sup>24</sup> Responding to a motion to dismiss from Peerenboom, the trial court found that the Perlmutter enjoyed a property right in their genetic information, sufficient to state a claim for conversion.<sup>25</sup>

*Cole v. Gene by Gene, Ltd.*, set for trial in May 2018, deals with the release of genetic information in conjunction with direct-to-consumer genetic testing. Michael Cole purchased an at-home DNA ancestry kit, which gave consumers the opportunity to participate in “projects” run by third-party volunteers related to their results.<sup>26</sup> Cole signed up for nine such projects.<sup>27</sup> After receiving a large amount of spam, he searched the internet for his email address and found it on a website, thereby learning that his genetic test results had been made publicly available.<sup>28</sup> He sued the genetic testing company alleging a violation of Alaska’s Genetic Privacy Act.<sup>29</sup> In denying the defendant’s motion to dismiss for lack of standing, the trial court ruled that Cole had successfully shown an injury-in-fact under the Genetic Privacy Act, as the statute includes an exclusive property interest in genetic information, which relates to the common-law torts of conversion and invasion of property.<sup>30</sup> Like the Myriad complaint, *Peerenboom* and *Cole* demonstrate that conflicts about the property status of genetic data are alive and well.

This Article provides a case study for progressive property: the ownership of genetic data. The status of genetic ownership is in flux and interest in personal health data—both as a resource and as a commodity—is growing. New spheres of ownership are rare in property law. Virtually all of the world’s territory is already spoken for, so the possibility of a new brand of entitlement, *creatio ex nihilo*, presents a particularly compelling opportunity to apply this new school of thought.

Whether to grant genetic ownership rights is widely regarded as a question for bioethics, the branch of moral philosophy dealing with science and the practice of medicine.<sup>31</sup> While consequentialism certainly has a place in biomedical ethics,<sup>32</sup> modern bioethics as a field regularly engages with deontological concerns, such as autonomy, privacy, and justice.<sup>33</sup> Remarkably,

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24 *Id.* at 19.

25 See *Peerenboom v. Perlmutter*, No. 2013-CA-015257 (Fla. Cir. Ct. Jan. 23, 2017) (order granting in part the counterdefendant’s motions to dismiss the counterclaim and dismissing the counterclaim in part).

26 *Cole v. Gene by Gene, Ltd.*, No. 1:14-cv-00004, 2017 U.S. Dist. LEXIS 101761, at \*2 (D. Alaska June 30, 2017).

27 *Id.*

28 *Id.* at \*3.

29 *Id.*

30 *Id.* at \*9.

31 See DAVID DEGRAZIA & THOMAS A. MAPPES, *BIOMEDICAL ETHICS* 1 (4th ed. 1996).

32 See *id.* at 6–17.

33 See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOETHICS* 13 (7th ed. 2013) (identifying four core bioethical principles: autonomy, beneficence, nonmaleficence, and justice).

though, the entire conversation surrounding ownership of genetic data—on both legal and theoretical levels—has been deeply entrenched in neoclassical economic theory with arguments almost universally framed in the language of costs, benefits, and incentives. I argue that a neoclassical economic approach to genetic ownership fails on both descriptive and intuitive levels. It does not explain why we have doctrines of informed consent and growing personal rights in genetic data that can lead to inefficient use, nor does it account for the intuition that we own our genetic information or for fears of commodifying the self. Can progressive property help shed light on this developing area of law and regulation where a neoclassical economic framework fails?

This Article argues it can. Progressive property presents a more complete perspective by considering the deontological concerns associated with genetic ownership alongside the consequentialist ones. However, this Article is not merely about what progressive property may offer genetic ownership. In exposing the hidden hegemony of neoclassical economic theory within this important bioethical debate and offering progressive property as a meaningful alternative, this Article also seeks to contribute to the conversation regarding progressive property as a theoretical lens beyond land use. A robust theory of progressive genetic ownership reveals progressive property's flexibility. Yet establishing progressive property's usefulness beyond the familiar context of land use does not demonstrate its universal appeal. Genetic data and land share certain surprising commonalities, such as their uniqueness, their connection to families and communities, and their intergenerational significance. It is these similarities that make progressive property appropriate in both contexts. Yet when the object of ownership is fungible and held purely instrumentally to facilitate financial gain, neoclassical law and economics remains an appropriate theoretical lens.

This Article proceeds in four parts. Part I describes the rise of progressive property as a response to the dominance of neoclassical law and economics within property theory and introduces the concept of genetic ownership. Part II asserts that, despite bioethics' deontological overtones, neoclassical law and economics has also been the primary theoretical lens for arguments both for and against entitlements in genetic data. Thus, the dominance of this frame extends beyond land use. Part III then shows how neoclassical law and economics fails both descriptively and intuitively to explain genetic ownership. Finally, Part IV advances a progressive property approach to resolving controversies over genetic data, thereby proving its theoretical versatility. The Article concludes by offering some insights regarding when progressive property is appropriate—and by contrast when neoclassical law and economics is sufficient—for deciding property disputes.



## I. OWNERSHIP DEBATES

Transformative debates are happening within property theory.<sup>34</sup> A group of scholars has challenged the hegemony of neoclassical law and economics within property law and has offered an alternative framework. However, despite the formative changes in the thinking surrounding property and ownership, perhaps one of the most exciting modern debates about these kinds of rights has gone largely unnoticed by property law scholars. It is the conflict surrounding the ownership of genetic data. This Part explores progressive property as a response to the dominance of neoclassical economic theory and then introduces the central controversies and entitlements that characterize genetic ownership.

### A. *What Is Progressive Property?*

A vast and diverse range of scholars and theories could fall under the umbrella of law and economics. Like the progressive property scholarship that inspired it, this Article responds specifically to a neoclassical economic approach to ownership, derived in part from the work of economist Harold Demsetz. Progressive property scholars argue that, despite its ubiquity, neoclassical law and economics falls short both descriptively and prescriptively with respect to property law and offer progressive property as an alternative.

#### 1. Neoclassical Economic Theories of Property

Demsetz revolutionized property scholarship with his 1967 article *Toward a Theory of Property Rights*. Unlike other economists of his day who took property rights as a given, Demsetz attempted to explain why they emerge by crafting what he called “an economic theory of property rights.”<sup>35</sup> In his words, “property rights arise when it becomes economic for those affected by externalities to internalize benefits and costs.”<sup>36</sup> As a neoclassical economist, Demsetz’s work rests on the three key assumptions of neoclassical economics: (1) people seek to maximize utility; (2) people have rational preferences between various possible outcomes; and (3) people are independent actors who make decisions based on complete and relevant information.<sup>37</sup> As used in this Article, then, the defining features of neoclassical economic theory—which forms the basis for neoclassical law and economics—are: (1) value monism; (2) rational choice theory; and (3) cost-benefit analysis. We can consider each of these guiding principles in turn.

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34 See Ezra Rosser, Essay, *The Ambition and Transformative Potential of Progressive Property*, 101 CALIF. L. REV. 107, 108 (2013).

35 Harold Demsetz, *Toward a Theory of Property Rights*, 57 AM. ECON. REV. 347, 347 (1967).

36 *Id.* at 354.

37 See E. Roy Weintraub, *Neoclassical Economics*, in THE CONCISE ENCYCLOPEDIA OF ECONOMICS (David R. Henderson ed., 2002), <http://www.econlib.org/library/Enc1/NeoclassicalEconomics.html>.

Because Demsetz believes that property functions to promote economic efficiency, he focuses exclusively on how ownership maximizes the value of the property.<sup>38</sup> Utilitarianism evaluates the morality of a law by considering whether it produces net welfare.<sup>39</sup> As a consequentialist theory, utilitarianism rejects the notion that particular actions might have value apart from the utility they produce.<sup>40</sup> Demsetz and his fellow neoclassical economists regard property and its accompanying entitlements from this sort of instrumental perspective. Utilitarianism in general, and the neoclassical economic approach in particular, has been the dominant theoretical lens for understanding property law for decades.<sup>41</sup>

First, neoclassical law and economics, like all utilitarian theories, evaluates particular outcomes in terms of a single metric: “welfare.”<sup>42</sup> The two major utilitarian schools are traditional utilitarianism, which defines welfare as a broad notion of happiness or well-being (frequently framed in terms of preference satisfaction),<sup>43</sup> and economic utilitarianism, which uses money and market value as a proxy for welfare.<sup>44</sup> Utilitarianism assumes that social welfare equals the sum of all the individual welfare for all the members of the society.<sup>45</sup> Even plural accounts of welfare—definitions of welfare that attempt to encompass multiple aspects of happiness or well-being—must be able to distill those plural values into a single unified definition. Neoclassical law and economics therefore views property rights and institutions in terms of their ability to maximize a single (monist) value: welfare, however defined.

Second, the neoclassical economic account of property assumes that people are rational actors. According to rational choice theory, when making a decision, a rational actor will consider all of the information available to her, think through the various probable outcomes of her decision, weigh the potential costs and benefits, and then take the action that serves her own best interests.<sup>46</sup> The rational-actor model assumes that a person is capable of

38 See Demsetz, *supra* note 35, at 355.

39 See J.J.C. SMART & BERNARD WILLIAMS, UTILITARIANISM: FOR AND AGAINST 4 (1973). Utilitarianism can also focus on either maximizing positive welfare or minimizing negative welfare. *Id.* at 28–30.

40 See *id.* at 84.

41 See DUKEMINIER ET AL., *supra* note 2, at 50.

42 Value monism is not exclusive to utilitarianism, as even some deontological theories may center on a single—albeit complex—moral value, e.g., the Kantian focus on human dignity. Gregory S. Alexander, *Pluralism and Property*, 80 *FORDHAM L. REV.* 1017, 1020 (2011).

43 See SMART & WILLIAMS, *supra* note 39, at 80 (describing utility/happiness as preference satisfaction).

44 See Michael B. Dorff & Kimberly Kessler Ferzan, *Is There a Method to the Madness? Why Creative and Counterintuitive Proposals Are Counterproductive*, in *THEORETICAL FOUNDATIONS OF LAW AND ECONOMICS* 21, 26 (Mark D. White ed., 2009).

45 See R.G. Frey, *Utilitarianism and Bioethics*, in 5 *ENCYCLOPEDIA OF BIOETHICS* 2531, 2531 (Stephen G. Post ed., 3d ed. 2004); *Utilitarianism*, in *A DICTIONARY OF ECONOMICS* (John Black et al. eds., 5th ed. 2017).

46 See *Rational Choice Theory*, in *A DICTIONARY OF SOCIOLOGY* 625, 625–27 (John Scott ed., 4th ed. 2014).

identifying the course of action that will offer her the most benefit and is motivated predominantly by the desire for personal gain. Among the key principles of economic theory is that people respond to incentives in these predictable, rational ways. The rational actor is thus deliberative, self-interested, and responsive to incentives.

Finally, rational actors decide which course of action to take using cost-benefit analysis.<sup>47</sup> In welfare terms, rational actors will seek to maximize benefits (positive welfare) while minimizing costs (negative welfare). This model reduces decisionmaking to a simple comparison of costs and benefits. Cost-benefit analysis also envisions a particular purpose for property. It presumes that owners' primary goal is simply to maximize the value produced by their land or chattels. Yet, as Demsetz notes, because they are motivated primarily by self-interest, rational actors are unlikely to consider all the possible effects their conduct might have on others, thus resulting in both positive and negative externalities.<sup>48</sup>

While neoclassical economics provides a useful lens in many cases, it fails to explain certain intuitions and behaviors related to ownership. For instance, it would not distinguish between an owner who recently purchased a house as a rental property and an owner who inherited a home her family had lived in for generations. Instead it would predict that both owners are motivated to extract the most value possible from their properties. However, our actual experience tells us that these two owners likely have very different relationships with their respective houses. While land's physical uniqueness is well-accepted within property law, land also enjoys a relational uniqueness regarding how a given individual or group of individuals interacts with a particular parcel of land.<sup>49</sup>

There is something intuitively different between the landlord and the heir that neoclassical economics cannot explain or predict. In fact, research shows that landlords and owner occupants invest their resources differently, as do absentee landlords and resident landlords.<sup>50</sup> Owners tend to invest more in their homes than landlords and resident landlords tend to invest more than absentee landlords.<sup>51</sup> But why?

While homeowners generally seek to preserve and increase the value of their homes, a neoclassical wealth-maximizing, rational choice model fails to account for a significant swath of homeowner behavior.<sup>52</sup> Why concentrate such a substantial portion of wealth in a single investment? It comes as no surprise, then, that Americans attach special significance to homeownership. A home represents more than an investment. Even after the Great Recession, most Americans continue to believe that owning a home represents the

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47 Demsetz, *supra* note 35, at 354–58 (describing both decisions to create systems of property and decisions about land use as the result of weighing costs and benefits).

48 *Id.* at 356.

49 See Peñalver, *supra* note 1, at 828–29.

50 *See id.* at 838.

51 *See id.*

52 *See id.* at 834.

“American dream.”<sup>53</sup> Additionally, Eduardo Peñalver shows that owners often customize their living spaces for their own comfort or simply to express their identities, even at the expense of market value.<sup>54</sup> Other important aspects of home ownership obscured by the neoclassical economic approach include access to social goods and networks like schools, parks, and communities.<sup>55</sup> Longtime homeowners are more likely to vote for tax *increases* to finance public schools than new residents, even though their own children have long since graduated.<sup>56</sup> Moreover, homeowners may object to changes within their neighborhood that would actually improve the value of their property if they believe those changes will alter the character of their community.<sup>57</sup> People act in ways regarding their homes and their communities that are independent of market value.

Properly understanding why people act—not just how they act—is essential to good policymaking. Consequently, policies that assume homeowners are primarily financially motivated will inevitably fall short. Take for example the common land use problem of how LULUs (“locally undesirable land uses”) lead to NIMBY (“not in my backyard”) objections. A particular land use, like creating a landfill, can have positive effects across an entire community, yet it will negatively impact the property owners in the immediate area. A neoclassical economic solution to a NIMBY problem would advocate compensating the affected owners for the cost the LULU would impose.<sup>58</sup> However, compensation programs have not been independently successful.<sup>59</sup> In actuality, they have at times increased opposition to the LULU.<sup>60</sup>

## 2. Progressive Property as an Alternative

Whereas the utilitarianism characteristic of neoclassical economics focuses on promoting welfare, progressive property seeks to support human flourishing by acknowledging the presence of plural and incommensurable

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53 See Dave Fagundes, *Buying Happiness: Property, Acquisition, and Subjective Well-Being*, 58 WM. & MARY L. REV. 1851, 1872–73 & n.89 (2017) (discussing the mythology of the single-family home as the “American dream”); see also Peñalver, *supra* note 1, at 835–36 (discussing the cultural and symbolic significance of homeownership).

54 Peñalver, *supra* note 1, at 837.

55 See *id.* at 838.

56 See Michael B. Berkman & Eric Plutzer, *Gray Peril or Loyal Support? The Effects of the Elderly on Educational Expenditures*, 85 SOC. SCI. Q. 1178, 1181 (2004); see also Peñalver, *supra* note 1, at 838.

57 See Peñalver, *supra* note 1, at 842–44.

58 See *id.* at 845.

59 See Vicki Been, *Compensated Siting Proposals: Is It Time to Pay Attention?*, 21 FORDHAM URB. L.J. 787, 824 (1994); Carissa Schively, *Understanding the NIMBY and LULU Phenomena: Reassessing Our Knowledge Base and Informing Future Research*, 21 J. PLAN. LITERATURE 255, 260 (2007); see also Peñalver, *supra* note 1, at 845.

60 See Bruno S. Frey et al., *The Old Lady Visits Your Backyard: A Tale of Morals and Markets*, 104 J. POL. ECON. 1297, 1299–301 (1996); Bruno S. Frey & Felix Oberholzer-Gee, *The Cost of Price Incentives: An Empirical Analysis of Motivation Crowding-Out*, 87 AM. ECON. REV. 746, 749–50 (1997); see also Peñalver, *supra* note 1, at 845.

values, the importance of community ties, and the fairness concerns raised by disparities.<sup>61</sup> While neoclassical law and economics uses (1) value monism, (2) rational choice theory, and (3) cost-benefit analysis, progressive property adopts (1) value pluralism, (2) communitarianism, and (3) redistribution.

Progressive property is value pluralist. While utilitarians might recognize the existence of other values, they view those values as merely instrumental in promoting the metavalue of welfare. Progressive property scholars reject the premise that all the concerns relevant to property can be condensed into a single, quantifiable welfare metric.<sup>62</sup> A key insight of progressive property is that property involves a mix of individual, social, and relational values that go beyond mere preference satisfaction, including—but not exclusively—physical security, knowledge acquisition, freedom of choice, wealth, and happiness.<sup>63</sup> These values also implicate the greater social values of justice (particularly just social relationships and just distributions) and democracy.<sup>64</sup>

Importantly, progressive property scholars also believe that the plural values relevant to property law are incommensurable. Incommensurability is about more than difference.<sup>65</sup> It is not a matter of comparing apples and oranges or black and white, but rather attempting to compare apples and white. Progressive property scholars believe that because the values at stake within property represent different aspects of the human experience, they cannot be compared or ranked without distorting their intrinsic value.<sup>66</sup> Plural accounts of welfare likewise fail because they take values that are inherently different and distinct and attempt to distill them into a single, all-encompassing value. Progressive property scholars assert that human flourishing as a concept is simply too complicated to be collapsed into a single criterion, no matter how complex. Progressive property is therefore value pluralist.

Second, progressive property rejects rational choice theory as an incomplete and simplified understanding of human behavior. Instead of placing an individualistic, self-interested, welfare-maximizing rational actor at the center of property, progressive property thinks in terms of communities. As social and political creatures, people need communities to have good lives.<sup>67</sup> In reality, we require others to survive—a reality that is clearest during

61 See Gregory S. Alexander & Eduardo M. Peñalver, *Properties of Community*, 10 THEORETICAL INQUIRIES L. 127, 127 (2009); see also ALEXANDER & PEÑALVER, *supra* note 6, at 80–101.

62 See ALEXANDER & PEÑALVER, *supra* note 6, at 98; Gregory S. Alexander et al., *A Statement of Progressive Property*, 94 CORNELL L. REV. 743, 744 (2009); Peñalver, *supra* note 1, at 858; Joseph William Singer, Essay, *Democratic Estates: Property Law in a Free and Democratic Society*, 94 CORNELL L. REV. 1009, 1037 (2009).

63 See Alexander et al., *supra* note 62, at 743; see also Alexander, *supra* note 42, at 1028.

64 See Alexander et al., *supra* note 62, at 743.

65 See Alexander, *supra* note 42, at 1043.

66 See Alexander et al., *supra* note 62, at 744; Alexander, *supra* note 42, at 1020.

67 See ALEXANDER & PEÑALVER, *supra* note 6, at 80–81.

infancy, illness, and old age.<sup>68</sup> Because of the inevitable dependency and interdependency of the human condition, flourishing is an “unavoidably cooperative endeavor.”<sup>69</sup> Communities are more than mere collections of individual, exogenous preferences. They are themselves preference-generating.<sup>70</sup> Individuals’ communities shape their identities. Progressive property scholars believe that ignoring this reality eliminates the possibility of a morally distinct sense of community (i.e., an independent view of community as separate from the collection of individuals that make up that community).<sup>71</sup>

This view of the community shapes how progressive property scholars view the purpose of property. On this account, property both allocates power within communities<sup>72</sup> and provides the opportunity to exercise certain virtues that benefit communities, such as responsible ownership, friendship, generosity, and moderation.<sup>73</sup> As a normative matter, then, progressive property scholars believe that property law should seek to enable people to participate fully in the social and political life of a free, democratic society.<sup>74</sup>

While the community is central to progressive property, it is worth noting that the importance of the community does not overshadow the interests of the individuals within that community. Human flourishing values practical reasoning and autonomy.<sup>75</sup> Thus, while progressive property considers communal well-being, it does not do so to the detriment of important individual rights and liberties, such as privacy, autonomy, and dignity.

Lastly, progressive property scholars have taken issue with cost-benefit analysis. To start, weighing costs and benefits assumes that welfare is both calculable and comparable.<sup>76</sup> Furthermore, relying on costs and benefits for decisionmaking ignores the other moral concerns that relate to property.<sup>77</sup> For example, utilitarianism neglects distributive concerns.<sup>78</sup> One action may make some people much, much better off and everyone else just slightly worse off, whereas another would make all people just a teeny bit better off, but would not make any one person very well off. Utilitarianism could situate both outcomes as “equally” welfare-generating, so which one should we select?<sup>79</sup> By looking only to aggregated interests, utilitarianism hides that a significant portion of welfare may be concentrated among a small group of people, thereby masking even serious disparities. Martha Nussbaum quips that utilitarianism does not explain “who has got the money, and whether

68 See Alexander & Peñalver, *supra* note 61, at 139.

69 Peñalver, *supra* note 1, at 869; see ALEXANDER & PEÑALVER, *supra* note 6, at 87; Alexander & Peñalver, *supra* note 61, at 138; Alexander, *supra* note 1, at 760–61.

70 See Alexander & Peñalver, *supra* note 61, at 139–40.

71 See *id.* at 129.

72 See Alexander et al., *supra* note 62, at 744.

73 See ALEXANDER & PEÑALVER, *supra* note 6, at 83.

74 See Alexander et al., *supra* note 62, at 744.

75 See Peñalver, *supra* note 1, at 870.

76 See *id.* at 858.

77 See *id.* at 860.

78 See SMART & WILLIAMS, *supra* note 39, at 142–43.

79 *Id.* at 34.

any of it is mine.”<sup>80</sup> Progressive property scholars believe that the issues of deep human concern raised by property law cannot, as Joseph Singer puts it, “be reduced to a math problem.”<sup>81</sup>

Unlike neoclassical law and economics, which suggests that markets may suffice to address distributive concerns, progressive property imagines a more robust role for the state to assure a just distribution of resources.<sup>82</sup> Because people need resources to flourish, according to progressive property, people have a right to the resources necessary for flourishing. This right warrants encouraging—if not requiring—the state to force the wealthy to share any surplus to allow the poor to flourish.<sup>83</sup> Hence, progressive property may at times require redistribution.<sup>84</sup> As a value pluralist school of thought, progressive property may consider both deontological and consequentialist justifications for redistribution.

Progressive property advocates view their approach as more honest than its welfarist counterpart because it reflects the kind of indeterminacy experienced in real-world decisionmaking.<sup>85</sup> They assert that utilitarians with their value monist theories are either sacrificing neatness for accuracy<sup>86</sup> or are “confused or disingenuous” regarding the complexities of human flourishing.<sup>87</sup> Utilitarians may see progressive property’s indeterminacy as a shortcoming. As pluralists, progressive property scholars conceive of the possibility of an irreducible value conflict as a plus because it better reflects the complexities of the lived experience of moral choice.<sup>88</sup> They maintain that this feature can be understood as a strength rather than a flaw.

Importantly, progressive property does not disregard wealth or welfare. There is plenty of room for those values within a pluralist framework. For instance, access to material wealth may impact a person’s ability to flourish, making neoclassical economic consequences relevant to progressive property.<sup>89</sup> Human flourishing theories may then consider wealth, but those considerations are not determinative: even when wealth is relevant, the right outcome may not be the one that produces the most aggregate welfare.<sup>90</sup>

80 Madhavi Sunder, *IP<sup>3</sup>*, 59 STAN. L. REV. 257, 284 (2006) (quoting MARTHA C. NUSSBAUM, *WOMEN AND HUMAN DEVELOPMENT: THE CAPABILITIES APPROACH* 61 (2001)).

81 Singer, *supra* note 62, at 1062.

82 See Alexander & Peñalver, *supra* note 61, at 146.

83 See ALEXANDER & PEÑALVER, *supra* note 6, at 95–96. Alexander and Peñalver propose that the state should guarantee individuals “a substantial basket of resources.” Alexander & Peñalver, *supra* note 61, at 147.

84 Alexander and Peñalver write that “the extreme need of some in the community trumps the property rights other people hold over their surplus resources.” Alexander & Peñalver, *supra* note 61, at 146.

85 See Alexander, *supra* note 1, at 749, 805.

86 See ALEXANDER & PEÑALVER, *supra* note 6, at 98–99.

87 Alexander, *supra* note 1, at 749.

88 See ALEXANDER & PEÑALVER, *supra* note 6, at 99; Alexander, *supra* note 42, at 1019; Alexander, *supra* note 1, at 749, 805.

89 See ALEXANDER & PEÑALVER, *supra* note 6, at 97.

90 See Peñalver, *supra* note 1, at 868.

Progressive property attempts to preserve the benefits of welfarism without succumbing to its shortfalls.<sup>91</sup> Because welfare matters, commercial entities will not always lose out in a progressive property analysis.<sup>92</sup> Consequently, the theoretical foundations of the progressive property school can be thought of as a form of “weak welfarism”<sup>93</sup> or as a modern, nonutilitarian theory that maintains a concern with a broadly defined conception of welfare.<sup>94</sup>

To understand how progressive property succeeds where neoclassical law and economics fails, we can return to the issue of the LULUs and NIMBYism. A progressive property approach to LULUs could well be more effective than its neoclassical economic counterpart. Recall that progressive property is value pluralist, communitarian, and at times redistributive. A progressive property approach to siting a LULU would thus involve communication, cooperation, and possible redistribution. When deciding where to site a LULU, a progressive property approach would consider the various values at stake related to the project. While a LULU could well reduce the market value of the surrounding property, it could also affect the landowners’ autonomy by limiting their choices regarding how to use their property, their privacy by increasing workers and traffic flow through the neighborhood, and their identities by changing the character of their community and surrounding areas.

Given the other values at stake, monetary compensation alone may—and often does—fall short. Instead of treating the affected owners as individualistic rational actors concerned only with market value, developers could address the broader concerns of the community. Studies show that effective communication can increase public trust.<sup>95</sup> When discussing the potential effects of LULUs, people want more than just having the risks communicated to them; they also want their fears regarding the project to be acknowledged.<sup>96</sup> Consensus building is an important aspect of overcoming NIMBY problems,<sup>97</sup> thus rendering progressive property’s communitarian orientation preferable to treating individuals as self-interested rational actors. Finally, empowering the citizenry to make decisions related to the LULU has also been effective.<sup>98</sup> Giving the impacted landowners some measure of control related to the LULU has a redistributive feel, which is also in tune with progressive property. It is also worth noting that the owners of the land surrounding the proposed LULU are not the only relevant parties. The con-

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91 *See id.* at 828, 867.

92 *See* Alexander, *supra* note 1, at 817.

93 *See* ALEXANDER & PEÑALVER, *supra* note 6, at 97 (quoting MATTHEW D. ADLER & ERIC A. POSNER, *NEW FOUNDATIONS OF COST-BENEFIT ANALYSIS* 25–26 (2006)).

94 *See id.* at 87.

95 *See* Schively, *supra* note 59, at 261.

96 *See id.*

97 *See id.* at 261–62.

98 *See id.* at 261.



cerns and values of the developers and of the greater community should also be considered.

At times progressive property also advocates limiting owners' entitlements—specifically the right to exclude—to recognize important social values, to better serve the community, or to facilitate redistribution. Two paradigmatic progressive property cases have come out of the Supreme Court of New Jersey.<sup>99</sup> The first case, *State v. Shack*,<sup>100</sup> involved aid workers who entered private land to provide health and legal services to the migrant farmworkers residing there. The owner attempted to exercise his right to exclude by asking them to leave and, when the workers refused, charging them with trespass.<sup>101</sup> In holding that no trespass occurred because a property owner has no right to bar access to government services, the court went a step further and stated that the migrant workers themselves were entitled to access. The justices opined that “the employer may not deny the worker his privacy or interfere with his opportunity to live with dignity and to enjoy associations customary among our citizens” because “[t]hese rights are too fundamental to be denied on the basis of an interest in real property and too fragile to be left to the unequal bargaining strength of the parties.”<sup>102</sup> Progressive property scholars read *Shack* as recognizing a property right for the workers: a right to have visitors.<sup>103</sup> By acknowledging an access right, the court arguably recognized the importance of health and justice, acted in the interests of the migrant community, and redistributed the entitlements from the landowner to the farm workers.

In the second case, *Matthews v. Bay Head Improvement Ass'n*,<sup>104</sup> the owner of the beach, which provided services for beachgoers, charged residents a fee for accessing the beach but barred members of the general public. An adjoining township and a would-be beachgoer sued, arguing that the beach should be subject to the public trust doctrine, which gives members of the public the right to enjoy tidal lands.<sup>105</sup> On appeal, the Supreme Court of New Jersey held that insofar as access to private dry land is “essential or reasonably necessary for enjoyment of the ocean,” the public trust doctrine applies.<sup>106</sup> In analyzing *Matthews*, Gregory Alexander explains that the infringement on the owner's right to exclude is limited: the public trust doctrine would not apply in cases where nonowners have reasonable beach access.<sup>107</sup> He understands this conditional incursion on the right to exclude as recognizing the social value of recreation and the reality of human inter-

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99 See Alexander, *supra* note 1, at 802–09; see also Peñalver, *supra* note 1, at 883–84.

100 277 A.2d 369 (N.J. 1971).

101 *Id.* at 370–71.

102 *Id.* at 374–75.

103 See Alexander, *supra* note 1, at 808–09; see also Rosser, *supra* note 34, at 118.

104 471 A.2d 355, 358–59 (N.J. 1984).

105 *Id.* at 358.

106 *Id.* at 365.

107 See Alexander, *supra* note 1, at 807; see also Rosser, *supra* note 34, at 117.

dependency.<sup>108</sup> Moreover, it serves the interests of the citizens of New Jersey and gives them an access right where none had previously existed.

In sum, progressive property recognizes that ownership is often bound up with human flourishing. As such, when deciding property disputes, progressive property advocates consider the diverse values at stake, the interests of the impacted communities, and the distributive implications. In the context of LULUs, progressive property means a collaborative, consensus-building process. For a judge deciding a dispute over title or access to land, it would mean accounting for the values at stake beyond wealth, furthering the communal good, and enforcing a fair distribution of property entitlements.

### B. *What Is Genetic Ownership?*

Neoclassical economic theory has been the dominant lens for understanding property for the last five decades.<sup>109</sup> Recently, progressive property scholars have rejected this approach in favor of a value pluralist, communitarian, and redistributive theoretical approach. While a few scholars have briefly considered how progressive property might apply to intellectual property (mainly patents and copyright),<sup>110</sup> most of progressive property scholarship has dealt with land.<sup>111</sup> To truly establish itself as a school of property thought and not merely a way of understanding land use, progressive property must apply to broader contexts. Genetic ownership and its newly emerging entitlements offer precisely this opportunity. This Article seeks to test

108 See Alexander, *supra* note 1, at 805–07; see also Rosser, *supra* note 34, at 117.

109 See *supra* note 1 and accompanying text.

110 See, e.g., ALEXANDER & PEÑALVER, *supra* note 6, at 200–03 (applying Aristotelian property theory to the field of intellectual property generally); Alexander, *supra* note 1, at 810–18 (applying social obligation theory to copyright and intellectual property); Laura R. Ford, *Patenting the Social: Alice, Abstraction, and Functionalism in Software Patent Claims*, 14 CARDOZO PUB. L. POL'Y & ETHICS J. 259, 294 (2016) (applying Aristotelian theories to patents related to social networks); David W. Opderbeck, *Beyond Bits, Memes and Utility Machines: A Theology of Intellectual Property as Social Relations*, 10 U. ST. THOMAS L.J. 738 (2013) (calling for a theological grounding for social theories of intellectual property). Additionally, in her path-breaking article *IP<sup>3</sup>*, Madhavi Sunder challenged IP scholars to go beyond the law and economics frame and applied Nussbaum's and Sen's capabilities approach to intellectual property. See generally Sunder, *supra* note 80. However, Sunder's article predates much of the progressive property movement. See David Fagundes, *Property Rhetoric and the Public Domain*, 94 MINN. L. REV. 652, 702 (2010) (arguing that scholars seek to differentiate copyright from physical property because they wrongly understand the latter to be dominated by a Demsetzian approach to ownership).

Importantly, this analysis is confined to “progressive property,” a school of thought within property law scholarship. Scholars have used the capability approach, which forms the basis for progressive property, in multiple areas, including certain aspects of health care. Most notably, Jennifer Prah Ruger has advocated a “health capability paradigm” as the basis for health care reform. JENNIFER PRAH RUGER, *HEALTH AND SOCIAL JUSTICE* 80 (2010).

111 The unique complexity of land is a central component to Peñalver's analysis in *Land Virtues*. See Peñalver, *supra* note 1, at 828–32. Moreover, he explicitly limits his analysis to land use. *Id.* at 823.

progressive property's adaptability by applying it to contemporary debates surrounding the ownership of genetic data.

In lay terms, genes are the units of heredity,<sup>112</sup> the biological mechanisms that allow parents to pass various traits down to their offspring. In more technical terms, genes are molecules of deoxyribonucleic acid (DNA) that store genetic information, located (primarily) in the chromosomes found in a cell's nucleus.<sup>113</sup> Genes are made up of combinations of four nucleotide bases—adenine (A), guanine (G), cytosine (C), and thymine (T)—the letters in the genetic alphabet.<sup>114</sup> The combinations of those As, Gs, Cs, and Ts dictate the way in which our genes “express” themselves.<sup>115</sup>

Genetic data is simultaneously personal and communal. It can communicate sensitive information about an individual, including a person's ancestry, familial relationships, presence at a crime scene, medical risk, and perhaps even behavioral tendencies.<sup>116</sup> Yet at the very same time, human beings are 99.9% genetically similar,<sup>117</sup> with even greater levels of homogeneity among family members.<sup>118</sup>

Genetic data is distinct from the genetic material from which it is derived. Genetic information is the intangible information about a person's genetic makeup.<sup>119</sup> By contrast, a genetic material is a DNA sample, the physical molecules of DNA.<sup>120</sup> Examples of genetic material include blood, tissue, and saliva. Some have argued in favor of understanding DNA samples

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112 Richard A. Spinello, *Property Rights in Genetic Information*, 6 ETHICS & INFO. TECH. 29, 29 (2004).

113 *Id.*; Molly A. Holman & Stephen R. Munzer, *Intellectual Property Rights in Genes and Gene Fragments: A Registration Solution for Expressed Sequence Tags*, 85 IOWA L. REV. 735, 742–43 (2000).

114 Holman & Munzer, *supra* note 113, at 742; Spinello, *supra* note 112, at 29.

115 Holman & Munzer, *supra* note 113, at 742–43.

116 See Merryk Ekberg, *Governing the Risks Emerging from the Non-Medical Uses of Genetic Testing*, 3 AUSTL. J. EMERGING TECH. & SOC'Y 1, 2 (2005); Anelka M. Phillips, *Only a Click Away—DTC Genetics for Ancestry, Health, Love . . . and More: A View of the Business and Regulatory Landscape*, 8 APPLIED & TRANSLATIONAL GENOMICS 16, 18–19 (2016); Mark A. Rothstein, *The Use of Genetic Information for Nonmedical Purposes*, 9 J.L. & HEALTH 109, 110–18 (1994–1995).

117 See *Frequently Asked Questions About Genetic and Genomic Science*, NIH NAT'L HUM. GENOME RES. INST., <https://www.genome.gov/19016904/faq-about-genetic-and-genomic-science/> (last updated Mar. 2, 2016); see also President William J. Clinton, Remarks on Completion of the First Survey of the Human Genome Project 1501 (June 26, 2000), <https://www.gpo.gov/fdsys/pkg/WCPD-2000-07-03/pdf/WCPD-2000-07-03-Pg1499.pdf> [hereinafter Clinton Remarks].

118 For a thoughtful discussion of how to allocate shared ownership interests in genetic data, see Ram, *supra* note 14, at 909.

119 See Spinello, *supra* note 112, at 29 (broadly defining genetic information as “information about genes, gene products, or one's inherited characteristics that is derived from a genetic test or a person's DNA sample”).

120 *Id.* (defining genetic material as “any human biological specimen such as human tissue or blood from which DNA can be extracted”).

or other bodily derivatives in property terms.<sup>121</sup> Yet as a practical matter, it is hard to keep track of all the genetic material that we discard. Every time we touch a doorknob, drink from a glass, or shake a person's hand, we leave some trace of our genetic material. It seems strange to say that we own all of that. Moreover, once a researcher or a company has access to a person's genetic information and puts that information in a database, the physical sample is far less important, as the information itself can be sold and mined. Hence, this Article focuses on genetic *data* because as an object of ownership it is both more manageable and more valuable. Yet given the close relationship between genetic data and the biospecimens from which the data came, this distinction is not always clear or maintainable.

## 1. Genetic Ownership Controversies

Who should own genetic data? A researcher who develops an immortal cell line from a human cancer cell might assert that she should own the result because of her scientific efforts. By contrast, the provider of the cancer cell could likewise claim ownership because the cell line was made possible by her unique genetic information. Different kinds of entities have staked ownership claims to genetic information. The biotech industry holds patents related to genetic and genomic research. Yet that has not stopped people who contribute DNA from claiming that the information in their genetic code rightfully belongs to them, even absent a legally recognized property interest. Deciding who owns genetic information has been an ongoing controversy for over two decades. There have been several high-profile genetic ownership disputes, which have generated litigation and media attention. Here I outline some of the key genetic ownership controversies to provide background for understanding the bioethical debates described in Part II. These disputes demonstrate the hotly contested question of who owns genetic data.

Historically, genetic ownership rights have been lopsided. The biotech industry has enjoyed longstanding legally recognized ownership rights related to genetic data and its derivatives. Specifically, researchers studying human genetics may patent and commercialize their findings.<sup>122</sup> Patents grant inventors exclusive rights to make, use, and sell their inventions for a twenty-year term in exchange for making their innovations public.<sup>123</sup> Given the broad scope of patentable subject matter,<sup>124</sup> individuals and institutions may hold patents on a wide variety of items related to genetic research,

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121 See Muireann Quigley, *Property and the Body: Applying Honoré*, 33 J. MED. ETHICS 631, 631 (2007); Leigh M. Harlan, Note, *When Privacy Fails: Invoking a Property Paradigm to Mandate the Destruction of DNA Samples*, 54 DUKE L.J. 179, 200–01 (2004).

122 The U.S. Constitution gives Congress the power “[t]o promote the Progress of Science and useful Arts, by securing for limited Times to Authors and Inventors the exclusive Right to their respective Writings and Discoveries.” U.S. CONST. art. I, § 8, cl. 8.

123 See generally WASHINGTON, *supra* note 11, at 17–18.

124 See *Diamond v. Chakrabarty*, 447 U.S. 303, 309 (1980) (quoting S. REP. NO. 82-1979, at 5 (1952)) (citing H.R. REP. NO. 82-1923, at 6 (1952)).

including synthetic DNA, genetic tests, and cell lines. However, in 2013, the Supreme Court invalidated patents on isolated genes on the theory that genes are products of nature and not human innovations.<sup>125</sup>

Biotech companies may also hold proprietary interests in their databases.<sup>126</sup> An extensive and reliable database of genetic information is essential to both treatment and research. Even massive amounts of genetic data are useless if the scientific and medical communities have no means of interpreting them. When a testing company collects genetic data from large numbers of people, it gains the ability to link genetic variations with health outcomes, family medical histories, and other factors.<sup>127</sup> Those actions, in turn, improve the quality of the database. As a result, genetic testing companies, like Myriad, jealously guard their databases.<sup>128</sup>

By contrast, individuals who contribute DNA have traditionally had no legally recognized property interests in their genetic data. In the well-known property chestnut, *Moore v. Regents of the University of California*, researchers—including the doctor who was treating John Moore—created and patented a cell line using tissue from Moore’s spleen.<sup>129</sup> Moore claimed a violation of his genetic ownership rights, alleging that the defendants unlawfully converted his cells by researching and commercializing them without his consent.<sup>130</sup>

Despite holding that Moore might have valid claims for lack of informed consent and/or breach of fiduciary duty, the Supreme Court of California denied his genetic ownership claim.<sup>131</sup> It reasoned that there could be no conversion and, by consequence, no ability to share in the immense profits generated by the cell line that bore his name,<sup>132</sup> because Moore lacked a cognizable property interest in his spleen once it left his body.<sup>133</sup> While damages are the typical remedy, succeeding on his conversion claim might have also entitled Moore to replevin (i.e., recovery of the converted property).<sup>134</sup> He could have stopped the research and had his cells—and possibly the resulting cell line—returned to him. Importantly, *Moore* does not stand for the proposition that the innovations made using Moore’s genetic infor-

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125 See *Ass’n for Molecular Pathology v. Myriad Genetics, Inc.*, 133 S. Ct. 2107, 2116–19 (2013).

126 See generally Conley et al., *supra* note 21.

127 See *id.* at 599.

128 See *id.* at 614–15.

129 793 P.2d 479, 480 (Cal. 1990). For a detailed and colorful account of *Moore*, see WASHINGTON, *supra* note 11, at 36–43.

130 *Moore*, 793 P.2d at 480.

131 See *id.*

132 See Radhika Rao, *Genes and Spleens: Property, Contract, or Privacy Rights in the Human Body?*, 35 J.L. MED. & ETHICS 371, 372 (2007).

133 *Moore*, 793 P.2d at 488–89.

134 See DAN B. DOBBS ET AL., *THE LAW OF TORTS* § 73 (2d ed.), Westlaw (database updated June 2017).

mation were not property, just that Moore himself had no property rights in that information.<sup>135</sup>

Perhaps the court in *Moore* did not feel compelled to recognize ownership rights because Moore could potentially recover on other legal theories.<sup>136</sup> Yet while Moore might have had breach of fiduciary duty or lack of informed consent claims, no such legal protection exists outside of the clinical setting. In *Greenberg v. Miami Children's Hospital*, a group of families of children with Canavan disease recruited a researcher to study the condition and supplied him with biospecimens and pedigrees of themselves and several other Canavan-affected families.<sup>137</sup> After the researcher successfully identified the genetic variation linked to the disease, Miami Children's Hospital patented the isolated gene and its related applications. The plaintiffs sued under a number of theories, including conversion. Citing *Moore*, the federal district court dismissed their genetic ownership claim.<sup>138</sup> However, the *Greenberg* court went one step further. It found because the plaintiffs were donors, not patients, the researcher owed them no fiduciary duties.<sup>139</sup> Without fiduciary duties, they had no claims for breach of fiduciary duty or for lack of informed consent.<sup>140</sup> The only claim to survive was unjust enrichment.

Despite *Moore* and *Greenberg*, courts have appeared more open to conversion claims recently. Recall that in both *Peerenboom* and in *Cole*, claims related to the conversion of genetic data survived motions to dismiss.<sup>141</sup>

Yet conversion claims are not the only legal actions that implicate genetic ownership. Although not including an explicit property claim, another legal controversy dealing with control of genetic data occurred in the early 2000s when members of the Havasupai tribe sued genetic researchers at Arizona State University (ASU) and the University of Arizona (UA) for using their donated biological specimens to conduct research on schizophrenia, inbreeding, and population migration.<sup>142</sup> The tribe made particularly desirable research subjects because they were a relatively isolated, and therefore relatively genetically homogenous, population.<sup>143</sup> While they agreed to

135 See Rao, *supra* note 132, at 372.

136 See Kara H. Ching, Note, *Indigenous Self-Determination in an Age of Genetic Patenting: Recognizing an Emerging Human Rights Norm*, 66 FORDHAM L. REV. 687, 707 (1997).

137 *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1066 (S.D. Fla. 2003). For a lively retelling of *Greenberg*, see WASHINGTON, *supra* note 11, at 193–96.

138 See *Greenberg*, 264 F. Supp. 2d at 1070–71.

139 See *id.* at 1071–72.

140 See *id.*

141 See *supra* notes 25–30 and accompanying text.

142 See Lori Andrews, *Havasupai Tribe Sues Genetic Researchers*, 31 PRIVACY J. 5, 5–6 (2005).

143 See Debra Harry, *Indigenous Peoples and Gene Disputes*, 84 CHI.-KENT L. REV. 147, 150–51, 182–84 (2009); LorrieAnn Santos, *Genetic Research in Native Communities*, 2 PROGRESS COMMUNITY HEALTH PARTNERSHIPS 321, 321 (2008); see also WASHINGTON, *supra* note 11, at 289.

research regarding diabetes, the litigants asserted that if they had known about the additional research, they would not have consented.<sup>144</sup> (Notably, the district court that heard one of the cases dismissed the claim for lack of informed consent.)<sup>145</sup> However, the parties ultimately settled with ASU, agreeing to pay \$700,000, return remaining blood samples and research documents, terminate any approvals for new or ongoing research on the samples, and provide a list of all the entities that received samples.<sup>146</sup> Although the Havasupai did not frame their arguments in property terms, the rights they sought—to control and to possess—fall within the property bundle.

In 2009, a genetic ownership dispute took place in Texas over 5.3 million blood spots that the state had been collecting without parental consent for its newborn screening program.<sup>147</sup> Parents sued when they discovered that the state had maintained the unconsented samples for research.<sup>148</sup> Again while not explicitly about property, the case involved rights frequently understood as components of the property bundle. Clearly, the parents wanted to *control* what happened to their children's DNA, and, as part of the settlement agreement, Texas agreed to *destroy* the blood spots.<sup>149</sup>

Perhaps the most familiar genetic ownership controversy is the story of Henrietta Lacks, the source of the well-known HeLa cell line. Lacks was a poor, black woman with a horrific case of cervical cancer.<sup>150</sup> In the course of her treatment, her physicians took some of her cancerous cells and used them to create the first immortal cell line. Even though extracting cells without the patient's consent was acceptable by the legal and ethical standards of the time, the descendants of Henrietta Lacks felt both she and they had been exploited.<sup>151</sup> Like the Havasupai and the Texas blood spot cases, the Lacks have not asserted property claims. However, the Lacks frequently stated that at a minimum they should share in the profits made from HeLa cells and

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144 See Andrews, *supra* note 142, at 5.

145 See *Tilousi v. Ariz. State Univ.*, No. 04-CV-1290, 2005 WL 6199562, at \*2 (D. Ariz. Mar. 3, 2005) (finding that (1) tribe members had agreed to having their blood drawn and to broad use and that (2) the regulations governing human subject research lack a private right of action).

146 See Jorge L. Contreras, *Genetic Property*, 105 GEO. L.J. 1, 23 (2016); Katherine Drabiak-Syed, *Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignitary Harms as Legitimate Risks Warranting Integration into Research Practice*, 6 J. HEALTH & BIOMEDICAL L. 175, 195 (2010); Amy Harmon, *Indian Tribe Wins Fight to Limit Research of Its DNA*, N.Y. TIMES (Apr. 21, 2010), <http://www.nytimes.com/2010/04/22/us/22dna.html?pagewanted=all>.

147 See Contreras, *supra* note 146, at 21.

148 *Id.*

149 *Id.* at 21–22.

150 See generally REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* (2010).

151 *Id.* at 5, 168–69. Lacks's daughter wrote that her mother was “[r]obbed of her cells” and “[r]obbed [of] [s]elf.” *Id.* at 196. Her husband stated, “As far as them selling my wife’s cells without my knowledge and making a profit—I don’t like that at all. They are exploiting both of us. If they’ve been making a profit they should give me some kind of restitution.” WASHINGTON, *supra* note 11, at 33 (quoting Harriet Washington, *Henrietta Lacks: An Unsung Hero*, EMERGE MAG., Oct. 1994, at 29).

from the research they enable.<sup>152</sup> They are thus articulating their perceived right to commercialize the family's genetic data.

In 2015, direct-to-consumer genetic testing company 23andMe announced that it had signed the first of approximately ten multimillion-dollar deals to sell access to its customer databases to pharmaceutical and biotech companies.<sup>153</sup> This agreement came as no real surprise, as commentators had long predicted that the company's true purpose was not to sell affordable genetic tests but to collect potentially lucrative data.<sup>154</sup> Importantly, approximately 600,000 of 23andMe's 800,000 customers formally consented to have the company share their genetic information with third parties.<sup>155</sup> Those individuals are therefore considered donors.<sup>156</sup> However, obtaining proper consent for the donations has not shielded the company from criticism. The company sold the data that it got for free, thus profiting from the altruistic actions of its customers. Furthermore, one article on the new business venture warned consumers, "[i]f you're paying a cut rate to have 23andMe sequence your DNA, you are 23andMe's product."<sup>157</sup> Even more recently, 23andMe announced that it had raised \$250 million dollars in start-up money for drug development, with one article titled "23andMe Raises Another \$250 Million—and Wants to Use Your Genetic Data to Make Drugs."<sup>158</sup> The specter of ownership and property again emerges here, yet related to the right *not* to commercialize one's genetic data (i.e., the desire to donate, perhaps for altruistic reasons), as well as fears of commodification in the form of the admonition that 23andMe's customers are also its products.

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152 See generally SKLOOT, *supra* note 150; WASHINGTON, *supra* note 11, at 168, 195, 197, 223, 233, 235, 247, 267.

153 See Matthew Herper, *Surprise! With \$60 Million Dollar Genentech Deal, 23andMe Has a Business Plan*, FORBES (Jan. 6, 2015), <http://www.forbes.com/sites/matthewherper/2015/01/06/surprise-with-60-million-genentech-deal-23andme-has-a-business-plan/>.

154 See Charles Seife, *23andMe Is Terrifying, But Not for the Reasons the FDA Thinks*, SCI. AM. (Nov. 27, 2013), <http://www.scientificamerican.com/article/23andme-is-terrifying-but-not-for-reasons-fda/>; see also David P. Hamilton, *23andMe: Will the Personal-Genomics Company Need Big Pharma to Make Money?*, VENTUREBEAT (Nov. 19, 2007), <http://venturebeat.com/2007/11/19/23andme-will-the-personal-genomics-company-need-big-pharma-to-make-money/>.

155 See Herper, *supra* note 153. According to the company, eighty percent of its customers consent to sharing their genetic data. See Lydia Ramsey, *23andMe CEO Defends Practice of Sharing Genetic Info with Pharma Companies*, YAHOO FIN. (July 7, 2015), <http://finance.yahoo.com/news/23andme-ceo-defends-practice-sharing-164857907.html>.

156 See *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1071 (S.D. Fla. 2003) (explaining that for donors of biological material "the voluntary nature of their submissions warrants different treatment" than research subjects).

157 See Sarah Zhang, *Of Course 23andMe's Plan Has Been to Sell Your Genetic Data All Along*, GIZMODO (Jan. 6, 2015), <http://gizmodo.com/of-course-23andmes-business-plan-has-been-to-sell-your-1677810999>.

158 Sy Mukherjee, *23andMe Raises Another \$250 Million—and Wants to Use Your Genetic Data to Make Drugs*, FORTUNE (Sept. 12, 2017), <http://fortune.com/2017/09/12/23andme-250-million-sequoia-drugs/>.



These stories exemplify the current controversies surrounding genetic ownership. Despite the absence of legally recognized ownership interests in *Moore* and *Greenberg*, individuals have continued to assert rights typically found within the property bundle regarding both their genetic data and their genetic material—mainly the right to control, the right to possess, the right to destroy, the right to commercialize, and the right to give away. The following subsection takes a closer look at the law of genetic ownership and its accompanying legal entitlements.

## 2. Genetic Ownership Entitlements

Despite the absence of widespread legally recognized property rights for individuals in their genetic data, people seem to presume that they own their DNA. Recall President Obama's intuition that a person owns her genetic data.<sup>159</sup> In fact, some states have explicitly recognized a person's DNA as her property. To date, five states—Alaska, Colorado, Florida, Georgia, and Louisiana—have deemed genetic data the property of the person from whom it came.<sup>160</sup> And more states may follow suit. Within the past six years, legislators in South Dakota, Alabama, Massachusetts, and Texas have introduced bills that would make a person's genetic information or DNA sample her property.<sup>161</sup>

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159 See *supra* notes 9–10 and accompanying text.

160 See ALASKA STAT. ANN. § 18.13.010(a)(2) (West 2017) (providing that both “a DNA sample” and “the results of DNA analysis” are “the exclusive property of the person sampled or analyzed”); COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West 2017) (stating that “[g]enetic information is the unique property of the individual to whom the information pertains”); FLA. STAT. ANN. § 760.40(2)(a) (West 2017) (proclaiming that the results of DNA analysis are “the exclusive property of the person tested”); GA. CODE ANN. § 33-54-1(1) (West 2017) (stating that “[g]enetic information is the unique property of the individual tested”); LA. R.S. § 22:1023(E) (West 2017) (providing that in the context of insurance “[a]n insured's or enrollee's genetic information is the property of the insured or enrollee”).

161 In 2012, the South Dakota legislature introduced a bill that would designate genetic information “the sole property of the person from whom it was derived.” H.B. 1260, 2012 Legis. Assemb., 87th Sess. (S.D. 2012), <http://legis.sd.gov/docs/legsession/2012/Bills/HB1260P.pdf>. The Alabama bill would have made genetic information “personal property,” and the legislation proposed in both Massachusetts and Vermont would have declared genetic information the “exclusive property” of the individual and “real property” as a matter of law. See Jennifer K. Wagner & Dan Vorhaus, *On Genetic Rights and States: A Look at South Dakota and Around the U.S.*, GENOMICS L. REP. (Mar. 20, 2012), <http://www.genomicslawreport.com/index.php/2012/03/20/on-genetic-rights-and-states-a-look-at-south-dakota-and-around-the-u-s/>. During Texas's last gubernatorial election, now-Governor Greg Abbott expressed his support for giving individuals a cognizable property interest in their genetic information. Citing *Moore* and the story of the Lacks family, Governor Abbott urged the legislators to “pass legislation that clearly recognizes an individual's property right in his or her DNA.” See Greg Abbott, *Recognize a Property Right in One's Own DNA*, GREGABBOTT.COM (2013), <http://townhall254.gregabbott.com/topic/recognize-a-property-right-in-ones-own-dna/>. Proposed Texas bills would have given an individual “an exclusive property right” in a sample of her DNA. H.B. 1220, 2015 Leg., 84(R) Sess. (Tex.

Moreover, policies from genetic testing companies also imply the existence of property rights. 23andMe's terms of service include a "Waiver of Property Rights,"<sup>162</sup> thereby indicating the potential presence of ownership interests. Another direct-to-consumer genetic testing company, AncestryDNA, explicitly acknowledges the existence of property interests, stating that "[y]ou always maintain ownership of your DNA and DNA data"<sup>163</sup> (with the proviso that the individual has no rights in the research or commercial products developed from her DNA) and granting the testing company a perpetual, royalty-free license to use that information.<sup>164</sup>

The current law of genetic ownership is a hodgepodge of statutory, intellectual property, tort, and contract law, as well as research regulations. As such, before developing a theory of genetic ownership, we must resolve which property rights comprise the genetic ownership bundle. While there are some clear legal rules, genetic ownership rights are also being implied from other doctrines and negotiated ad hoc.

As a legal matter, property is frequently thought of as a set of independent entitlements, or more colloquially, as a "bundle of sticks."<sup>165</sup> Thus, any meaningful discussion of genetic ownership requires outlining the entitlements at stake. Patent holders have clearly defined genetic ownership rights. In particular, they have the right to prevent others from making, using, or selling the patented innovation over the course of the patent term. Owners of proprietary databases can likewise restrict access and use. However, personal genetic ownership rights are much less clearly defined. With respect to a person's rights in her DNA, this Article identifies three limited property entitlements that make up the personal genetic ownership bundle: (1) a right to exclude, (2) a right to access, and (3) a right to commercialize.

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2015); H.B. 3582, 2015 Leg., 84(R) Sess. (Tex. 2015); S.B. 475, 2015 Leg., 84(R) Sess. (Tex. 2015).

162 *Terms of Service*, 23ANDME, <https://www.23andme.com/about/tos/> (last visited Jan. 18, 2018).

163 *Privacy Statement*, ANCESTRY, <http://www.ancestry.com/cs/legal/privacystatement#Intro> (last visited Jan. 18, 2018).

164 *See Terms and Conditions*, ANCESTRY, <https://www.ancestry.com/dna/en/legal/us/termsAndConditions#Term3> (last visited Jan. 18, 2018).

165 *See, e.g.*, HENRY SIDGWICK, *ELEMENTS OF POLITICS* 66 (1891) (identifying three interests in the property bundle: the right to exclusive use, the right to destroy, and the right to alienate); Anthony M. Honoré, *Ownership*, in *OXFORD ESSAYS IN JURISPRUDENCE* 107, 112–28 (A.G. Guest ed., 1961) (describing eleven "standard incidents of ownership": the right to possess, the right to use, the right to manage, the right to income from the object of ownership, the right to capital (including the right to alienate, as well as the rights "to consume, waste, or destroy"), the right to security over time, the right of transmissibility, the absence of term, the duty to avoid harm, the liability for the execution of debts, and residuary (meaning that when limited interests expire, such as those of a lessee, the property interest reverts back to the owner)); *see also* ALEXANDER & PEÑALVER, *supra* note 6, at 4.

a. Right to Exclude

Individuals enjoy a limited right to exclude pertaining to their genetic data. Take the doctrine of informed consent, which applies both to treatment and to research. Physicians must disclose their research interests when treating patients.<sup>166</sup> Outside the treatment relationship, the Common Rule requires consent for human subject research, including research on identifiable biospecimens.<sup>167</sup> Internationally, the Convention on Biological Diversity gives states rights concerning access to their “genetic resources” and provides that any access to those resources must be done with informed consent.<sup>168</sup>

In a recent article, Jorge Contreras argued that informed consent creates a de facto property regime for genetic data. According to Contreras, requiring consent for genetic research mimics Blackstonian property by giving potential research subjects a right to exclude, a right to destroy, an ability to consent to some studies but not others (i.e., divisibility), deadhand control, and a right to alienate with respect to their genetic data.<sup>169</sup> As evidence of this property-like control, Contreras describes the Texas blood spot controversy<sup>170</sup> and the case of the Havasupai,<sup>171</sup> as those disputes ended with the research being stopped and the samples being either destroyed or returned.

It is worth noting, however, that despite superficial similarities, informed consent differs from property in at least one significant way: remedies. To be sure, not all property interests are protected by “property rules.”<sup>172</sup> However, while a plaintiff who succeeds in a claim for conversion may be entitled to the return of her property, an action for informed consent can only result in damages.<sup>173</sup> The destruction of the blood spots in Texas and the return of the Havasupai’s samples were the result of settlement agreements, not court ordered relief. Had the litigants gone to trial, the only available remedy would have been monetary. Thus, the rights to exclude and destroy exercised in those cases were products of contract law (settlement) rather than informed consent. Although litigants have successfully halted research on their genetic data through settlement negotiations, once valid consent is obtained, the sources of genetic material have little say in what happens to

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166 See *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 506 (Cal. 1990); see also COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS’N, CODE OF MEDICAL ETHICS § 2.08 (2008–2009 ed.).

167 See General Requirements for Informed Consent, 45 C.F.R. § 46.116 (2014).

168 Convention on Biological Diversity art. 15, June 5, 1992, 31 I.L.M. 818.

169 Contreras, *supra* note 146, at 20–37.

170 *Id.* at 21–22.

171 *Id.* at 22–23.

172 Property rules require voluntary transactions between buyers and sellers. See Guido Calabresi & A. Douglas Melamed, *Property Rules, Liability Rules, and Inalienability: One View of the Cathedral*, 85 HARV. L. REV. 1089, 1092 (1972).

173 See BETH HOLLIDAY, 49 CAUSES OF ACTION 2d 573 (2011) (describing the remedies for informed consent, which consist only of damages).

their tissues and data.<sup>174</sup> Hence, an informed consent–based right to exclude is limited.

Beyond informed consent, *Peerenboom* and *Cole*, described in the Introduction, could demonstrate a newfound willingness of courts to recognize an individual's right to exclude with respect to genetic information. Both cases reference the property tort of conversion—the very claim rejected by the *Moore* and *Greenberg* courts—as the basis for legal protection. The right to exclude is at the very heart of actions for conversion. As a result, the outcomes of these cases could result in more robust common law (conversion) and statutory (Alaska's Privacy Act) rights to exclude.

The Lacks family also arguably negotiated a right to exclude with NIH regarding the distribution of the HeLa genome. Pursuant to an agreement between the family and the agency, two members of the Lacks family serve on the board that determines whether to grant research access to the HeLa genome and any publications resulting from that research will acknowledge the Lacks family.<sup>175</sup> Thus, the Lacks now enjoy a limited right to exclude with respect to the HeLa genome.

#### b. Right to Access

Individuals also enjoy genetic access rights. Recent amendments to the governing regulations for HIPAA and the Clinical Laboratory Improvement Amendments (CLIA) grant a right to access. Previously, CLIA labs were legally unable to provide individuals with direct access to the results of their lab tests in some states.<sup>176</sup> Following the amendments, patients and subjects participating in research conducted by covered entities can now independently access their results pursuant to HIPAA's Privacy Rule.<sup>177</sup> The latest complaint against Myriad asserts that HIPAA gives individuals unfettered access to their genetic information regardless of purpose.<sup>178</sup> Moreover, this right is exclusive. Only the individual herself or the people and institutions involved in the testing can access the results. Everyone else needs permission.

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174 See 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, 98 (2017).

175 See Ram, *supra* note 14, at 875.

176 CLIA Program and HIPAA Privacy Rule; Patients' Access to Test Reports, 79 Fed. Reg. 7290 (Feb. 6, 2014) (codified at 42 C.F.R. pt. 493 and 45 C.F.R. pt. 164 (2014)) (stating that "[i]n states that do not allow individuals to access their own test results, the individuals must receive their test results through their health care providers").

177 See 45 C.F.R. § 164.524(a)(1), (a)(2)(iv).

178 See Health Information Privacy Complaint, *supra* note 17, at 5 ("Patients have a right to access their genetic information, regardless of the purpose for which they seek it, under the HIPAA Privacy Rule.").

c. Right to Commercialize

Lastly, individuals are finding ways to commercialize their genetic data. Sharon and Patrick Terry formed the research advocacy organization, PXE International, after their two children were diagnosed with pseudoxanthoma elasticum (PXE) in 1994.<sup>179</sup> Unlike the *Greenberg* plaintiffs, before the Terrys approached researchers with the extensive blood and tissue banks they had amassed, they incorporated themselves.<sup>180</sup> They consented to offering access to this valuable resource only if researchers agreed to share their profits.<sup>181</sup> Thus, the Terrys used contract law to negotiate their genetic ownership interests.<sup>182</sup>

Several genetic testing companies are considering offering their clients commercial interests. As of 2016, genetic testing company Genos will compensate customers for sharing their genomic data with researchers, describing themselves as “an app store for data.”<sup>183</sup> The executive chairman explains: “The model is that you own your genome. . . . When a researcher is paying to access a genome, they are not paying us directly, they are paying the individual, and we are taking a percentage in order to maintain a secure website.”<sup>184</sup> Similarly, the CEO of the genetic testing company Invitae indicated that once it accumulated a large enough consumer database, it would sell access to third parties, allowing the contributors of DNA to share in the resulting revenues.<sup>185</sup> Likewise, DNAsimple pays people \$50 for an initial saliva sample and another \$50 for additional samples.<sup>186</sup>

The updates to the Common Rule may give individuals even more opportunities to bargain for commercial interests in their genetic data. One change requires researchers, as part of the informed consent process, to tell research subjects whether the research from their biospecimens will be used for commercial purposes and if they will share in the resulting profits.<sup>187</sup>

179 Rao, *supra* note 132, at 375.

180 *See id.*

181 *See id.*

182 *See id.* The relationship between property and contract law is often underappreciated. To start, people frequently contract for ownership rights. After all, leases and title agreements are contracts. In the context of genetic ownership, Russell Korobkin has argued that legal scholars have misconstrued *Moore* as a property law case when it is better understood as a contract law case articulating a “no compensation” default rule for donated tissues. *See* Russell Korobkin, “No Compensation” or “Pro Compensation”: *Moore v. Regents and Default Rules for Human Tissue Donations*, 40 J. HEALTH L. 1 (2007).

183 Julia Karow, *Consumer Genomics Startup Genos Research Plans to Let Customers Explore, Share Their Data*, GENOMEWEB (June 13, 2016), <https://www.genomeweb.com/molecular-diagnostics/consumer-genomics-startup-genos-research-plans-let-customers-explore-share>.

184 *Id.*

185 *See* Alex Lash, *What’s Your DNA Worth? The Scramble to Cash in on the Genome*, XCONOMY (Oct. 20, 2015), <http://www.xconomy.com/national/2015/10/20/whats-your-dna-worth-the-scramble-to-cash-in-on-the-genome/>.

186 Daley & Cranley, *supra* note 16.

187 *See* Federal Policy for the Protection of Human Subjects, 82 Fed. Reg. 7266 (Jan. 19, 2017) (to be codified at 45 C.F.R. pt. 46).

People might not be aware there was the opportunity for commercial gain in the first place. Thus, the new disclosure requirements could inform people who are currently unaware that their biospecimens have potential commercial value, thereby giving them the opportunity to negotiate a profit-sharing arrangement.<sup>188</sup>

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Two exciting conversations about property are currently taking place. First, progressive property scholars are challenging the hegemony of neoclassical law and economics as property's dominant theoretical lens. Second, bioethicists are grappling with the implications of granting entitlements in genetic data. This Article seeks to combine these dialogues to test whether progressive property would provide a useful lens for understanding genetic ownership and, in so doing, prove this new school of thought's utility beyond land use. Interestingly enough, as with real property, current genetic ownership debates have also been entrenched in neoclassical economic theory.

## II. HEGEMONY OF NEOCLASSICAL LAW AND ECONOMICS IN GENETIC OWNERSHIP

The debates surrounding genetic ownership described in Part I deal with the extent to which individuals, researchers, and biotech companies should be able to exercise their respective entitlements. As with physical property, discussions of actual, implied, or potential genetic ownership rights have been steeped in the language of neoclassical economic theory. Adopting a familiar trope within property theory, this Article classifies genetic ownership debates as either comedies or tragedies.<sup>189</sup> It uses the terms "comedy" and "tragedy" broadly to mean whether a given entitlement will lead to either positive or undesirable consequences. Yet comedic or tragic, many debates surrounding genetic ownership are framed in terms of incentives, efficiency, costs, benefits, and market value. Through these discussions, Part II establishes that the dominance of neoclassical economic theory in property law is not confined to land but rather is also the central narrative in the legal and theoretical discussions surrounding the ownership of genetic data.

### A. *Genetic Comedies*

One reaction to the genetic ownership rights described in Part I regards this trend as creating positive incentives for researchers, biotech companies,

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188 Jessica L. Roberts, *Negotiating Commercial Interests in Biospecimens*, 45 J.L. MED. & ETHICS 138, 140 (2017).

189 Interestingly, literature equates "tragedy" with "inefficiency." The paradigmatic property tragedy of course is the tragedy of the commons: the theory that too much public ownership leads to overuse. See Garrett Hardin, *The Tragedy of the Commons*, 162 SCIENCE 1243 (1968); Carol Rose, *The Comedy of the Commons: Custom, Commerce, and Inherently Public Property*, 53 U. CHI. L. REV. 711, 723 (1986) (defining comedic "in the classical sense of a story with a happy outcome").

or individuals. These viewpoints are genetic comedies—arguments in favor of recognizing entitlements in genetic data—in that they tell an optimistic story that genetic ownership rights maximize the value of genetic information. They also fit methodically into the neoclassical economic tradition, since they are based on rational choice theory and use cost-benefit analysis as their major analytical tool. As these arguments go, genetic ownership rights create incentives for rational actors to engage in value-generating genetic research, making genetic ownership desirable.

### 1. Research Incentives

The very nature of intellectual property is incentive-based. The Patent and Copyright Clause states that the purpose of intellectual property is “[t]o promote the Progress of Science and useful Arts, by securing for limited Times to Authors and Inventors the exclusive Right to their respective Writings and Discoveries.”<sup>190</sup> This goal is decidedly utilitarian on its face: the law recognizes IP interests to maximize creative output.<sup>191</sup>

The reasoning goes that, because information is nonrivalrous and nonexcludable, rational actors will not innovate out of concern for free riders.<sup>192</sup> A rational actor would not invest valuable time, energy, or resources in developing something that another person could use for free. Without an exclusive right, the researcher or the company might simply not innovate at all or might attempt to keep the work secret to preserve their market share.<sup>193</sup> Giving innovators exclusive rights in their intellectual property generates a financial incentive to create. Thus, a patent can be understood as a bargain: the inventor trades disclosure for a temporary monopoly. (Of course, entities may no longer patent isolated genes. However, other kinds of innovations related to genetic data remain patentable.) As with patents, proprietary interests in genetic databases incentivize companies to assemble and share valuable genetic information.<sup>194</sup> Here genetic ownership entitlements are the agents of good by encouraging researchers and companies to

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190 U.S. CONST. art. I, § 8, cl. 8.

191 See Sunder, *supra* note 80, at 283.

192 See Henry E. Smith, *Property as Platform: Coordinating Standards for Technological Innovation*, 9 J. COMPETITION L. & ECON. 1057, 1076 (2013); see also WASHINGTON, *supra* note 11, at 18; Rebecca S. Eisenberg, *Patents and the Progress of Science: Exclusive Rights and Experimental Use*, 56 U. CHI. L. REV. 1017, 1024–28 (1989); Mark A. Hall, *Property, Privacy, and the Pursuit of Interconnected Electronic Medical Records*, 95 IOWA L. REV. 631, 653 (2010); Ching, *supra* note 136, at 695–96.

193 See Eisenberg, *supra* note 192, at 1028–30; Ching, *supra* note 136, at 695–96.

194 Of course, by assuming that legally recognized property interests are necessary for facilitating development and investment, IP seems to reject the notion of creation for creation’s sake. As Sunder has observed, “market failure is cited as the *raison d’être* for intellectual property, explaining copyright, patent, and even trademark.” Sunder, *supra* note 80, at 283. She explains that this orientation results in several familiar attributes of the law and economics frame, including dependence on the market for distributive purposes, use of willingness to pay to determine access, and limited government intervention in addressing market failures. *Id.*

invest and innovate. In fact, the neoclassical economic view of the patent system is so well-accepted that even progressive property theorists have embraced welfarism in the context of patents.<sup>195</sup>

## 2. Participation Incentives

Some advocates of genetic ownership rights for individuals have adopted a similarly neoclassical economic approach. The raw materials for human genetic and genomic research must inevitably come from people. While not as clearly tied to market value as patents, encouraging people to participate in research is framed as welfare-enhancing. The mission statement of the Precision Medicine Initiative emphasizes the importance of individuals working with researchers to improve health care.<sup>196</sup>

Studies indicate that trust in both researchers and in their institutions is a necessary prerequisite for participating in research.<sup>197</sup> Relatedly, mounting evidence shows that people expect to be told—and to maintain some measure of control over—how researchers use their genetic data.<sup>198</sup> Distrust could undermine research if people are unwilling to share their genetic data because they are wary of potential exploitation.<sup>199</sup>

The subjects of genetic ownership controversies, like John Moore,<sup>200</sup> the *Greenberg* plaintiffs,<sup>201</sup> and the Havasupai, have all expressed feelings of dis-

195 See Alexander, *supra* note 42, at 1026 (“In yet other domains (Dagan gives the example of patents), utilitarian welfare maximization is and should be the dominant value.”).

196 See *So What Is Precision Medicine?*, WHITE HOUSE, <https://www.whitehouse.gov/precision-medicine> (last visited Oct. 29, 2017).

197 See Mark A. Rothstein et al., *Citizen Science on Your Smartphone: An ELSI Research Agenda*, 43 J.L. MED. & ETHICS 897, 900 (2015).

198 See Kulynych & Greely, *supra* note 174, at 125–26 (discussing patient expectations and possible reactions to learning genetic data has been studied without consent).

199 See Harald Schmidt & Shawneequa Callier, *How Anonymous Is ‘Anonymous’? Some Suggestions Towards a Coherent Universal Coding System for Genetic Samples*, 38 J. MED. ETHICS 304, 304, 308 (2012).

200 Moore stated: “How does it feel to be patented? There was a sense of betrayal. I mean, they owned a part of me that I could never recover. I certainly have no objection to scientific research . . . but it was like a rape. In a sense you’ve been violated, for dollars. My genetic essence held captive.” WASHINGTON, *supra* note 11, at 11 (omission in original); see also Peter Carlson, *A Seattle Man Vents His Spleen Against Those Who Would Use It for Profit*, PEOPLE (Sept. 23, 1985), <http://people.com/archive/a-seattle-man-vents-his-spleen-against-those-who-would-use-it-for-profit-vol-23-no-13/>; Dennis McLellan, *John Moore, 56; Sued to Share Profits from His Cells*, L.A. TIMES (Oct. 13, 2001), <http://articles.latimes.com/2001/oct/13/local/me-56770>.

201 One parent said, “We were shocked. . . . This is a desecration of all the good that came out of Jonathan and Amy’s lives. We gave our DNA and that of our children to help develop testing and prenatal diagnosis. We sent our blood and skin samples to a doctor at Miami Children’s Hospital.” WASHINGTON, *supra* note 11, at 195 (quoting Dan Greenberg). Another asked, “Is it right that they use our genes—given to help others—in a way that restricts access and increases cost to testing?” *Id.* (quoting Judith Tsipis).



trust and exploitation.<sup>202</sup> These high-profile stories of perceived exploitation could chill participation in biomedical research. The more widely publicized the feelings of exploitation, the greater their potential impact. If concerns about a distrust contagion seem overblown, consider that Oprah Winfrey starred in a heavily promoted HBO original feature about Lacks, released in early 2017.<sup>203</sup>

Current strategies to improve research participation assume people are rational actors weighing costs and benefits.<sup>204</sup> Studies speculate that individuals will not participate in research when the potential benefits are unclear and the potential costs are too high.<sup>205</sup> On the benefit side, a person might consider how her actions could help her family members, members of her communities, and the public at large.<sup>206</sup> On the cost side, she might consider the ways in which research could lead to stigma or disadvantage.<sup>207</sup> The cost side of the equation tends to be higher for certain populations—like people of color—that have experienced past discrimination and exploitation.<sup>208</sup>

A neoclassical economic solution to low rates of research participation would be to offer some kind of an exclusive right in one's own genetic data to tip the scales in favor of participation. Not surprisingly, several scholars have argued in favor of increased genetic ownership rights to encourage people to participate in research. Although she would not frame the entitlements she proposes in ownership terms, Barbara Evans fears that without adequate access to or control over their information, instead of participating in

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202 The Havasupai also reported feeling taken advantage of, explaining that their distrust now affects the willingness of some tribe members to seek medical care, let alone to participate in research. See Jana Bommersbach, *Arizona's Broken Arrow: Did Arizona State University Genetically Rape the Havasupai Tribe?*, PHX. MAG., Nov. 2008, at 134; Rob Capriccioso, *Havasupai Blood Case Lives On*, INDIAN COUNTRY TODAY MEDIA NETWORK (Jan. 2, 2009), <https://indiancountrymedianetwork.com/news/havasupai-blood-case-lives-on/>; Drabiak-Syed, *supra* note 146, at 212; Howard Fischer, *Havasupai Blood Lawsuit Reinstated*, ARIZ. DAILY SUN (Nov. 28, 2008), <http://azdailysun.com/news/havasupai-blood-lawsuit-reinstated/html>; Harmon, *supra* note 146; Paul Rubin, *Indian Givers*, PHX. NEW TIMES (May 27, 2004), <http://www.phoenixnewtimes.com/news/indian-givers-6428347>. When asked what she would tell the President of ASU or Board of Regents, one member of the tribe told a reporter she would say, "You've hurt us so bad that we feel like we don't trust anyone anymore. We don't want anything to do with the university anymore. We hate you all." Bommersbach, *supra*, at 134 (quoting Aral Putesoy Kaska).

203 See *The Immortal Life of Henrietta Lacks*, IMDB, <http://www.imdb.com/title/tt5686132/> (last visited Nov. 4, 2017).

204 See A.J. Goldenberg et al., *Patient Perspectives on Group Benefits and Harms in Genetic Research*, 14 PUB. HEALTH GENOMICS 135, 139 (2010).

205 See WASHINGTON, *supra* note 11, at 203.

206 *Id.*

207 *Id.*

208 See Mark A. Rothstein, *Ethical Issues in Big Data Health Research: Currents in Contemporary Bioethics*, 43 J.L. MED. & ETHICS 425, 427 (2015).

research, people will “take their data and go home.”<sup>209</sup> Mark Hall and Kevin Schulman propose offering people the opportunity to negotiate revocable or term-limited licenses for accessing their health data information to encourage data sharing.<sup>210</sup> Independently of Schulman, Hall adopts the lens of network economics to argue for allowing patients to assign interests in their health data to a trusted third party that will commercialize them according to “their value and best use.”<sup>211</sup> Patient advocacy groups have also argued in favor of increased ownership rights. One such group, UnPatient, characterizes health data as a form of “surplus resource” that is not generating value absent personal ownership rights.<sup>212</sup> The leaders of UnPatient believe ownership rights will create an incentive to share data to maximize its value.<sup>213</sup>

And finally, the commercial interests being offered by genetic testing companies are also incentives to encourage people to participate in research.<sup>214</sup> By compensating its customers for sharing their data, the chairman of Genos aspires to build a large customer database and to profit by connecting them with researchers.<sup>215</sup> The CEO of Invitae hopes that revenue sharing will encourage people to stay on his platform over the competition, explaining “If you go to a social networking site, and every time an advertiser was pinging you the network made money and you also got a piece of the action, would you still stay in a network where they’re taking your private information and making money off you?”<sup>216</sup> DNAsimple’s CEO explains that people are more willing to participate in research because they “feel [like] part of the process when they get compensated.”<sup>217</sup>

The happy ending produced from this genetic comedy is a world where researchers, biotech, and society at large benefit from scientific advances while the individuals who provide the genetic information get the benefit of being compensated for their willingness to participate in research. In short, everyone wins.

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209 Barbara J. Evans, *Barbarians at the Gate: Consumer-Driven Health Data Commons and the Transformation of Citizen Science*, 42 AM. J.L. & MED. 651, 658 (2016).

210 See Mark A. Hall & Kevin A. Schulman, *Ownership of Medical Information*, 301 J. AM. MED. ASS’N 1282, 1284 (2009).

211 Hall, *supra* note 192, at 631.

212 Leonard J. Kish & Eric J. Topol, Commentary, *Unpatients—Why Patients Should Own Their Medical Data*, 33 NATURE BIOTECHNOLOGY 921, 923 (2015).

213 See *id.*

214 I have also joined the conversation about the kinds of incentives these interests might create. See Jessica L. Roberts et al., Correspondence, *Should You Profit from Your Genome?*, 35 NATURE BIOTECHNOLOGY 18, 18 (2017).

215 See Karow, *supra* note 183.

216 Lash, *supra* note 185.

217 Daley & Cranley, *supra* note 16.

### B. Genetic Tragedies

Entitlements in genetic data could lead to tragedies—socially costly outcomes—as well. These arguments also adopt a neoclassical law and economics frame: they presuppose that people are rational actors who respond to incentives, but suggest that “proPERTIZING” genetic data will lead to inefficient or other kinds of undesirable outcomes.

#### 1. Anticommons

A tragedy of the anticommons is probably the most familiar property tragedy invoked in bioethics. Turning the infamous tragedy of the commons on its head, Michael Heller and Rebecca Eisenberg famously argued that too much private ownership leads to underuse. While this problem can occur in a variety of settings,<sup>218</sup> in the context of biomedical research, they argued that patents lead to underuse by creating overlapping property rights.<sup>219</sup> Separately, Heller asserts that patents changed the culture of biomedical research, shifting it from a commons to an anticommons.<sup>220</sup>

Imagine, for example, that numerous different entities own patents on a cell line itself, the cDNA of the cell line’s genome, and various processes and applications related to the cell line. If a particular line of research requires all owners to consent to licensing, any one owner could undermine the project by withholding her permission, thereby creating the opportunity for strategic holdouts.<sup>221</sup> The costs of coordinating all of these ownership interests drive up the price of the end product, an expense that ultimately gets passed down to the consumers in an already largely unaffordable health-care system.<sup>222</sup> Sometimes the coordination costs will be so high that they will far exceed what the innovation would be worth on the market.<sup>223</sup> A researcher may then decide to abandon a particular project because obtaining all the necessary permissions is too costly or time-consuming. If such issues become systemic, members of the biotech industry may opt to move away from genetics and genomics entirely.<sup>224</sup> These holdout and coordination problems

218 See MICHAEL HELLER, *THE GRIDLOCK ECONOMY* 3–4 (2010).

219 See Michael A. Heller & Rebecca S. Eisenberg, *Can Patents Deter Innovation? The Anticommons in Biomedical Research*, 280 *SCIENCE* 698, 698 (1998); see also WASHINGTON, *supra* note 11, at 120; Arti K. Rai & Rebecca S. Eisenberg, *Bayh-Dole Reform and the Progress of Biomedicine*, 66 *LAW & CONTEMP. PROBS.* 289, 290–91 (2003).

220 HELLER, *supra* note 218, at 58; WASHINGTON, *supra* note 11, at 5.

221 See D. Theodore Rave, *Governing the Anticommons in Aggregate Litigation*, 66 *VAND. L. REV.* 1183, 1199 (2013).

222 WASHINGTON, *supra* note 11, at 5, 127.

223 See HELLER, *supra* note 218, at 5; WASHINGTON, *supra* note 11, at 126.

224 See Jay P. Kesan, *Carrots and Sticks to Create a Better Patent System*, 17 *BERKELEY TECH. L.J.* 763, 767 (2002); Sapna Kumar, *Standing Against Bad Patents*, 31 *BERKELEY TECH. L.J.* (forthcoming 2018) (manuscript at 12); Robert P. Merges, *As Many as Six Impossible Patents Before Breakfast: Property Rights for Business Concepts and Patent System Reform*, 14 *BERKELEY TECH. L.J.* 577, 592 (1999).

demonstrate how several concurrent ownership interests could create an anticommons or what Heller has recently called “gridlock.”<sup>225</sup>

Anticommons or gridlock in the context of biomedical research has serious consequences. Companies lose profits but more importantly people cannot access needed medical care, get sick, and die. Heller calls the medical innovations thwarted by anticommons “a silent tragedy.”<sup>226</sup> However, the extent to which an anticommons is harmful is hard to measure and even harder to address. Heller asks: “Where do you go to complain about lifesaving drugs that could exist—*should exist*—but don’t?”<sup>227</sup> He asserts that the solution to gridlock is to grant the least amount of ownership possible that will preserve the patent system’s incentives for investment and innovation.

Anticommons result from the undesirable cumulative effects of individual rational choices.<sup>228</sup> The holdouts who ultimately undermine research are simply rational actors responding to the incentives created by the patent system. Heller calls gridlock “a free market paradox.”<sup>229</sup> Thus, despite its potential life-and-death impacts, anticommons is, at its core, an argument about inefficient use.

The traditional anticommons arguments have been aimed at physical property and patents, including biopatents. However, arguments against giving individuals property rights in their genetic information can also be understood in anticommons terms. Some argue that individuals should not own their genetic data because they could use those rights to chill research.<sup>230</sup> While a researcher might need some incentive to study it and a biotech company might need some incentive to commercialize it, I don’t need an incentive to create my genetic data.<sup>231</sup> As evinced in *Moore* and *Greenberg*, courts have been reluctant to recognize common-law property interests in DNA out of a concern that people might exercise those rights in a way that would chill research. In these scenarios, the holdouts creating gridlock would not be biotech companies extracting value from their patents, but individual people extracting value from their genetic data.

In *Moore*, the biotech industry spoke out in response to the lawsuit, arguing that recognizing an individual’s property rights in her cells would undermine scientific research.<sup>232</sup> In dismissing the conversion claim, the Supreme Court of California framed its decision in terms of costs and incentives. It opined that “[t]he extension of conversion law into this area will hinder

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225 HELLER, *supra* note 218, at xiv.

226 *Id.* at 6.

227 *Id.*; *see also id.* at 78.

228 *Id.* at 196 (explaining that tragedies of the commons and anticommons occur when “individual rational choices add up to collective misery”).

229 *Id.* at xiv.

230 *See* Arthur R. Miller, *Personal Privacy in the Computer Age: The Challenge of a New Technology in an Information-Oriented Society*, 67 MICH. L. REV. 1089, 1225 (1969); Spinello, *supra* note 112, at 29.

231 *See* Cohen, *supra* note 4, at 1148.

232 WASHINGTON, *supra* note 11, at 42.

research by restricting access to the necessary raw materials.”<sup>233</sup> The court feared that because “conversion is predicated on a continuing ownership interest,” those claims could undermine research incentives and deter investment by creating an opportunity for holdouts that result in underuse.<sup>234</sup> It concluded that recognizing property interests in excised cells “would not further the public interest.”<sup>235</sup> Put differently, it would not maximize welfare.

Like the Supreme Court of California, the Southern District of Florida in *Greenberg* also referenced concerns about impeding research. The court found that recognizing a property right for the families in *Greenberg* would “cripple medical research.”<sup>236</sup> It explained that “this extra duty would give rise to a type of dead-hand control that research subjects could hold because they would be able to dictate how medical research progresses.”<sup>237</sup> Interestingly, even the Northern District of Illinois, when finding it lacked personal jurisdiction and transferring the case, wrote in terms of costs and incentives, explaining that such claims “would put an undue burden and potentially ‘creat[e] disincentives to the conduct of socially beneficial research’ to hold that researchers must bear the cost of potentially litigating claims by unhappy donors in every jurisdiction from which they have received samples.”<sup>238</sup>

## 2. Collective Action Problems

Genetic databases could lead to another type of tragedy: collective action problems.<sup>239</sup> A collective action problem occurs when a group as a whole would benefit from cooperation, yet individual members have disincentives to act in furtherance of that goal.<sup>240</sup> Here too, individual rational actions rooted in cost-benefit analysis lead to widespread inefficiency and underuse.

Some people, like John Moore, have uniquely and individually valuable biospecimens. However, most genetic data is only valuable in the aggregate, like Myriad’s database. The value of a database depends on the agreement of multiple people to share their genetic data. A neoclassical economic view would assert that individuals would not contribute their genetic data if the costs of contributing outweighed the benefits of contributing. Some scholars

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233 *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 494 (Cal. 1990).

234 *Id.* at 496.

235 *Id.* (quoting *Brown v. Superior Court*, 751 P.2d 470, 480 (Cal. 1988)).

236 *Greenberg v. Miami Children’s Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1076 (S.D. Fla. 2003).

237 *Id.* at 1071.

238 *Greenberg v. Miami Children’s Hosp. Research Inst., Inc.*, 208 F. Supp. 2d 918, 927 (N.D. Ill. 2002) (alteration in original) (quoting *Moore*, 793 P.2d at 494).

239 Some have instead framed this as an anticommons issue, arguing that compiling a database is akin to acquiring several parcels of land for development, thereby opening the door for holdouts. See Marc A. Rodwin, *Patient Data: Property, Privacy and the Public Interest*, 36 AM. J.L. & MED. 586, 589 (2010). However, because the relative value of the remaining parcels does not increase with each transaction, what Rodwin describes looks more like a collective action problem than a holdout problem.

240 *Collective Action Problem*, CONCISE OXFORD DICTIONARY OF POLITICS (Iain McLean & Alistair McMillan eds., 3d ed. 2009).

fear that because the costs are individual and the benefits are diffuse, rational actors will not share genetic data.

Jane Bambauer argues against giving people property rights in their data—genetic and otherwise—for these very reasons. She asserts that rational actors would remove their data from the collective pool to avoid even small amounts of potential privacy risk, thereby decreasing the data’s research value.<sup>241</sup> Allowing people to opt out creates the potential for selection bias: as people choose not to participate due to these features, the data ceases to reflect the general population, thus reducing its reliability.<sup>242</sup> Bambauer thus fears that property rights in personal data “would allow holdouts to wreak disproportional havoc on research.”<sup>243</sup>

Marc Rodwin also argues that private ownership could thwart the creation of databases.<sup>244</sup> Yet he does not advocate avoiding property altogether but rather instituting public data ownership. Rodwin would require private entities to report anonymous, “de-identified” data to public authorities, which in turn would aggregate that data and make it available in public databases that private entities could access for research.<sup>245</sup> He believes that this arrangement would facilitate beneficial uses of health data in both the public and private sectors, avoiding collective action problems.<sup>246</sup>

### 3. Perverse Incentives

Perverse incentives constitute a third type of genetic tragedy. A perverse incentive creates unintended undesirable results that run contrary to the purpose for which the incentive was created in the first place.<sup>247</sup> Thus, rational actors respond to the incentive but not in the intended way. Arguments about perverse incentives tend to focus on researchers and members of the biotech industry, assuming—often rightly—that they behave like wealth-maximizing rational actors.

Specifically, critics fear that patents may have the opposite of their desired effect discussed above. Instead of encouraging disclosure and spurring innovation, they may actually promote secrecy and hinder progress.<sup>248</sup> Advances in research could make a patent less valuable by introducing a com-

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241 See Jane Yakowitz, *Tragedy of the Data Commons*, 25 HARV. J.L. & TECH. 1, 4 (2011).

242 Barbara J. Evans, *Much Ado About Data Ownership*, 25 HARV. J.L. & TECH. 69, 95–96 (2011); Rodwin, *supra* note 239, at 598; Yakowitz, *supra* note 241, at 64–65; see also Rothstein, *supra* note 208, at 428 (describing consent bias).

243 Yakowitz, *supra* note 241, at 64–65. While invoking the language of holdouts, she describes more of a collective action problem than an anticommons problem.

244 See Rodwin, *supra* note 239, at 589.

245 *Id.*

246 See Rodwin, *supra* note 239, at 590; Mark A. Rodwin, *The Case for Public Ownership of Patient Data*, 302 J. AM. MED. ASS’N 86, 87 (2009).

247 For example, when the French colonial government in Hanoi decided to place a bounty on rat tails to get villagers to exterminate the vermin, the villagers began to farm rats. See Michael G. Vann, *Of Rats, Rice, and Race: The Great Hanoi Rat Massacre, An Episode in French Colonial History*, 4 FRENCH COLONIAL HIST. 191, 196 (2003).

248 See Eisenberg, *supra* note 192, at 1028–29.

petitor to the market or by making a previous innovation obsolete.<sup>249</sup> A patent holder might then refuse to offer a license, regardless of the asking price, for fear that the entity requesting the license may discover a flaw or shortcoming in the patent holder's own research.<sup>250</sup> Thus, as wealth-maximizing rational actors, patent holders have good reasons for withholding licenses to preserve the value of their patents, even if their actions stall innovation. Paradoxically then, patents could actually decrease competition and stifle the scientific progress they are intended to promote.<sup>251</sup> This possibility is particularly troubling in the context of biomedical research where advances are not simply building a better mousetrap but creating a more accurate diagnostic test. Unfortunately, these damaging kinds of restricted uses go largely unchallenged.<sup>252</sup>

Myriad gained notoriety for taking aggressive actions to preserve its monopoly in the market for breast and ovarian cancer genetic testing. It restrictively enforced its patents to shut down cancer research,<sup>253</sup> stalling advances in cancer science in the United States.<sup>254</sup> It is no surprise, then, that the first legal challenge against Myriad in 2009 garnered significant support from the research community.<sup>255</sup> And, in a letter in support of the most recent complaint against Myriad, the Executive Director of Breast Cancer Action wrote that her organization is "deeply concerned about the ways that the patent monopoly held by Myriad Genetics for nearly 20 years impeded scientific and medical progress."<sup>256</sup>

While Myriad successfully used its patents to chill research, it is worth emphasizing that its conduct is not an example of an anticommons. Gridlock happens when several overlapping ownership interests create coordination issues, not when a single patent holder strategically exercises its

249 In the short term, patents may encourage secrecy, as innovations must be novel to be patentable. See 35 U.S.C. § 102(a) (2012). However, what concerns most commentators is longer term behavior. See Eisenberg, *supra* note 192, at 1029.

250 WASHINGTON, *supra* note 11, at 184 (quoting Lori Andrews).

251 *Id.* at 188.

252 Generally, members of the public lack the standing to challenge patents, even when those patents cause them clear harm. See *generally* Kumar, *supra* note 224. For other arguments that patents should consider third-party harms, see Megan M. La Belle, *Patent Law as Public Law*, 20 GEO. MASON L. REV. 41, 96–98 (2012); Amelia Smith Rinehart, *Patent Cases and Public Controversies*, 89 NOTRE DAME L. REV. 361 (2013).

253 WASHINGTON, *supra* note 11, at 190.

254 While Myriad was effectively limiting research in the United States, scientists in France discovered new mutations and genetic variations linked to breast and ovarian cancers that Myriad's test failed to detect. *Id.* at 185. They concluded that Myriad's test missed between ten and twenty percent of the relevant genetic attributes. *Id.*

255 Researchers feared that, should Myriad win, the company's patent monopoly would "lead to a loss of expertise and information among physicians and research scientists in Europe, as they will no longer be allowed to improve diagnostic technologies and methods." *Id.* at 190. One commentator, an oncology professor in Sweden, went as far as to call Myriad's gene patents "dangerous." *Id.* at 185 (quoting Håkan Olsson, M.D.).

256 Health Information Privacy Complaint, *supra* note 17, at Exhibit 8.

rights.<sup>257</sup> Perverse incentives do not lead to underuse but rather improper or undesirable use.

Of course, Myriad's actions eventually backfired when a lawsuit against the company reached the Supreme Court in 2013. In his majority opinion invalidating patents on isolated genes, Justice Thomas alluded to perverse incentives. He adopted the language of incentives, explaining that "patent protection strikes a delicate balance between creating 'incentives that lead to creation, invention, and discovery' and 'imped[ing] the flow of information that might permit, indeed spur, invention.'"<sup>258</sup> According to the Court, products of nature are not patentable subject matter because "without this exception, there would be considerable danger that the grant of patents would 'tie up' the use of such tools and thereby 'inhibit future innovation premised upon them.' This would be at odds with the very point of patents, which exist to promote creation."<sup>259</sup> Even the Supreme Court has adopted a neoclassical economic approach to these issues.

Furthermore, changes to the patent system within the last four decades have arguably created perverse incentives regarding what to study. In 1980, Congress passed the Bayh-Dole Act, which encouraged academic and other institutions doing federally funded research to patent and commercialize their findings.<sup>260</sup> While universities held less than three hundred patents before the Act, they now obtain roughly three thousand per year.<sup>261</sup> Some believe that Bayh-Dole and a focus on profits have shifted the norms and priorities for scientific research.<sup>262</sup> In particular, patents have created the incentive to focus primarily—perhaps even exclusively—on research that can be lucratively commercialized. This new focus has arguably created two related perverse incentives: (1) research, no matter how socially beneficial, may never be done if there is no market, and (2) choices between projects will be made based on profitability. These well-founded fears, of course, assume that researchers and biotech are rationally considering costs and benefits in an effort to extract as much market value from their research as possible.

Assuming they are rational actors, researchers would be reluctant to invest time and resources when no market exists for the resulting innovations. This intuition seems correct as medical issues that disproportionately affect poor people—both in the United States and abroad—do not receive as much scientific attention, arguably because the affected populations will not

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257 See HELLER, *supra* note 218, at 76–77.

258 *Ass'n for Molecular Pathology v. Myriad Genetics, Inc.*, 133 S. Ct. 2107, 2116 (2013) (alteration in original) (quoting *Mayo Collaborative Servs. v. Prometheus Labs., Inc.*, 566 U.S. 66, 92 (2012)).

259 *Id.* (quoting *Mayo*, 566 U.S. at 86).

260 See Bayh-Dole Act, Pub. L. No. 96-517, 94 Stat. 3015 (1980) (codified as amended at 35 U.S.C. §§ 200–12 (2012)).

261 See *id.*; HELLER, *supra* note 218, at 58.

262 See WASHINGTON, *supra* note 11, at 5, 16.



be able to afford the resulting vaccines, medications, and other treatments.<sup>263</sup>

Likewise, there are also concerns that, when deciding what research to pursue, patents create incentives to select the research that will generate the greatest revenue with the least costs. When trying to maximize wealth, a rational researcher might abandon a study, regardless of its medical potential, if the results will not be profitable enough.<sup>264</sup> Within a neoclassical law and economics framework, profitability determines priority. Madhavi Sunder explains that this view “leads to the mistake that drugs for baldness are more important than drugs for malaria because the former enjoys a multi-billion dollar market, while those who need the latter are too poor to offer much to save their own lives.”<sup>265</sup>

The case of guevedoce babies provides a particularly useful hypothetical. In a small, isolated population in the Dominican Republic, approximately two percent of the births during the 1970s resulted in children who were physiologically female when born but who developed male sex characteristics, including penises and testicles, during puberty.<sup>266</sup> Research on these individuals led to the development of drugs that could treat both male pattern baldness and prostate cancer.<sup>267</sup> The research on guevedoces raises a provocative question: What use should be the focus?<sup>268</sup> Suppose that 100,000 people will pay \$1000 each for the baldness treatment but that the cancer drug would only save 100 lives and none of the affected individuals have health insurance or the ability to afford treatment because they are part of a cancer cluster made up exclusively of low-income workers.<sup>269</sup> The baldness research therefore has a market value of \$100,000,000 and the cancer research has no market value. If the researchers in the hypothetical are wealth-maximizing rational actors, they will focus on the baldness research.

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Perhaps unwittingly, commentators on all sides of the genetic ownership debate have adopted a neoclassical economic frame. Despite the diversity of stakeholders and interests, commentators across the spectrum articulate their

263 See *id.* at 4.

264 See *id.*

265 Sunder, *supra* note 80, at 284.

266 See Julianne Imperato-McGinley et al., *Androgens and the Evolution of Male-Gender Identity Among Male Pseudohermaphrodites with 5 $\alpha$ -Reductase Deficiency*, 300 NEW ENG. J. MED. 1233, 1233–37 (1979); see also Andrew Siegel, *The Guevedoces: How an Intersex Genetic Defect Led to a Blockbuster Class of Medicines*, OUR GREATEST WEALTH IS HEALTH BLOG (Feb. 18, 2012, 8:38 AM), <https://healthdoc13.wordpress.com/2012/02/18/the-guevedoces-how-an-intersex-genetic-defect-led-to-a-blockbuster-class-of-medicines/>.

267 See Siegel, *supra* note 266.

268 While the same class of drugs resulting from research on guevedoces could treat both conditions, it is more interesting to think of them as different potential uses of the same genetic resource.

269 See Norman Daniels, *Is There a Right to Health Care and, if so, What Does It Encompass?*, in A COMPANION TO BIOETHICS 362 (Helga Kuhse & Peter Singer eds., 2d ed. 2009).

positions in terms of creating incentives, weighing costs and benefits, and maximizing value. The neoclassical law and economics frame is so ubiquitous and unquestioned within these discussions that it almost goes unnoticed. Ironically, however, the neoclassical economic approach for understanding genetic ownership ultimately falls short of capturing the plural and incommensurable values implicated by recognizing—or failing to recognize—ownership interests in DNA.

### III. FAILURE OF NEOCLASSICAL ECONOMIC THEORY FOR GENETIC OWNERSHIP

The hegemony of neoclassical economic theory has gone largely unquestioned in the law and in the legal scholarship surrounding genetic ownership. Yet as a lens for understanding the various interests at stake when deciding who should own genetic data, it is inadequate. Thinking merely in terms of market value, incentives, costs, and benefits ignores the multivariant nature of the issues surrounding genetic ownership. As such, neoclassical law and economics fails both doctrinally (in terms of justifying the current status of the law) and intuitively (in terms of explaining people's moral intuitions surrounding genetic ownership). Part III establishes that—despite the popularity of the neoclassical economic approach—it is incomplete as a theory of genetic ownership.

#### A. *Doctrinal Failures*

There are two major doctrinal failures in viewing genetic ownership through a neoclassical law and economics lens. First, a true wealth-maximizing utilitarian property model in this context would favor a genetic takings doctrine. If researchers thought enough value could be generated from the DNA of a particular person or group, it might be well worth the effort to obtain that genetic data, even over strong objections or in the face of possible harm. Second, while some of the new commercial rights in DNA may be intended to incentivize research participation, neoclassical law and economics does not adequately explain the expanding set of genetic ownership rights, especially given concerns related to chilling research and dead hand control.

#### 1. Informed Consent

Utilitarianism has appeal in broad theoretical terms but requires its adherents to commit to some morally dubious outcomes. The infamous trolley problem, which asks the reader whether she should redirect a runaway train headed for five people onto a different track where there is only one person who will be harmed, exemplifies the dilemma.<sup>270</sup> A true utilitarian would say that it is preferable to sacrifice one person to save five. The good of individuals or minorities is thus subsumed into the collective good. Utilita-

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270 See, e.g., Judith Jarvis Thomson, *The Trolley Problem*, 94 *YALE L.J.* 1395, 1395 (1985).

rianism privileges the interests of the many over the interests of the few, even when the result is unpleasant for the minority.<sup>271</sup>

As noted, with respect to genetic information, a utilitarian framework would therefore favor using someone's DNA without her consent—or even against her objections—if the proposed use would generate enough value. Take for example an indigenous population that has a particularly desirable genetic makeup but is isolated and impoverished. Even if the group itself has no opportunity to benefit and has strongly held beliefs against such research, obtaining and using their genetic information is clearly favorable under a pure Benthamite utilitarian regime, assuming the research would produce sufficient welfare.<sup>272</sup> Hence, a utilitarian view of genetic ownership could at least permit—and at worst encourage—the exploitation of minorities, so long as the resulting research generates enough net value.<sup>273</sup>

In other words, utilitarianism brings the possibility of a genetic takings doctrine.<sup>274</sup> With adequate justification, the government—or perhaps even a private party—could theoretically seize an individual's genetic information and use it against her will. Of course, the Fifth Amendment would require “just compensation” for any such takings.<sup>275</sup> In his recent article, Contreras effectively advocates a genetic takings doctrine, arguing that when stubborn individuals refuse to participate in valuable research it undermines important interests in social justice and public health.<sup>276</sup> Instead, he advocates permitting unconsented research on genetic data and then compensating people later if they experience harm.<sup>277</sup>

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271 See SMART & WILLIAMS, *supra* note 39, at 105 (describing how utilitarianism can end up disadvantaging minorities). For more on distributional concerns, see *infra* note 376 and accompanying text.

272 One could understand the infamous holding in *Kelo v. City of New London*, 545 U.S. 469 (2005), which justified the taking of a family home by a city corporation to further economic development, in these terms.

273 In fact, utilitarianism would arguably support even more harmful and invasive studies than unconsented genetic research. Imagine a situation in which excruciatingly torturing one individual would create huge medical advances for society as a whole and would save millions of lives. Now also imagine that the torture could be done in complete secret and that no one would ever discover it. It would seem that a true utilitarian would have to support such a scenario. To act differently would be to effectively renounce utilitarianism. See SMART & WILLIAMS, *supra* note 39, at 69–71 (discussing a similar hypothetical).

274 A taking occurs when the government seizes private property for public use. See 2A JULIUS L. SACKMAN, NICHOLS ON EMINENT DOMAIN § 6.01 (3d ed. 2006).

275 U.S. CONST. amend. V.

276 See Contreras, *supra* note 146, at 31–32.

277 See *id.* at 37–39 (stating that “rather than requiring informed consent from contributors of genetic data to a study, data-based research should be broadly permitted without consent”). Yet even Contreras opposes torture. He seems to assume that once research leads to physical and psychological harm it falls outside the realm of law and economics, but he declines to explain why. See *id.* at 11–12 (discussing the Tuskegee Syphilis Study and other examples of unethical research). One possible reason is that Contreras believes that research on data and research on human subjects are fundamentally different. See *id.* at 15 (asserting that “data-based research is materially different than the invasive noncon-

The possibility that researchers and the biotech industry might want to override the rights of the few to serve the interests of the many is not mere conjecture. Various individuals and populations have had their DNA taken and used without their consent, over their objections, against their interests, or without any benefit to them. Well-known examples, of course, include Henrietta Lacks, John Moore, and the Havasupai. And there are still others.

In addition to the Havasupai, researchers have targeted other indigenous people thought to have uniquely appealing genetic profiles.<sup>278</sup> Researchers have repeatedly hounded the Kanaka Maoli, an isolated group of Native Hawaiians, for their genetic material, despite their belief that their genetic information is “sacred and inalienable.”<sup>279</sup> Attempts to profit from indigenous populations happen internationally as well. One company, Axys Pharmaceuticals, successfully patented and commercialized genetic data from the entire impoverished island nation of Tristan da Cunha; a small Jewish community in India; inhabitants of Easter Island; and families living in isolation in Brazil and China.<sup>280</sup> Although Axys obtained consent for the samples it collected, it is unclear whether these populations truly understood exactly what they were consenting to. In short, it is unclear whether the consent was meaningful, especially given the poverty and lack of education of the groups being studied. The U.S. government has even gotten in on the action, obtaining and doing lucrative research on the tissue of a Guaymi Indian woman from Panama.<sup>281</sup> The Guaymi challenged the patents, going all the way to the United Nations. Ultimately, the United States withdrew its patent application but continues to sell the cell line.

While these kinds of efforts line the pockets of researchers and the biotech industry, they also may violate the populations’ dignity, autonomy, privacy, and cultural or religious beliefs. Harriet Washington has drawn parallels between these issues regarding genetic ownership and historical conflicts over real property, asserting that the bioprospecting of indigenous groups represents a new form of colonialism.<sup>282</sup> Of course, these examples assume questionable consent from and possible harm to the studied population and no benefit or meaningful compensation in return. Yet even under a genetic takings doctrine that offers just compensation, research may implicate certain sacred interests like religious beliefs or matters of human dignity for which no amount of money would truly make the injured party whole again.

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sensual research condemned at Nuremburg and Tuskegee and even the damaging psychological experimentation carried out by Milgram and others”).

278 Indigenous people were of interest to researchers both because of their isolation as well as their potential resistance to disease. See Harry, *supra* note 143, at 182–84; see also Ching, *supra* note 136, at 687–88.

279 WASHINGTON, *supra* note 11, at 295.

280 *Id.* at 290.

281 *Id.* at 291.

282 See *id.* at 287; see also Spinello, *supra* note 112, at 34; Ching, *supra* note 136, at 697–99, 701.

Pursuant to the doctrine of informed consent, a researcher cannot simply go in and take a person's genetic data without her permission—no matter how lucrative or medically useful the potential research. Likewise, a person can refuse to participate in even highly valuable research for any reason—rational or not—regardless of whether the benefits outweigh the costs. In theory, under current law, people can choose not to participate in research when there is *absolutely no harm* to them whatsoever and the research would have *massive market value*. As such, a robust informed consent doctrine inevitably leads to genetic ownership market failures. And these decisions can be longstanding. If an individual fails to give consent during her lifetime, researchers cannot simply decide to go in and study her genetic data after she dies.<sup>283</sup> Thus, informed consent arguably creates dead hand control.<sup>284</sup>

Informed consent protects individual, not collective, interests. Advocates of informed consent caution against introducing any cost-benefit analysis into the doctrine because doing so could weaken protections and result in a regime of de facto consent for a significant portion of research.<sup>285</sup> Rather than focusing on maximizing welfare, informed consent protects ideals like justice, beneficence, and human dignity.<sup>286</sup> Informed consent is, therefore, decidedly anti-utilitarian and can lead to outcomes that favor individual rights over wealth creation and net social welfare.<sup>287</sup> Given informed consent's rejection of value monism and cost-benefit analysis, a purely neoclassical economic account cannot fully explain informed consent.

## 2. Growing Genetic Ownership Rights

According to Demsetz, property rights emerge to internalize externalities. Property will not arise if the costs of creating and enforcing an ownership regime outweigh its benefits. Arguably, however, the costs of a genetic ownership regime may well exceed the welfare it produces.

As explained in Part II, many scholars tend to be skeptical of allocating too many interests in genetic data, particularly for individual people. Setting aside the genetic comedies described above, fears related to anticommons, collective action problems, and perverse incentives have historically carried the day.<sup>288</sup> Judging from the extensive scholarship on the subject, many commentators believe genetic ownership rights, including patents, informed consent, and negotiated rights to possess and destroy, actually stand in the

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283 See Contreras, *supra* note 146, at 26–28 (discussing dead hand control).

284 See *id.*

285 See Rothstein, *supra* note 208, at 426.

286 *Id.*

287 See Allen E. Buchanan, *The Right to a Decent Minimum of Health Care*, 13 PHIL. & PUB. AFF. 55, 56 (1984).

288 Arguments for giving people rights in their genetic data are relatively new with much of the writing in this area taking place in the last year or two. See, e.g., Daley & Cranley, *supra* note 16; Evans, *supra* note 209, at 653–54; Karow, *supra* note 183; Kish & Topol, *supra* note 212; Lash, *supra* note 185. By contrast, arguments against individual ownership predate *Moore*, which was decided in 1990.

way of welfare creation by stymieing research. The general consensus seems to be that too many genetic ownership rights already exist—whether held by researchers, private companies, or individuals—and that those rights lead to inefficient use and genetic market failures. Following this line of reasoning, the solution then seems to be loosening the binds to allow genetic data to flow more freely and efficiently.

Yet despite this skepticism, individual entitlements in genetic data continue to grow. In addition to the right to exclude inherent in informed consent, courts appear increasingly open to conversion claims. Beyond the right to exclude, people are enjoying new rights to access and to commercialize their genetic data. Moreover, states continue to consider creating their own sets of genetic ownership.<sup>289</sup> Many of these actual and implied genetic ownership rights are not designed to promote wealth or to create welfare. As noted, autonomy is the basis for informed consent. Likewise, the right to access is about giving individuals the ability to view and potentially act on their genetic data. Individuals have expressed resentment that they have to go through a third party to get information about themselves, and instead favor direct, unfettered access.<sup>290</sup> The desire for access does not appear grounded in market value but rather autonomy and a sense of identity. The fact that some individuals seeking access want those rights solely for the ability to give them away further reinforces the position that values beyond wealth are in play.<sup>291</sup>

Moreover, unlike paying people for participating in research, many of the new genetic ownership rights are not designed to create incentives for any particular welfare-creating action. These new rights give people something in exchange for nothing and without the expectation that individuals will respond in any particular way. Thus, they cannot be explained by rational choice theory.

Because these new genetic ownership rights are potentially costly to enforce and could stifle research, they may decrease—rather than increase—net welfare. Moreover, they are not designed to prompt people to engage in any particular set of rational behaviors. As such, neoclassical law and economics does not readily offer an explanation for their existence.

### B. *Intuitive Failures*

Not only is neoclassical law and economics incomplete as a legal theory of genetic ownership, it also clashes with core intuitions. People have two primary, and perhaps conflicting, intuitions about the ownership of genetic data. First, a significant proportion of the population believes that they

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289 See *supra* note 161.

290 See Sandra Soo-Jin Lee, *American DNA: The Politics of Potentiality in a Genomic Age*, 54 CURRENT ANTHROPOLOGY S7 577, 580 (2013).

291 See *infra* note 374 and accompanying text.

should—or even that they do—own their own genetic data.<sup>292</sup> This belief seems to come from an identity affiliation people experience with their genetic information and is perhaps the driving force behind the biorights movement.<sup>293</sup> Second, individuals have argued that genetic data is too personally meaningful to be left to the market. And third, some evidence shows that compensation may actually decrease people’s willingness to participate in research. Intuitions about personal ownership, commodification anxiety, and decreased research altruism all seem to be rooted in concerns about genetic data totally unrelated to its financial worth.

## 1. Personal Ownership

When President Obama declared “I would like to think that if somebody does a test on me or my genes, that that’s mine . . .” he was expressing the commonly held intuition that we own our genetic information.<sup>294</sup> Often these arguments are based on the notion that owning one’s own genetic information is “natural” or “a basic right.”<sup>295</sup> Perhaps we have a strong intuition in favor of genetic ownership because, at the advent of the Human Genome Project, researchers presented genetic information as the biological blueprint for our uniqueness as persons.<sup>296</sup> Casting DNA as the source of our individuality supports the proposition that genetic information might rightfully—perhaps exclusively—belong to the person from whom it came.<sup>297</sup>

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292 Scholars on all sides of the genetic ownership debate manage to agree on this point. *See, e.g.,* Contreras, *supra* note 146, at 6 (noting “a widespread belief that individuals ‘own’ their personal [health] data [and genetic information]”); Evans, *supra* note 209, at 659 (observing that a 2014 survey indicated that of people who track their health data “54% believe they own their data; 30% believe they share ownership with the sensor company or service provider that enables collection of their data; [and] 4% believe the service provider owns the data,” while “only 13% profess indifference”); Rothstein, *supra* note 208, at 427 (indicating that “many individuals strongly believe that their biological specimens and health records ‘belong to them’”); Yakowitz, *supra* note 241, at 63 (explaining that “[m]any people want (and probably believe they have) a property interest in information that describes them”). It is not surprising then that people have expectations regarding what they will be told when research is done on their genetic data. *See* Kulynych & Greely, *supra* note 174, at 96.

293 *See* Daley & Cranley, *supra* note 16.

294 Davis, *supra* note 9.

295 *See* Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 750–58 (2004) (outlining the arguments in favor of, but ultimately rejecting, the property model for protecting genetic information). *See generally* Pilar N. Ossorio, *Property Rights and Human Bodies*, in WHO OWNS LIFE? 224–25 (David Magnus et al. eds., 2002) (reasoning that individuals may be the initial owners of their bodily materials).

296 *See* George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded ‘Future Diaries,’* 270 J. AM. MED. ASS’N 2346 (1993).

297 *See* Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 49 (Mark A. Rothstein

Perhaps not surprisingly, individuals have raised concerns about identity, dignity, privacy, and autonomy related to genetic information. To them, genetic data has intrinsic, noncommercial value because it relates to their sense of self.<sup>298</sup> 23andMe capitalizes on this perceived connection between genetic information and identity when marketing its products. The front of its test kit reads “Welcome to You” and its website entices potential consumers with the phrase “23 pairs of chromosomes. One unique you.”<sup>299</sup> Another company, ConnectMyDNA, markets one of its products as a “DNA Self-Discovery Starter Kit.”<sup>300</sup> Considering this framing, it is not terribly surprising that some people felt violated when 23andMe turned around and sold their genetic information to the highest bidder in 2015.

The two manifestos posted on the UnPatient website are also instructive. The organization declares: “Data that reflects you should belong to you. You should control access. These include: your genetic code, your lab data, and your images to name a few. These should be property to use as the owner sees fit.”<sup>301</sup> The UnPatient Health Data Ownership Manifesto articulates a series of genetic ownership rights.<sup>302</sup> In this single document, the founders of UnPatient blend descriptive and normative claims, asserting rights to ownership and access alongside rights to privacy and human dignity. While the right to profit from data is certainly a crucial element to UnPatient’s platform, commercial interests are far from the only values at stake.

But the belief that genetic information is linked to a sense of self pre-dates 23andMe’s clever advertising campaign and UnPatient’s heart-felt

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ed., 1997); Jeffery Lawrence Weeden, Note, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611, 617 (2006).

298 Somewhat hyperbolically, one author declares that “[t]here is no information more personal and private[ ] than an individual’s genetic information,” as it “defines who we are as individuals both physically and mentally.” Deborah L. McLochlin, Comment, *Whose Genetic Information Is It Anyway? A Legal Analysis of the Effects that Mapping the Human Genome Will Have on Privacy Rights and Genetic Discrimination*, 19 J. MARSHALL J. COMPUTER & INFO. L. 609, 609 (2001). Another proclaims that “[g]enes and the information they contain are fundamental building blocks of a people’s identity.” Ching, *supra* note 136, at 687; *see also* Weeden, *supra* note 297, at 627 (referring to genetics as “our biological identity”). In a similar vein, in a statement before the Senate, Senator Pete Domenici called the human genome “a blueprint containing the most personal and most private information that any human being can have” and described genetic information as “the essence of our individuality.” *Id.* at 631 (quoting 151 CONG. REC. S1595, S1595 (daily ed. Feb. 17, 2005) (statement of Sen. Domenici)). More reasonably, Sonia Suter simply writes that “our genetic information is about us, and it is deeply connected to our sense of ourselves.” Suter, *supra* note 295, at 737. Anita Allen has referred to DNA as “the thing that makes individuals special and perhaps unique.” Allen, *supra* note 297, at 49.

299 *See* 23ANDME, <https://www.23andme.com>.

300 I have received many emails from Groupon marketing this test. *See* \$29 for a DNA Self-Discovery Test Kit from ConnectMyDNA (US \$89.95 Value), GROUPOUN, <https://www.groupon.com/deals/dc-bst-connectmydna-abbotsford> (last visited Jan. 20, 2018).

301 *Health Data Ownership Manifesto*, UNPATIENT, <http://unpatient.org/health-data-ownership-manifesto/> (last visited Jan. 20, 2018).

302 *See id.*



manifestos. For example, in arguing for his conversion claim, one theory Moore asserted was that he had a property right in his persona. Moore asked, “If the courts have found a sufficient proprietary interest in one’s persona, how could one not have a right in one’s own genetic material, something far more profoundly the essence of one’s human uniqueness than a name or a face?”<sup>303</sup> Although Moore surely had commercial interests in asserting rights in his genetic data, he also asserted that the researchers violated his dignity and sense of self, holding his “genetic essence . . . captive.”<sup>304</sup>

Like John Moore, Henrietta Lacks’s family expressed concerns related to their mother’s dignity and identity in addition to their financial interests in her genetic information. As one researcher described a picture of chromosomes: “Within the DNA in that picture is all the genetic information that made Henrietta *Henrietta*.”<sup>305</sup> The Lacks family frequently referred to HeLa cells as though the cells were themselves Henrietta<sup>306</sup> and, by consequence, the immortal cell line was keeping “Henrietta” alive.<sup>307</sup>

Not surprisingly, because people believe they own their genetic information they tend to regard its unauthorized use as a violation. John Moore articulated an identity affiliation with his genetic data and his perception of a property violation in the same breath, saying: “Without my knowledge or consent, the doctors and the research institutions *used a part of me* for their own gain. . . . They *stole* something from me.”<sup>308</sup> Moore felt dehumanized. He stated that his doctors did not view him as a person but rather “a mine from which to extract biological material. I was harvested.”<sup>309</sup> Likewise, Henrietta’s daughter wrote that her mother was “[r]obbed of her cells” and “[r]obbed [of] self.”<sup>310</sup>

Certain populations might have collective beliefs that relate to their genetic data. For example, the Havasupai objected to the population migration research on their genetic information because it directly contradicted the tribe’s origin story and spiritual beliefs.<sup>311</sup> While Contreras and others

303 *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 490 (Cal. 1990); *see also* Harlan, *supra* note 121, at 207 (quoting Patty Gerstenblith, *Identity and Cultural Property: The Protection of Cultural Property in the United States*, 75 B.U. L. REV. 559, 568 (1995)).

304 WASHINGTON, *supra* note 11, at 11; *see also supra* note 200.

305 SKLOOT, *supra* note 150, at 264.

306 *Id.* at 262 (“‘Oh God,’ she gasped. ‘I can’t believe all that’s my mother.’”); *see also id.* at 266 (“God, I never thought I’d see my mother under a microscope—I never dreamed this day would ever come.”).

307 *Id.* at 164 (“Them doctors never said nuthin about keepin her alive in no tubes or growin no cells.”); *see also id.* at 189 (“[T]heir mother will never die as long as the medical science is around, she will always be such a famous thing.”).

308 McLellan, *supra* note 200 (emphasis added).

309 WASHINGTON, *supra* note 11, at 43.

310 SKLOOT, *supra* note 150, at 196.

311 Drabiak-Syed, *supra* note 146, at 218 (describing how several of the studies based on the Havasupai’s genetic data violated the tribe’s beliefs either about their spirituality or their origin); Jonathan Turley, *Indian Tribe Sues Researchers for Using Blood Samples to Disprove*

dismiss the Havasupai's claims as overblown,<sup>312</sup> the tribe experienced any number of psychological and dignitary harms, like shame, humiliation, low self-esteem, stereotyping, and stigmatization.<sup>313</sup> Similarly, the president of the Guaymi, when approached regarding genetic research on the tribe that could potentially be patented, explained that "[i]t's fundamentally immoral, contrary to the Guaymi view of nature, and our place in it. To patent human material . . . to take human DNA and patent its products . . . violates the integrity of life itself, and our deepest sense of morality."<sup>314</sup> Moreover, given the small size and insularity of tribal populations, tribal membership raises special concerns as research done on a single individual has the power to impact the entire group.<sup>315</sup>

It is worth emphasizing that not all of these feelings of exploitation resulted from illegal or unethical conduct. In fact, taking Henrietta Lacks's cells, using the Havasupai's blood samples for additional studies, and selling access to the 23andMe database were all legally and ethically permissible, at least when they occurred. When people feel exploited, they are not thinking in terms of efficiency or welfare creation. They are expressing a range of dignitary violations related to their sense of self, identity, bodily integrity, privacy, and autonomy. These things cannot be calculated in terms of dollars and cents. They are wholly unaccounted for by a purely economic approach to genetic ownership. The whole reason the Havasupai fought for the return of their blood samples was because of their spiritual value.<sup>316</sup> Money could not compensate them. Only returning the blood would make them whole.

## 2. Commodification Anxieties

An alternative intuition related to genetic ownership maintains that an individual's genetic data is too personal to be subject to the market. Instead of Moore's and the Lacks family's arguments that the genetic data is so intimately a part of the person from whom it came that it *must* be that person's property, anticommodification arguments assert that allowing monetary

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*Religious Beliefs*, JONATHAN TURLEY (Nov. 30, 2008), <https://jonathanturley.org/2008/11/30/indian-tribe-sues-researchers-for-using-blood-samples-to-disprove-religious-beliefs/> (explaining the research "challenge[d] their belief systems"); see also WASHINGTON, *supra* note 11, at 293; Fischer, *supra* note 202; Harmon, *supra* note 146.

312 The researcher responsible for the study dismissed the tribe's reaction as "hysterical." Drabiak-Syed, *supra* note 146, at 195–96 ("According to one of the plaintiffs' attorneys, Robert Rosette, officials at ASU told him during mediation that there had been 'no broken bones—[the tribe had not] been harmed.' Similarly, Markow classified the plaintiffs' claims as 'hysterical,' insisting she was only 'doing good science.' Both comments echo the sentiment that the tribe's claims and request for damages merely represented an extreme irrational or anti-science sentiment, rather than a genuine attempt to signify the harm they incurred." (alteration in original)).

313 See *id.* at 216–17.

314 Ching, *supra* note 136, at 700 (alterations in original) (quoting Philip L. Bereano, *Patent Pending: The Race to Own DNA*, SEATTLE TIMES, Aug. 27, 1995, at B5).

315 Drabiak-Syed, *supra* note 146, at 216–17.

316 *Id.* at 208.

transactions for things we hold dear could cheapen their value and thus weaken our social fabric.<sup>317</sup> Perhaps for the same reasons the law prohibits selling organs or babies, maybe people should not be able to profit from their genetic information.<sup>318</sup> Opponents of giving people property rights in their genetic data argue that those entitlements threaten to commodify the body. Commodification anxieties are not about inefficiency but rather the symbolic meaning of property.

According to this view, commodification is troubling because it could take things with deep intrinsic human value and thrust them into the market. Sonia Suter argues that “because of the importance of genetic information to the self, identity, and formation of relationships of trust and intimacy, it diminishes the personal value of our own genetic information to describe it as a commodity.”<sup>319</sup> Justice Arabian also took this perspective in his concurrence in *Moore*:

Plaintiff has asked us to recognize and enforce a right to sell one’s own body tissue *for profit*. He entreats us to regard the human vessel—the single most venerated and protected subject in any civilized society—as equal with the basest commercial commodity. He urges us to commingle the sacred with the profane. He asks much.<sup>320</sup>

Of course, the ultimate fear lies in the concern that at the bottom of the slippery slope lurks the commodification of living, fully functioning, and intact human beings.<sup>321</sup>

These critics of genetic ownership maintain that a property model is the wrong approach to protect something that transcends market value. Some believe that giving people property rights in their genetic data takes a “reductionist view of personhood.”<sup>322</sup> They assert that privacy law is better suited to protecting interests related to identity and self.<sup>323</sup> The court in *Moore* adopted a similar view. In rejecting Moore’s conversion claim, the court cautioned against “forc[ing] the round pegs of ‘privacy’ and ‘dignity’ into the square hole of ‘property.’”<sup>324</sup> This preference comes largely from the belief that property safeguards commercial interests, whereas noneconomic interests like dignity, autonomy, and bodily integrity are privacy’s dominion.<sup>325</sup>

317 See MICHAEL J. SANDEL, *WHAT MONEY CAN’T BUY: THE MORAL LIMITS OF MARKETS* 10 (2013); Margaret Jane Radin, *Market-Inalienability*, 100 HARV. L. REV. 1849, 1903 (1987).

318 See DUKEMINIER ET AL., *supra* note 2, at 51, 70–88.

319 Suter, *supra* note 295, at 799–800.

320 *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 497 (Cal. 1990) (Arabian, J., concurring).

321 Ossorio, *supra* note 295, at 224.

322 *Id.* at 232; see also Suter, *supra* note 295, at 737.

323 Allen, *supra* note 297, at 49; Suter, *supra* note 295, at 773–74.

324 *Moore*, 793 P.2d at 491.

325 See Ossorio, *supra* note 295, at 229; Suter, *supra* note 295, at 746, 769; see also Evans, *supra* note 209, at 663; Miller, *supra* note 230, at 1226. For example, in arguing for a privacy paradigm over a property paradigm, Sonia Suter asserts that, to individuals like the plaintiffs in *Greenberg*, “[genetic] information had personal value; to the researchers, it was simply a commodity.” Suter, *supra* note 295, at 741. One scholar splits the difference,

### 3. Declining Research Altruism

Finally, offering compensation may not actually increase the willingness to participate in research. According to neoclassical economic theory, paying someone to share her genetic data should generally create an added incentive to participate in research. However, studies have shown that financial incentives might actually backfire in certain circumstances.

People may want to participate in uncompensated research simply to help humanity—not for personal gain. Richard Titmuss strikingly demonstrated that paying donors actually decreases their willingness to give blood.<sup>326</sup> He hypothesized that compensating people monetarily erodes their sense of civic duty. In other words, money may negatively impact research altruism. Similarly, Bruno Frey and Felix Oberholzer-Gee found that, in the NIMBY context, offering people money for agreeing to site a LULU in their community actually lowered the acceptance of the project from 50.8% of residents to 24.6% of residents.<sup>327</sup>

This result confounds neoclassical economic theory. Any added incentive—no matter how small—should increase, not decrease, participation. If the willingness to participate in research when faced with financial incentives declines, that result indicates that other values must be in play. Neoclassical economics tends to focus on extrinsic motivation, in the form of financial compensation, to the detriment of internal motivations like loyalty, civic duty, or generosity. Perhaps people might feel that a low level of compensation cheapens their selfless act and undervalues their genetic information.<sup>328</sup> Regardless of the explanation, it seems more is at stake than dollars and cents.

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Although neoclassical economics has enjoyed near unquestioned dominance as a theory of genetic ownership, it is incomplete both doctrinally and intuitively. On the doctrinal level, it cannot adequately explain why informed consent trumps even value-generating research or provide reasons for the increasing legal recognition of individual genetic ownership rights that do not incentivize research participation. On an intuitive level, neoclassical economic theory offers an unsatisfying explanation of how people feel about owning and commercializing their genetic data. Neoclassical economics therefore falls well short of being a complete model of genetic ownership that is able to explain the relevant law and intuitions.

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advocating privacy under particular circumstances and property under others. Rao, *supra* note 132, at 378–80.

326 See RICHARD M. TITMUSS, *THE GIFT RELATIONSHIP* (1970).

327 Frey & Oberholzer-Gee, *supra* note 60, at 749.

328 Frey and Oberholzer-Gee assert that these results are consistent with rational choice theory because the extrinsic motivation (price incentive) crowds out the intrinsic motivation (civic duty). *Id.* at 750–51.

#### IV. PROGRESSIVE GENETIC OWNERSHIP

A neoclassical economic account fails to capture all the social interests at stake within genetic ownership. Entitlements in genetic data promote important goals and values beyond maximizing welfare or ferreting out market failures. This incompleteness invites consideration of whether the progressive property framework would supply a superior model. Part IV thus begins by introducing a progressive model of genetic ownership. It then applies that model to some of the difficult cases from earlier in the Article. This analysis reveals that a progressive property approach—which would incorporate wealth- and welfare-related concerns alongside deontological values—would provide a more complete and satisfying account of genetic ownership.

##### A. *Progressive Model of Genetic Ownership*

Neoclassical law and economics fails as a model for the laws and regulations governing genetic ownership because it cannot explain the existing and emerging rights associated with genetic data or people's behaviors and intuitions. In particular, it ignores the plural values in play, like dignity, autonomy, privacy, identity, culture, and spirituality. Because someone's genetic information may be personally meaningful and related to family, people will not always behave like self-interested rational actors, calmly weighing costs and benefits.

Progressive property may not settle all the possible issues that could arise with respect to genetic ownership, but it provides a much more coherent and complete theoretical framework than neoclassical law and economics.

##### 1. Plural Genetic Values

Plural values abound in the context of genetic ownership. Individuals who provide biospecimens have concerns related to privacy, identity, and autonomy, apart from their financial self-interest.<sup>329</sup> Market value does not fully account for the deontological concerns in play with respect to genetic ownership. And even a plural account of welfare is potentially problematic, as the values associated with genetic ownership are complex and resist being neatly collapsed or aggregated into a singular definition of welfare. In fact, pure consequentialism may be ill-suited to issues of bioethics generally. As Mark Rothstein has pointed out that “[t]he ethical basis of research ethics . . . is not consequentialism, but deontology.”<sup>330</sup> The Presidential Commission for the Study of Bioethical Issues explicitly rejects treating people as a means to an end, regardless of the potential benefit.<sup>331</sup> Leading bioethicists are clear that safeguarding dignity is central to regulating scientific research and,

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329 See Rothstein et al., *supra* note 13, at 161–62.

330 Rothstein, *supra* note 208, at 426.

331 See *id.*

consequently, protections for research subjects seek to prevent physical and dignitary harms.<sup>332</sup>

Progressive property is particularly well-suited to unraveling the complex issues surrounding genetic ownership because it can recognize—and account for—the plural and incommensurable values at stake. By embracing value pluralism, progressive property theorists have identified diverse and varied values implicated in ownership. Among the virtues analyzed by Peñalver, for example, are industry (material wealth), justice, and humility.<sup>333</sup> He also notes but does not explore the virtues of distributive justice, charity, liberality, and moderation.<sup>334</sup> Singer's democratic model of property incorporates several different values, including autonomy, mobility, distribution and access, freedom of contract (but with minimum economic and social standards), and both stability and change.<sup>335</sup> Although not a self-identified member of the progressive property school, Sunder discusses several diverse values at stake in IP, such as efficiency, personhood, dignity, liberty, fairness, and distributive justice,<sup>336</sup> as well as autonomy, culture, democracy, equality, and economic development.<sup>337</sup>

Progressive property, with its consideration of plural and incommensurable values, fits comfortably within the framework of bioethics, which—at least in theory if not in practice—is deontological in nature. In fact, some bioethicists have asserted that treating people as ends unto themselves requires helping them achieve their desired goals and fostering their capabilities as agents.<sup>338</sup> In short, at least some bioethicists have advocated researchers taking a human flourishing approach to human subject research.

It should come as no surprise then that there are several contenders for core values related to genetic ownership. Much of genetic ownership deals with research science. Among the leading values associated with scientific research are “communalism, universalism, disinterestedness, and organized skepticism.”<sup>339</sup> The Belmont Report, the United States' founding document establishing the rights of human subjects, adopts respect for persons, beneficence, and justice as its governing ethical principles.<sup>340</sup> More recently, the Global Alliance for Genomics and Health created a Framework for Responsible Sharing of Genomic and Health-Related Data.<sup>341</sup> It grounded its approach in two human rights from the Universal Declaration of Human

332 *See id.*

333 *See* Peñalver, *supra* note 1, at 876–86.

334 *See id.* at 877.

335 *See* Singer, *supra* note 62, at 1054–55.

336 *See* Sunder, *supra* note 80, at 315.

337 *See id.* at 324–25.

338 *See* BEAUCHAMP & CHILDRESS, *supra* note 33, at 107.

339 Conley et al., *supra* note 21, at 634.

340 *See* NAT'L COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1979), <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>.

341 *See* Rothstein et al., *supra* note 13, at 170.

Rights: the right of citizens to benefit from advances in medical research and the right of scientists to be acknowledged.<sup>342</sup> The Framework adopts the key values of consent, privacy, security, and accountability.<sup>343</sup>

Autonomy, the ability to make one's own decisions free from coercion, is of course a key genetic value. It forms the foundation of many important legal doctrines, such as medical malpractice,<sup>344</sup> the constitutional right to refuse treatment,<sup>345</sup> and—most importantly for this Article—*informed consent*, in both the treatment<sup>346</sup> and research contexts.<sup>347</sup>

Privacy is also frequently cited as a core value associated with genetic ownership. In her work on genetic privacy, Anita Allen identifies what she calls “proprietary privacy”: privacy interests that deal with the appropriation and ownership of human personalities.<sup>348</sup> Proprietary privacy reveals the clear connections between property, privacy, and autonomy.<sup>349</sup> Allen explains that “[p]roprietary genetic privacy is suggested by the idea that the human DNA is a repository of valuable human personality.”<sup>350</sup> Thus, one way to provide meaningful protection for privacy would be through property protections.<sup>351</sup> In fact, at times, the distinction between property and privacy may collapse completely.<sup>352</sup>

Genetic information can also raise identity concerns. One need not adopt the position that genetic information is *determinative* of identity to adopt the position that it is *relevant* to identity.<sup>353</sup> People's genetic data

342 *See id.*

343 *See id.*

344 *See* Ingrid H. Heide, *Negligence in the Creation of Healthy Babies: Negligent Infliction of Emotional Distress in Cases of Alternative Reproductive Technology Malpractice Without Physical Injury*, 9 J. MED. & L. 55, 60 (2005) (“Medical malpractice has historically been used to protect the individual's interest in physical autonomy from interference and injury.”).

345 *See* Alan Meisel, *Managed Care, Autonomy, and Decisionmaking at the End of Life*, 35 HOUS. L. REV. 1393, 1397, 1400–02 (1999).

346 *See* Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429, 430–31 (2006).

347 *See* Federal Policy for the Protection of Human Subjects, 82 Fed. Reg. 7149 (Jan. 19, 2017) (to be codified in scattered titles of the C.F.R.).

348 Allen, *supra* note 297, at 33.

349 *See* Radin, *supra* note 5, at 957 (explaining that “the personhood perspective is often implicit in the connections that courts and commentators find between property and privacy or between property and liberty”).

350 Allen, *supra* note 297, at 49.

351 *See* Miller, *supra* note 230, at 1223. *But see id.* at 1223–24 (invoking the economic/noneconomic, property/privacy dichotomy rejected by this Article above).

352 When arguing in favor of an antidiscrimination paradigm for protecting genetic information (and by consequence *against* a privacy paradigm), Anita Silvers and Michael Stein actually equate privacy and property, stating that “[o]n the privacy model, a person's genetic information is her property and, consequently, should be under her control.” Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1355 (2002).

353 Some scholars engage in a fallacy of genetic supremacy—i.e., arguing that saying my genetic data is part of my identity is to say my genetic data is definitive of my identity—to reject property interests. For an example of such an argument, see Evans, *supra* note 209,

clearly matters to them, regardless of whether it is anonymous. In one study, eighty-one percent of those surveyed indicated that they would want to know about research on their identifiable samples and seventy-two percent said they would want to know about the research being conducted on anonymous samples.<sup>354</sup> In fact, nineteen percent of those individuals believed that they maintained rights in their anonymous sample.<sup>355</sup> If identity was not a central concern related to genetic ownership, then the concepts of “de-identifying” or “anonymizing” would not carry nearly so much weight. Thus, regardless of the state of the law, people believe they have an identity interest in their genetic data.

The Havasupai’s beliefs illustrate that genetic information can implicate group identity as well. Blood had a special significance to the tribe.<sup>356</sup> Consequently, while doing genetic research beyond diabetes did not harm the tribe physically, it had a negative impact on their tribal identity in light of their spiritual and cultural beliefs.<sup>357</sup> Perhaps the clearest identity claims are not in the As, Gs, Cs, and Ts themselves, but rather in what they represent: ancestry, lineage, and cultural membership.

Of course, a discussion of genetic values would not be complete without mentioning the values that have dominated the commentary for the last two and a half decades: wealth and welfare. Theorists dating back to Aristotle have recognized the need to reward intellectual efforts to encourage virtuous behavior.<sup>358</sup> Rewarding innovation with financial gain can also encourage the development of the capabilities necessary for human flourishing.<sup>359</sup> A progressive account of genetic ownership would not reject the ability of genetic ownership entitlements to create wealth. For instance, the biotech industry also creates jobs and stimulates the economy.<sup>360</sup> Employment and economic growth surely contribute to human flourishing. Thus, a progressive approach to genetic ownership would acknowledge that offering incentives might be necessary to encourage investment in scientific research. Moreover, for some researchers, biotech executives, shareholders, and investors, genetic ownership could have an even more direct connection to flourishing by contributing to their quality of life by allowing them to express creativity, fulfill curiosity, and generate knowledge.

It is therefore worth emphasizing that, despite considering wealth and welfare alongside other relevant values, progressive property takes researchers’ interests seriously.<sup>361</sup> As a result, corporate entities like biotech compa-

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at 678–79 (asserting that claiming genetic—or other health-related—data “is integral to selfhood lends credence to Taylor’s alarm about impoverished ontological accounts of the modern Self”).

354 Schmidt & Callier, *supra* note 199, at 307.

355 *Id.*

356 Drabiak-Syed, *supra* note 146, at 213–14.

357 *Id.*

358 ALEXANDER & PEÑALVER, *supra* note 6, at 200.

359 *Id.* at 202.

360 Biotech is an incredibly profitable industry. See WASHINGTON, *supra* note 11, at 48.

361 See ALEXANDER & PEÑALVER, *supra* note 6, at 200.



nies will not always lose out in a progressive property analysis.<sup>362</sup> Given the need to strike a balance between promoting intellectual production and honoring other important human values, a progressive approach to genetic ownership could, when appropriate, focus primarily on improving welfare through increasing social and material wealth.<sup>363</sup> However, when the potential ownership rights of the biotech industry undermine human flourishing, the law should not respect them. For instance, when Myriad aggressively enforced its patents solely to maintain its patent monopoly it did so out of pure self-interest and without regard for the public good—hardly the kind of socially conscious virtue associated with human flourishing.

Progressive property incorporates several different kinds of values, and consequently avoids the concerns associated with using value-monist utilitarianism as its operative framework. For example, while informed consent rights are potentially costly, we have them to safeguard autonomy, privacy, and identity. Growing ownership interests in genetic data also appear to be grounded in these principles as they give individuals heightened control over the genetic information for those very same reasons. Thus, progressive property, which would consider those values, explains these legal rights in a way that neoclassical law and economics cannot. Similarly, the concerns about autonomy, privacy, and identity better explain why people believe they should own their genetic data or why they fear its commodification. Finally, a desire to promote welfare—not wealth—explains why individuals who wish to be good citizens might be willing to share genetic data for free but not when compensated. A value pluralist approach is thus superior to a value monist one in part because it better accounts for the complex interests at stake in genetic ownership, thereby offering justifications for informed consent, growing ownership rights, intuitions of personal ownership, fears of commodification, and possible declines in research altruism when faced with financial incentives.

## 2. Genetic Communities

Progressive property's communitarian vantage makes it particularly appealing as a theory of genetic ownership for a second reason. Neoclassical law and economics does not capture the strong attachment people feel to their genetic information. Because of its ties to family and cultural heritage (or even spirituality), genetic data can be deeply personal and emotional. Just as Peñalver demonstrated with respect to the family home, people may not behave like self-interested rational actors when it comes to their genetic information.

As noted in Part I, genetic information is at once personal and communal. Recall that while our DNA provides the basis for our biological individuality, we also share 99.9% of our genetic information with our fellow human

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362 See Alexander, *supra* note 1, at 817.

363 See ALEXANDER & PEÑALVER, *supra* note 6, at 203.

beings, and an even greater percentage with our family members.<sup>364</sup> Natalie Ram points out that the extent to which we share genetic data has implications for our ability to control that information.<sup>365</sup> Understanding genetic data in terms of genetic communities, as opposed to self-interested individual rational actors, more accurately reflects the shared nature of our genetic information.

Of course, the contributors of DNA are not the only communities relevant to genetic ownership. Genetic and genomic research itself requires a different kind of community—research scientists themselves. Much of science is inherently collaborative. Creating an innovation like the Mo or HeLa cell line involves several different people, including the team of scientists who grow the cells, the investors and institutions that fund and support them, and the people that provide the genetic material.<sup>366</sup>

And of course, society as a whole constitutes yet another relevant community. By their very nature, advances in genetic and genomic science are meant to serve the common good. Among the primary justifications for studying human genetics and genomics are to promote health and prevent disease. When President Clinton announced the completion of the first phase of the Human Genome Project in 2000, he emphasized the health impact of that accomplishment, stating that genomic science “will revolutionize the diagnosis, prevention, and treatment of most, if not all, human diseases” and describing genetic information as “life-enhancing.”<sup>367</sup> DNA forensics offers another useful application of genetic and genomic science. The use of DNA for both conviction and exoneration has revolutionized the way law enforcement investigates crimes and prosecutes suspects.<sup>368</sup> Finally, human genetics and genomics further the pursuit of knowledge, allowing us to engage in acts of self-discovery about our identity as a species.<sup>369</sup> All of these functions promote our shared welfare. The core purpose of all the uses of genetic and genomic science is thus to benefit humanity.

Furthermore, progressive property’s communitarianism captures concerns related to the common good while also avoiding many of the distributive justice concerns raised by utilitarianism. Instead of asking which property allocation will produce the most aggregate welfare, it asks which allocation will afford community members the basic rights and resources necessary to live fulfilling lives. This community orientation is key. While utilita-

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364 For a discussion of the shared nature of genetic information, see Ram, *supra* note 14, at 876–79.

365 *Id.* at 899. Ram writes that “[i]f identifiable genetic information is worthy of protection, then legal institutions must take its inherently shared nature seriously.” *Id.* at 877.

366 SKLOOT, *supra* note 150, at 203–04 (quoting a researcher responsible for another cell line arguing that “numerous parties” have “legitimate property interests in any cultured cells”).

367 See Clinton Remarks, *supra* note 117, at 1500.

368 See generally John P. Cronan, *The Next Frontier of Law Enforcement: A Proposal for Complete DNA Databanks*, 28 AM. J. CRIM. L. 119 (2000).

369 See, e.g., Kim TallBear, *Narratives of Race and Indigeneity in the Genographic Project*, 35 J.L. MED. & ETHICS 412, 413 (2007).

rianism may initially appear egalitarian and communitarian, it would support sacrificing individuals to the collective good, assuming the right utility calculus. Alternatively, progressive property acknowledges that communities are themselves independent entities, made up of more than just the aggregated preferences of their members. Thus, exploiting one person—even if that exploitation would personally benefit other members—could still harm the community itself by violating its core values, such as privacy, autonomy, or equality.

Progressive property's communitarian orientation offers explanations that the utilitarianism associated with neoclassical law and economics cannot. Because the communal good is more than just the aggregation of interests, human flourishing would not support taking and using an individual's genetic information without her consent, regardless of net welfare. Progressive property therefore both protects against exploitation and explains informed consent in a way that neoclassical economic theory does not.

Regarding people's intuitions of ownership and fears of commodification, progressive property recognizes the role that communities play in identity. Alexander explains that our identities are inevitably bound up in the communities to which we belong.<sup>370</sup> Nowhere is the connection between identity and genetic community clearer than in the case of the Havasupai. As one author explains, "mishandling one person's blood causes significant damages and disrupts the community, the family, and that person's spiritual welfare."<sup>371</sup> Of course, genetic communities are not linked only by family heritage. They could also be the result of shared genetic traits, such as the populations affected by Tay-Sachs or breast cancer. Progressive property recognizes the value that genetic data might hold and can thus better explain why people believe they should own their genetic information or fear its commodification.

And, unlike neoclassical law and economics, progressive property's communitarianism can explain why people participate in research even without financial incentives to do so. Research participants sometimes speak in terms of civic duties.<sup>372</sup> Take breast cancer survivor and recent Myriad complainant AnneMarie Ciccarella, who stated that she did not want access to her genetic information for herself but rather so she could pass that data on to researchers.<sup>373</sup> She explained that, "I want to see that the research community has access to every bit of data that has been generated from my body."<sup>374</sup> Similarly, the executive chairman of Genos described his company's services as "a way of being a philanthropist for [the] \$400" cost of sequencing because it enabled individuals to share their data with researchers.<sup>375</sup> Pro-

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370 Alexander, *supra* note 1, at 766–67.

371 Drabiak-Syed, *supra* note 146, at 214.

372 See Lee, *supra* note 290 (discussing civic republicanism as a motivation for personal genetic testing).

373 Health Information Privacy Complaint, *supra* note 17, at 12.

374 See Hayden, *supra* note 17.

375 Karow, *supra* note 183.

gressive property can therefore explain research altruism in a way that pure neoclassical law and economics cannot.

### 3. Genetic Distributive Justice

Whereas progressive property's value pluralism and communitarian attributes offer better descriptive accounts for laws, intuitions, and behaviors, distributive justice provides a better normative framework for law and policymaking than its neoclassical law and economics counterpart, cost-benefit analysis. While cost-benefit analysis has a place in bioethics, it should not be the only analytical tool.

Analyzing costs and benefits collectively may generate deeply troubling distributional questions and obscure key issues of social justice. As both Martha Nussbaum and Madhavi Sunder have made clear, utilitarianism neglects distributive questions.<sup>376</sup> By looking only to aggregated interests, as a property theory, utilitarianism hides that a significant portion of wealth may be concentrated among a small group of people, thereby masking even serious disparities. Thus, neoclassical economic theory, with its pure Benthamite underpinnings, cannot begin to capture the distributive justice concerns associated with genetic ownership.

By contrast, progressive property allows for redistribution. As such, it may avoid the sense of exploitation that tends to be overlooked in a neoclassical economic regime. In the case of Native American communities, one scholar has criticized research on those populations as rendering them "passive pincushions" with no input on the studies being done on their biospecimens.<sup>377</sup> Criticisms of this practice reflect the utilitarian tendencies of biomedical research: researchers have thought in terms of the benefit to society as a whole and not in terms of the individuals affected or the principles of the tribes to which they belong.<sup>378</sup> A progressive property approach would not allow such a result. It would ensure that the idea of genetic ownership attends to the values—like dignity, cultural identity, and spirituality—that were implicated by, but ignored in, the Havasupai case.

Under a progressive property framework, individuals would have sufficient genetic ownership rights to allow them to make meaningful choices about how to exercise their capabilities. Acknowledging genetic ownership interests for people who contribute genetic material could facilitate their flourishing in a variety of ways. Having those rights would create the necessary trust and predictability for people to feel comfortable participating in genetic and genomic research. Individual genetic ownership rights may then assuage anxieties about misuse and exploitation.

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376 Sunder, *supra* note 80, at 284.

377 Harry, *supra* note 143, at 189 (citing JONATHAN MARKS, *WHAT IT MEANS TO BE 98% CHIMPANZEE* 217 (2002)); *see also* Drabiak-Syed, *supra* note 146, at 212 (quoting Harry, *supra* note 143, at 189).

378 *See* Drabiak-Syed, *supra* note 146, at 212.

Additionally, legally recognized genetic ownership rights could result in financial compensation or access to new technologies. Sources of genetic data would enjoy some measure of wealth in the exchange. This wealth exchange could contribute to flourishing by giving DNA contributors access to resources that could improve their health and well-being, such as genetic and genomic diagnostics and treatments, or simply money to improve their lot in life.

Finally, an individual may willingly forgo her genetic ownership rights and donate her DNA because she finds that choice personally fulfilling. One benefit of recognizing genetic ownership rights for sources of biospecimens is that it provides the opportunity to be generous,<sup>379</sup> and generosity is frequently part of a life well-lived. Perhaps counterintuitively, part of the value of genetic ownership rights for people who contribute DNA is their ability to give those very same rights away.

As in the context of real property, the existence of community can create obligations to fellow community members in the context of genetic data. Recall that communities are necessary for flourishing because having and exercising capabilities requires social structures that provide the necessary resources and opportunities. In stark contrast to rational choice theory, a progressive property approach to genetic ownership does not assume uninhibited self-interest. Instead, it obliges both members of the biotech industry and people who contribute DNA to consider the interests of other stakeholders when invoking their genetic ownership rights. Progressive property by its very nature not only avoids exploitation but also promotes dignity and respect. Such an approach to genetic ownership would repair the damage done to research relations by the stories of John Moore, Henrietta Lacks, the *Greenberg* plaintiffs, and the Havasupai.

### B. *Applying the Model*

Having made the case for progressive genetic ownership and laid out its basic characteristics, the Article now revisits the genetic ownership entitlements from Part I to assess how a progressive property approach might address some famous genetic ownership controversies.

#### 1. Right to Exclude

The need for people to participate in research is akin to a NIMBY problem. While society as a whole could benefit from the LULU or the research, only a particular subset of individuals personally bears the risks and potential costs of those endeavors. As argued by Contreras, the right to exclude via the doctrine of informed consent constitutes the greatest obstacle for researchers and members of the biotech industry. While some genetic companies are entertaining offering financial incentives, they run the risk of crowding out other, nonmonetary reasons for research participation. Does progressive

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379 See ALEXANDER & PEÑALVER, *supra* note 6, at 83–84.

property offer a better solution for the genetic ownership controversies that implicate a right to exclude?

It does. To illustrate, consider the Havasupai who asserted that they were denied the opportunity to exclude research on mental illness, migratory patterns, and inbreeding. Recall that a district judge in that case dismissed the tribe's informed consent claim, finding that by having their blood drawn and signing broad consents, the tribe had effectively agreed to the research.<sup>380</sup> This result is arguably satisfying from a neoclassical economic perspective. The tribe had incurred any costs related to the research when members had their blood drawn for the diabetes study, and using broad consents promotes efficiency by eliminating the costs of having to go back and obtain additional consent for subsequent research. However, progressive property would yield a different result. A judge adopting a progressive property framework would consider the genetic values at stake within the relevant communities. Some values will always be present in the context of genetic research, such as the social welfare concerns associated with scientific advancement and the efficient use of scarce resources. Another near ubiquitous value in genetic research, at least in the United States, is industry or material wealth, assuming the resulting innovations would be commercialized. Finally, society has an overarching interest in justice and human dignity. Researchers themselves will have their own autonomy and identity concerns related to their work. For the Havasupai, the relevant values pertain to respect for identity, personhood, dignity, and culture, as the nondiabetes research violated their beliefs and was potentially stigmatizing. The judge hearing the case for the Havasupai might well then decide that one line of research would so violate the tribe's deontological interests that no amount of social benefit or wealth creation could justify it without obtaining clear subsequent consent.

However, a progressive property-oriented judge will not always find in favor of enforcing informed consent-based rights to exclude. The Havasupai cited very clear deontological concerns that the research on their genetic data raised. By contrast, the parents in the Texas newborn blood spot controversy had less specific objections. Mainly, they were outraged that unconsented samples were being used for research of any kind, not because any proposed research project violated a specific moral value. In cases that do not raise specific deontological concerns, a judge might well decide that the potential benefits of the research make a broad consent—or even an exception to the doctrine of informed consent, as with the newborn screening program—acceptable under the circumstances.

## 2. Right to Access

Individuals also enjoy certain access rights in their genetic data. Like the right to exclude, judges could decide whether enforcing those rights in a

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380 See *Tilousi v. Ariz. State Univ.*, No. 04-CV-1290, 2005 WL 6199562, at \*2 (D. Ariz. Mar. 3, 2005).

given context would promote human flourishing. If allowing access would, for example, empower individuals and facilitate advances in research, a judge may be inclined to enforce the access rights to genetic test results granted under the HIPAA regulations broadly. A broad construction of access rights would be most useful in situations where database administrators, like Myriad, are trying to restrict access due to perverse incentives.

As with the right to exclude, a progressive property-oriented judge may not always decide that exercising a right to access will lead to human flourishing. State newborn screening programs offer a useful analogy. Texas is not the only state that pricks the heels of its newborns. Every state has a screening program that tests for certain genetic conditions.<sup>381</sup> While the number of tests varies by state, all of the programs share at least one common attribute: they only screen for early onset, treatable diseases.<sup>382</sup> Likewise, adoption agencies conduct genetic screening of children before placing them, but again typically only for diseases that manifest during childhood.<sup>383</sup> In other words, a newborn screening program or an adoption agency will not test a child for cancer or Alzheimer's risk. Restricting genetic testing to childhood diseases demonstrates that sometimes stakeholders believe that it is best *not* to access certain genetic information.<sup>384</sup> A judge might then grant a potential adoptive parent's request for genetic test results about childhood disease but deny it with respect to a request for genetic test results about conditions that manifest in adulthood.

### 3. Right to Commercialize

Judges could opt to enforce individuals' commercial rights negotiated via contract using a progressive property model. Imagine a contractual dispute over research proceeds from a lucrative line of study, in which researchers had agreed to share profits and pay royalties for accessing the genetic data.<sup>385</sup> A judge hearing the case could consider the various values in play when deciding whether to enforce the contract. How integral was the genetic data to the research? What were the expectations of the parties? Would failing to enforce a particular result compromise the DNA contributor's autonomy or sense of identity? Would enforcing the right undermine future socially valuable research? All of these questions could inform how broadly a judge reads the contract or resolves the dispute.

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381 Ang Xu et al., *Delays in State Adoption of Newborn Screening Tests*, PEDIATRICS, Dec. 2017, <http://pediatrics.aappublications.org/content/early/2017/12/18/peds.2017-0300>.

382 *Id.*

383 See AM. SOC'Y OF HUMAN GENETICS SOC. ISSUES COMM. & AM. COLL. OF MED. GENETICS SOC., ETHICAL, AND LEGAL ISSUES COMM., *Genetic Testing in Adoption*, in 66 AM. J. HUM. GENETICS 761, 761-62 (2000).

384 See *id.* at 764; see also Ellen Wright Clayton, *Screening and Treatment of Newborns*, 29 Hous. L. REV. 85, 103 (1992) (discussing the effects of labeling a child as "deviant" via newborn screening).

385 See Rao, *supra* note 132, at 375.

Of course, not all people want to commercialize their genetic data. Take the *Greenberg* plaintiffs, who freely gave their genetic information with the expectation that all resulting research would remain in the public domain.<sup>386</sup> For them, the foremost concern was diagnosing and treating the disease. When they settled their case, one condition of the settlement agreement was that their genetic data would *not* be aggressively commercialized.<sup>387</sup> A judge might then also be confronted with an agreement *not* to commercialize genetic data. Using progressive property as the predominant model would allow the judge to consider how enforcing an agreement not to commercialize would impact human flourishing.

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As compared to neoclassical economic theory, a progressive property approach better reflects the plural values, communitarian interests, and distributive justice concerns that are inherent in the genetic ownership context. Accordingly, it offers superior descriptive and normative accounts of genetic data. Value pluralism and communitarianism more readily explain the existence of genetic ownership rights, as well as people's intuitions and behaviors related to their genetic data; and distributive justice offers a normative approach that reflects concerns about exploitation and social justice. The advantages of a progressive property lens play out when revisiting several of the genetic ownership entitlements and controversies outlined in Part I.

#### CONCLUSION

The preceding pages have demonstrated that progressive property has much to offer in genetic ownership disputes—yet do disputes over genetic ownership have anything to offer progressive property? It might initially seem that successfully applying progressive property to genetic data indicates its superiority across all kinds of property disputes. After all, the differences between a parcel of real property and a DNA sequence are immediately apparent. But genetic data shares more with land than might initially appear. Both are unique, both are inheritable, and both are tied to family and community. This Article concludes by outlining the analogy between land and genetic data to consider progressive property's utility beyond land use.

Genetic data differs from property in several key ways. First, land is both tangible and rivalrous. The limited and finite supply of land is the very reason why the law tends to reject the notion that land is fungible.<sup>388</sup> Once we run out of land we cannot simply make more.<sup>389</sup> And giving one person rights in land may limit the ability of others to use that land.

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386 *See id.* at 373.

387 *Id.* at 374.

388 *See* Peñalver, *supra* note 1, at 832.

389 Of course, that does not stop people from trying. *See, e.g.,* Samanth Subramanian, *How Singapore Is Creating More Land for Itself*, N.Y. TIMES MAG. (Apr. 20, 2017), <https://>



By contrast, genetic data is neither tangible nor rivalrous. Unlike tracts of land, or even blood and hair, two different parties can have complete possession of the exact same genetic information at the exact same time and not inhibit the other party's use.<sup>390</sup> If a lab is analyzing my DNA for a study, my organs will still function, my cells will still replicate, and I can still pursue my hopes and dreams. The intangible, nonrivalrous nature of genetic data makes it especially challenging to regulate. While a landowner can build a fence or a tollbooth, owners have more difficulty policing the use of genetic data,<sup>391</sup> especially once it is in the hands of a third party.

Because of its physicality, changes to land are determinative and enduring. As Peñalver observes, once you make a tract of land into a garbage dump it will probably stay a garbage dump.<sup>392</sup> Although genetic data is arguably "fixed" (we are born with our genetic information and can do little to change it), because DNA replicates, researchers can experiment with all kinds of uses, discard a sample, and make more.

Moreover, land ownership—particularly homeownership—gives owners access to nonfungible goods in a way genetic ownership does not. These goods include things like adult independence, personal responsibility, access to the American dream, social personhood, the ability to craft one's living space to one's preferences, access to communal resources like schools, and social relationships among neighbors.<sup>393</sup> There are not equivalents for genetic data. Put simply, you do not need a right in your genetic data in the same way you need a place to sleep at night. Consequently, genetic ownership is not as immediately bound up with human flourishing.

Alienability represents yet another way that genetic data differs from land. Alienability is the characteristic of property that allows owners to transfer rights. However, we share our genetic information with our relatives immutably and, even if we sell rights to access and use that data, we will never be able to transfer away all of our genetic data.<sup>394</sup>

Given the profound differences between these two kinds of property, successfully applying progressive property to genetic ownership seems to demonstrate its applicability beyond land use. If progressive property provides an equally effective lens for resolving ownership disputes both related to land (a tangible, rivalrous, and scarce object of ownership) and related to genetic data (an intangible, nonrivalrous, and replenishable object of ownership), it suggests progressive property's potential as a model for all types of

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[www.nytimes.com/2017/04/20/magazine/how-singapore-is-creating-more-land-for-itself.html](http://www.nytimes.com/2017/04/20/magazine/how-singapore-is-creating-more-land-for-itself.html).

390 As Pilar Ossorio quips, "If a researcher creates an immortalized cell line from my cells and . . . licenses that cell line to a biotechnology company for a million dollars, that will not prevent me from traveling on my vacation, writing a play, or getting a pet." Ossorio, *supra* note 295, at 232.

391 See Contreras, *supra* note 146, at 52.

392 See Peñalver, *supra* note 1, at 829–30.

393 See *id.* at 835–38.

394 See Ram, *supra* note 14, at 903–04; see also Hall, *supra* note 192, at 657.

conflicts over ownership. However, the differences between land and genetic data turn out to be largely superficial.

Indeed, genetic data and land may have more in common than meets the eye. First, both are unique. Peñalver uses the uniqueness of land as his point of departure in *Land Virtues*, explaining that the land—unlike most other resources—“resists generalization.”<sup>395</sup> Likewise, an individual’s genetic data is unique. Recall the discussion regarding the personal and communal relevance of DNA. Despite the fact that we share 99.9% of our genetic information with other humans,<sup>396</sup> that small bit of difference is entirely our own. Even identical twins, born from the same egg and sperm, do not have the exact same genetic profiles.<sup>397</sup> The uniqueness of our genetic data is the very thing that raises concerns about the de-identifiability of genetic information in research. It would seem that if a researcher is studying genetic variation, the DNA could always be traced back to the individual, or at least the family, from which it came.

Second, both land and genetic information are inherited, giving them familial and intergenerational elements. As Singer points out, people not only acquire property through the market but also from their families, via inheritance and marriage.<sup>398</sup> This connection to family gives land an element of intergenerational stability.<sup>399</sup> Individuals may thus experience both temporal and intergenerational psychological attachments to the land they own if it has been in the family for a significant period of time.<sup>400</sup> Land also represents a connection to neighborhoods and communities. The place someone is born can shape her opportunities and preferences,<sup>401</sup> raising issues of intergenerational justice.

People also have psychological attachments to their genetic data that include familial and temporal elements. Parents pass down their genetic information, which they received from their own parents, to their biological children. Hence, we share even more genetic similarity with our close relatives than with the general population. Genetic data literally ties us to our ancestors through strings of DNA, giving our genetic profiles intergenerational significance. We are born into the same “genetic neighborhood” as our parents and grandparents, sisters and brothers, cousins, and so on. Although Ram discusses the involuntary sharing of genetic information with family members to distinguish genetic data from property,<sup>402</sup> we likewise do

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395 Peñalver, *supra* note 1, at 828.

396 See *supra* note 117 and accompanying text.

397 See Anne Casselman, *Identical Twins’ Genes Are Not Identical*, SCI. AM. (Apr. 3, 2008), <https://www.scientificamerican.com/article/identical-twins-genes-are-not-identical/>; Tia Ghose, *Identical Twins Are Genetically Different, Research Suggests*, LIVE SCI. (Nov. 9, 2012), <https://www.livescience.com/24694-identical-twins-not-identical.html>.

398 Singer, *supra* note 62, at 1022.

399 See Peñalver, *supra* note 1, at 822, 830 (discussing intergenerational relevance of land).

400 *Id.* at 830.

401 See *id.* at 831 (discussing the significance of neighborhoods).

402 See Ram, *supra* note 14, at 904.

not choose the community into which we are born. Furthermore, where we are born may affect where we live in the future. Even as adults, we do not have free rein to select our communities because of the resources and choices available to us.<sup>403</sup> If we did, we might all live in Beverly Hills. Our genetic neighborhoods may then be more like our physical neighborhoods than might first appear.

These shared attributes generate a complexity of values surrounding both land and genetic data. The unique, familial, and intergenerational aspects are precisely what cause neoclassical economics to fail as a sound theoretical basis in both contexts. Peñalver explains that it is “land’s intrinsic complexity, and the complexity of its interactions with human well-being” that makes a wealth-maximizing, rational actor account fall short.<sup>404</sup> Because of these deontological concerns, homeowners do not behave like rational actors seeking only to maximize market value.<sup>405</sup> He observes that at least some of the failure of neoclassical law and economics in the context of land use stems from the absence of markets for certain socially important values, like preserving the wetlands, protecting endangered species, and providing housing for the homeless.<sup>406</sup> Another “nonmarketable good” inadequately captured by cost-benefit analysis is the interest of future generations.<sup>407</sup> Peñalver asks whether the tendency to discount the future effects of one’s actions undermines the ability of a current owner to adequately account for future concerns of the generations to come.<sup>408</sup> The discounting of future costs may raise issues of distributive justice that neoclassical economic theory and utilitarianism would be hard-pressed to resolve.

Peñalver’s insights apply with equal force to genetic ownership. Because genetic data is unique and replete with familial and intergenerational meaning, it confounds rational choice theory. Likewise, there are not well-developed markets for deontological concerns related to genetic information like autonomy, privacy, and identity. Finally, genetic ownership also raises concerns of discounting future costs. As C.S. Lewis poignantly describes in *The Abolition of Man*, genetic research may in fact lead to fewer—not more—options for future generations.<sup>409</sup> He explains:

[I]f any one age really attains, by eugenics and scientific education, the power to make its descendants what it pleases, all men who live after it are the patients of that power. They are weaker, not stronger: for though we may have put wonderful machines in their hands we have pre-ordained how they are to use them.<sup>410</sup>

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403 See generally David Schleicher, *Stuck! The Law and Economics of Residential Stagnation*, 127 YALE L.J. 78 (2017).

404 Peñalver, *supra* note 1, at 847.

405 *Id.* at 834.

406 *Id.* at 850.

407 *Id.* at 853.

408 *Id.* at 854.

409 C.S. LEWIS, *THE ABOLITION OF MAN* (1943).

410 *Id.* at 29.

Lewis goes on to assert that “[t]he last men, far from being the heirs of power, will be of all men most subject to the dead hand of the great planners and conditioners and will themselves exercise the least power upon the future.”<sup>411</sup> Thus, the lack of markets for important values and the tendency to discount future costs also affect genetic ownership. In sum, despite their fundamental differences, land and genetic data share common attributes, and it is these commonalities that make a progressive property model appropriate for both.

While disputes involving land and genetic data may be particularly well suited to progressive property, not all property conflicts require a value pluralist, communitarian, and redistributive model. The reason neoclassical law and economics fails both with respect to land use and to genetic data stems from specific qualities related to those forms of property and the parties who are fighting over them. With their uniqueness and their ties to family, community, and identity, both land and genetic data may implicate multiple plural and incommensurable values. Likewise, disputes over ownership of these assets affect communities with various kinds of concerns, not just individual rational actors. Finally, the relevant parties may not be equally situated with respect to distribution. Large development companies and the government have significant advantages when acquiring and cultivating land and researchers and biotech companies have significant advantages when commercializing genetic data.

This observation even allows us to refine our understanding of progressive property within land use. Progressive property might be the proper lens for resolving ownership conflicts when large developers or the government come into low-income communities and seek to displace people with little means for recourse. However, neoclassical economic theory may be a perfectly sufficient theoretical lens when the property dispute occurs between two equally sophisticated commercial entities driven only by economic considerations. In short, we may not need progressive property in the context of commercial real estate. Thus, it is the nature of the object of ownership, as well as the parties involved, that dictates the appropriate property theory in a given case.

In conclusion, genetic ownership demonstrates the versatility of the progressive view of property. However, this case study does not establish progressive property as a universally desirable theory. Genetic data shares some surprising commonalities with land, including uniqueness, a link to identity, and community/family ties. Thus, progressive property offers a useful lens for ownership conflicts when the entitlement implicates plural and incommensurable values, when the parties do not act with self-interest, and when the dispute raises distributive concerns. However, for conflicts involving fungible assets that lack deontological significance or that do not raise questions of distributive justice—such as shares of stock, mass-produced commercial

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411 *Id.* at 30.

goods, or even commercial real estate—neoclassical law and economics may still offer a better approach.