# NOTE: GENETIC LIBERTY, GENETIC PROPERTY: PROTECTING GENETIC INFORMATION

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# **Highlight**

Information wants to be free. <sup>1</sup>

Information is valuable and easily stolen. <sup>2</sup>

#### **Text**

## [\*613]

Introduction

Though it has clearly taken on a life of its own, most people attribute the origins of the phrase to Stewart Brand, The Media Lab 202, 211 (1987); see also Jon Katz, The Netizen, Birth of a Digital Nation, Wired, Apr. 1997, available at <a href="http://www.wired.com/wired/5.04/netizen">http://www.wired.com/wired/5.04/netizen</a> pr.html ... (reviewing a survey of network users, noting that "the single dominant ethic in this community is that information wants to be free").

R. Polk Wagner, Information Wants to Be Free: Intellectual Property and the Mythologies of Control, 103 Colum. L. Rev. 995, 999 n.14 (2003) (original internal citation format and web address). "Ideas should freely spread from one to another over the globe, for the moral and mutual instruction of man, and the improvement of his condition, seems to have been peculiarly and benevolently designed by nature ...." Letter from Thomas Jefferson to Isaac McPherson (Aug. 13, 1813), in Thomas Jefferson: Writings 1286, 1291 (Merrill D. Peterson ed., 1984) [hereinafter Letter from Jefferson]. To be clear, Jefferson, who reviewed the first patent granted by the United States, certainly believed in the protection of the creators of intellectual property under intellectual property regimes, but that these rights were given "for the benefit of society." Id. at 1292.

<sup>&</sup>lt;sup>1</sup> R. Polk Wagner identifies the origin of this ubiquitous phrase:

<sup>&</sup>lt;sup>2</sup> These words imply a property right in information. But see Lawrence Lessig, The Future of Ideas: The Fate of the Commons in a Connected World, at vii-viii (2001) (noting that information is heavily regulated, Lessig argues against the use of property regimes for protecting information that he believes is a part of a collective commons).

"Police hunting for the BTK serial killer kicked down Roger Valadez's door and went in with guns drawn. They handcuffed the Wichita man, then took a sample of DNA <sup>3</sup> from his mouth with a swab. That swab proved Valadez was not [the] BTK [killer]. Now he wants it destroyed ... ." <sup>4</sup> Valadez's lawyer, Dan Monnat, "warned DNA information is maybe the most intimate information about a person. There is no reason for that information to be unnecessarily in the government's files. Who knows what future use the 21st century will find for DNA?" <sup>5</sup>

One single strand of your hair, a drop of your blood, or a cheek cell from inside your mouth can reveal your deepest genetic secrets, **[\*614]** potentially exposing you to tremendous peril. <sup>6</sup> This genetic material is the physical material in which genetic information is contained and from which it can be extracted. <sup>7</sup> The control of this genetic information is at the heart of controlling and protecting an individual's rights.

"Genetic Liberty" is defined as the personal control of all aspects of a person's genetic make-up, including genetic material and information. <sup>8</sup> This note surveys the literature written on the control and misuse of genetic information and also examines current federal and state laws regarding genetics and an individual's genetic liberty. This includes an analysis of the latest incarnation of the Genetic Information Nondiscrimination Act ("GINA"). <sup>9</sup> Finally, this note explores solutions to the problems regarding the use and control of genetic information.

The Supreme Court's "misuse" and "misunderstanding of genetics" in Buck v. Bell <sup>10</sup> left a dark and fearful legacy regarding the **[\*615]** use of genetic information. <sup>11</sup> The fears associated with the misuse of genetic information spring, in part, from knowledge of society's "often moralistic attitudes toward sickness and the continuing human

<sup>&</sup>lt;sup>3</sup> DNA" is the abbreviation for "deoxyribonucleic acid." Black's Law Dictionary 516 (8th ed. 2004).

<sup>&</sup>lt;sup>4</sup> Roxana Hegeman, Former BTK Suspect Seeks Destruction of DNA Profile, Laredo Morning Times, Mar. 22, 2005, at 8A.

<sup>&</sup>lt;sup>5</sup> Id. (citation and quotations omitted).

<sup>&</sup>lt;sup>6</sup> Even a person's birth date, while not usually thought of as genetic information, is at least analogous to or related to genetic information and is tied to a propensity to certain maladies. See Erika Niedowski, Birth Month May Predict Future Disease, Ann Arbor News, Aug. 21, 2004, at A8. See also infra Part I.E.

<sup>&</sup>lt;sup>7</sup> There is a standing controversy regarding whether body parts and genetic material are actually property. See, e.g., *Moore v. Regents of the Univ. of Cal., 793 P.2d 479 (Cal. 1990)*; Mary Taylor Danforth, Cells, Sales, and Royalties: The Patient's Right to a Portion of the Profits, 6 Yale L. & Pol'y Rev. 179 (1988); Melvin S. Faigus, Moore v. Regents of the University of California - A Breach of Confidentiality Within the Physician-Patient Relationship: Should Unique Genetic Information be Considered a Trade Secret?, 24 UWLA L. Rev. 299 (1993). I argue that body parts and genetic material are property. Furthermore, I argue that genetic information, as distinct from mere genetic material, is property as well. This note focuses on genetic information. In this note, genetic information is conceptualized as both the information contained in and derived from genetic material.

<sup>&</sup>lt;sup>8</sup> See Robert C. King & William D. Stansfield, A Dictionary of Genetics 140 (5th ed. 1997) ("Genetic information" in the field of genetics is "the information contained in a sequence of nucleotide bases in a nucleic acid molecule."); Nora O'Callaghan, Human Origins and Human Rights in the Genome Age, <u>3 Ave Maria L. Rev. 123, 123 (2005)</u> (positing that a person is substantially more than just his genetic materials and information). This note adopts a slightly broader definition of genetic information to include information derivable from and manifested in the body by genetic information. The term "liberty" in this note means not necessarily license, or a right to do whatever on wishes, but rather carries with it the duties and responsibilities that are inherent to any recognition of rights.

<sup>&</sup>lt;sup>9</sup> Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005) [hereinafter Genetic Information Nondiscrimination Act]. As of publication, this bill passed in the Senate on Feb. 17, 2005, but the House version (H.R. 1227) is still pending in committee. See infra Part II.A.1.a.

<sup>&</sup>lt;sup>10</sup> <u>274 U.S. 200 (1927)</u>. This case memorializes the infamous words of Justice Oliver Wendell Holmes that "three generations of imbeciles are enough," said in regards to the sterilization of a mentally retarded female inmate by salpingectomy, a procedure that severs the fallopian tubes. <u>Id. at 207</u>. Holmes wrote that "society can prevent those who are manifestly unfit from continuing their kind." Id.

<sup>&</sup>lt;sup>11</sup> Barry R. Furrow et al., Bioethics: Health Care Law and Ethics 172 (4th ed. 2001).

history of exclusion and discrimination against minorities and the disabled," and the "pseudo-genetic genocidal campaign in Nazi Germany." <sup>12</sup> The missteps of the past, however, can be avoided in the future by properly protecting genetic information.

The "recent explosion in [genetic] information," in large part due to the completion of the Human Genome Project ("HGP"), <sup>13</sup> will impact legal and policy issues, including social and ethical issues, privacy and confidentiality, criminal justice, informed consent, discrimination, intellectual property, and fairness in risk assessment. It will even influence our understanding of concepts such as illness and health. <sup>14</sup>

Current state and federal legislation does not protect genetic information as it should. Despite state and federal legislation, information can be gleaned from our genetic material without our consent. <sup>15</sup> Genetic information may give insurers a convenient excuse to deny or limit insurance to you and your progeny. <sup>16</sup> The misuse of genetic information raises the possibility that you and your children [\*616] could become uninsurable or unemployable in perpetuity. <sup>17</sup> The current insurance infrastructure simply will not work in a world where we can predict with great precision the diseases a person will acquire. <sup>18</sup>

If genetic information is not protectible, then no one is accountable for stealing, using, selling, or otherwise wrongfully appropriating your genetic information. <sup>19</sup> It is res nullius, <sup>20</sup> an ownerless chattel that belongs to no one

Knowledge of the complete chemical sequence of all human genes promises greatly increased powers for genetic screening of individuals and embryos. Numerous studies are already seeking to correlate phenotypic traits (and not only those connected with disease) with the presence or absence of certain genetic markers. Scientists have reported early success with directed genetic change in embryos of non-human animals (including primates), though many more attempts have failed.

Id. at 31 (footnote omitted).

<sup>14</sup> See Furrow et al., supra note 10, at 172, 175. Diseases identified with a significant genetic basis include Huntington's Disease, Alzheimer's Disease, cystic fibrosis, obesity, sickle cell anemia, and breast cancer. See id. at 172-73.

<sup>15</sup> Manipulation of human genes creates new threats to the health of individuals and their offspring, and endangers human rights, privacy and dignity." Council for Responsible Genetics, The Genetic Bill of Rights (2000), in Rights and Liberties in the Biotech Age: Why We Need a Genetic Bill of Rights app. at 223 (Sheldon Krimsky & Peter Shorett, eds., 2005) [hereinafter Genetic Bill of Rights].

- <sup>16</sup> Genetic information also provides information that employers can use to discriminate. The possibilities for potential harm and mischief regarding the misuse of genetic information touch every aspect of life from work to insurance to the way we are viewed in our families and communities. See infra Part I.D. (examining the implication of the misuse of genetic information in the contexts of employment, criminal law, and social structures). This note focuses primarily on the impact of genetic information on forms of insurance.
- <sup>17</sup> See infra Part I.D. Certain market mechanisms would provide insurance and perhaps employment opportunities of some kind, but likely at a relatively high cost.
- <sup>18</sup> Recently, Senator Michael Enzi correctly framed the genetic information dilemma when he stated: "Operating according to the instructions contained in the DNA, cells in the body produce proteins that control the expression of our individual heredity, e.g., color of hair and eyes, and determine, in part, whether we will be sick or well." 151 Cong. Rec. S1596 (daily ed. Feb. 17, 2005) (statement of Sen. Enzi) (emphasis added).
- <sup>19</sup> The author realizes that "protectible" is not yet universally recognized as an English word. Its lack of grace and beauty is compensated for by its directness and efficiency in replacing such phrases as "able to be protected." Furthermore, the word "protectible" is used in legal opinions. See, e.g., *Elk Grove Unified Sch. Dist. v. Newdow, 542 U.S. 1, 15 n.7 (2004)*; *Wisconsin v. Yoder, 406 U.S. 205, 243 (1972)* (Douglas, J., dissenting); *Laureyssens v. Idea Group, Inc., 964 F.2d 131, 140-42 (2d Cir. 1992)*.

<sup>&</sup>lt;sup>12</sup> Id.

<sup>&</sup>lt;sup>13</sup> Id. at 171. See also President's Council on Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Happiness (2003)

- and everyone. <sup>21</sup> A person's genetic information, including his genetic code, <sup>22</sup> should be protectible as intangible personal property, or at least as quasi property, intellectual property, or a privacy interest protected by tort. This would exclude others from taking, using, receiving, selling, or otherwise misusing an individual's genetic information without the express consent of the owner. <sup>23</sup>

An individual's genetic liberty is best protected by laws that treat genetic information as a kind of private property and not through a privacy regime. Genetic information can be protected as personal property in many ways, including as quasi property, as jura in re **[\*617]** propria, <sup>24</sup> or what I call "quasi in rem property." <sup>25</sup> One can make a principled argument that genetic information is best protected as tangi non possunt - an incorporeal thing - "the subject matter of a right ... within the sphere of proprietary or valuable rights." <sup>26</sup> "Our concept of "things' can be "reframed'" <sup>27</sup> over time and must be reframed to include genetic information. Personal genetic information is certainly personal property; no other individual or entity has a clearer or more justifiable claim over the information than the person to whom it pertains. This note concludes that a person's genetic information should be protected as personal property and not as a privacy interest.

- <sup>20</sup> Black's Law Dictionary, supra note 3, at 1337. As such, one's genetic information becomes subject to a kind of profit a prendre for anyone who wishes to take away this something of value that is part of the "soil" and soul of man. See id. at 1247.
- <sup>21</sup> Cf. Garrett Hardin, The Tragedy of the Commons, 162 Science 1243, 1244 (1968) (exploring implications of holding commodities in common).
- <sup>22</sup> Genetic code [is] the consecutive nucleotide triplets (codons) of DNA and RNA that specify the sequence of amino acids for protein synthesis." King & Stansfield, supra note 8, at 138.
- <sup>23</sup> An essential element of individual property is the legal right to exclude others from enjoying it. If the property is private, the right of exclusion may be absolute; if the property is affected with a public interest, the right of exclusion is qualified." *Int'l News Serv. v. Associated Press, 248 U.S. 215, 250 (1918)* (Brandeis, J., dissenting) (emphasis added). But see John G. Sprankling, Understanding Property Law 5 (2000) (arguing that the right to exclude is not "a necessary component of property"). Professor Sprankling's examples, however easements, leasing, and rent control all recognize an implicit right to exclude that is abrogated only by law and is never abrogated completely without transfer of the property. Id.
- <sup>24</sup> Black's Law Dictionary, supra note 3, at 1253 (defining "jura in re propria").
- <sup>25</sup> Although cumbersome, the phrase "quasi in rem property" literally and properly conveys the idea that property is to be treated like the thing the thing being the body.
- <sup>26</sup> Black's Law Dictionary, supra note 3, at 1518 (defining "thing"). Despite danger of oversimplification and injuring the Latin, the author suggests that tangi non possunt, in the genetic information context, be called "intangible personal property." It is also useful to compare res sua, id. at 1339 ("one's own property"), with res incorporales, id. at 1336 (defining incorporeal, intangible things). Control of one's genetic information should be included in what was called in Roman and civil law a person's universitas juris, or the whole of an individual's rights, duties, and liabilities. See id. at 1573.
- <sup>27</sup> Martin v. Reynolds Metals Co., 342 P.2d 790, 793 (Or. 1959). The conceptualization of a "thing" can change and be "reframed" properly over time. In 1959, the Oregon Supreme Court, applying modern scientific observation to the law of trespass, which required the invasion of a trespassory "thing," expanded the concept of a "thing" to include gasses and microscopic particles:

It is quite possible that in an earlier day when science had not yet peered into the molecular and atomic world of small particles, the courts could not fit an invasion through unseen physical instrumentalities into the requirement that a trespass can result only from a direct invasion. But in this atomic age even the uneducated know the great and awful force contained in the atom and what it can do to a man's property if it is released. In fact, the now famous equation E=mc2 has taught us that mass and energy are equivalents and that our concept of "things" must be reframed.

Id. (emphasis added). Although this change is recognition of a distinction both of degree (recognizing very small particles as things) and of kind (mass and energy as equivalents), it illustrates that the law can expand to fit modern conceptualizations. It is possible that the reframing of intangible property can likewise properly expand to include genetic information.

Following the present introduction, Part I of this note examines genetic liberty, the biotechnology or bioinformatics revolution, and the dangers of the misuse of genetic information. Part II surveys the federal and state protection regimes. Part III explores the protection of an individual's genetic liberty in the context of property and quasi-property, intellectual property, tort, and privacy, and by using three hypothetical situations. A brief summary and conclusion then [\*618] follows. An appendix at the end of this note briefly describes the biology behind genetic information.

I.

"Genetic Liberty" and the Risks of the Misuse of Genetic Information

The information in one's genetic code can be thought of as a coded probabilistic future diary because it describes an important part of a unique and personal future. <sup>28</sup>

The rapidly increasing pace of technological change magnifies the many dangers inherent in the possible misuse of an individual's genetic information. <sup>29</sup> Some aspects of our genetic identity are **[\*619]** relatively obscure and intangible. <sup>30</sup> For example, a propensity to develop prostate cancer cannot be detected through normal observation. However, even data not easily hidden, such as our age <sup>31</sup> and birth date, may point toward our dispositions for developing diseases. <sup>32</sup>

<sup>28</sup> George J. Annas et al., Genetic Privacy Act and Commentary 5 (1995), <a href="http://www.ornl.gov/sci/techresources/Human">http://www.ornl.gov/sci/techresources/Human</a> Genome/resource/ privacy/privacy1.html. For further commentary on the Genetic Privacy Act, see Patricia (Winnie) Roche et al., The Genetic Privacy Act: A Proposal for National Legislation, <a href="https://www.ornl.gov/sci/techresources/Human">37 Jurimetrics J. 1 (1996)</a>.

<sup>29</sup> For an excellent law review article dealing with genetic information, see Catherine M. Valerio Barrad, Genetic Information and Property Theory, <u>87 Nw. U. L. Rev. 1037 (1993)</u>. Valerio Barrad explores rights in genetic information from the perspective of natural rights, Lockean labor, and traditional social utility and economic utility theories, concluding that:

No single theory of property justification is the obvious choice for the basis of all judicial analysis....

The courts should recognize that an individual has protectible property interests in the information encoded in his genetic material. The scope of those interests, however, will be determined by the reasoning process of the court and the theory of property justification that animates that process. At a minimum, it should respect individual autonomy and self-determination by encompassing the exclusive right of control over the use of genetic information. Only the person whose cells contain the genetic information should have the right to determine how that information will be used and to whom it should be disclosed.

Id. at 1085-86 (emphasis added). Other excellent articles include: Robyn B. Nicoll, Comment, Long-Term Care Insurance and Genetic Discrimination - Get It While You're Young and Ignorant: An Examination of Current Discriminatory Problems in Long-Term Care Insurance Through the Use of Genetic Information, 13 Alb. L.J. Sci. & Tech. 751 (2003); David F. Partlett, Misuse of Genetic Information: The Common Law and Professionals' Liability, 42 Washburn L.J. 489 (2003); Ralph Ruebner & Leslie Ann Reis, Hippocrates To HIPAA: A Foundation For a Federal Physician-Patient Privilege, 77 Temp. L. Rev. 505 (2004); and Natalie Anne Stepanuk, Comment, Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information, 47 Cath. U. L. Rev. 1105 (1998). Several helpful symposia also provide useful information. See, e.g., Symposium, At the Crossroads - Public/Private Priorities Concerning Access to Genetic Information, 6 J. Health Care L. & Pol'y 194 (2003); Symposium, Personal Genetic Information: Implications for the Workplace and Criminal Justice, 18 N.Y.L. Sch. J. Hum. Rts. 1 (2001); Symposium, Probing the Human Genome: Who Owns Genetic Information?, 4 B.U. J. Sci. & Tech. L. 67 (1998) [hereinafter Probing the Human Genome].

<sup>30</sup> This note uses the phrase "genetic identity" in a broad sense as connected to an individual's persona. A Dictionary of Genetics provides a more technical definition of "genetic identity" as "a measure of the proportion of genes that are identical in two populations." King & Stansfield, supra note 8, at 140.

<sup>31</sup> Children of Older Fathers Likelier to Develop Schizophrenia, AFP, Oct. 21, 2004, <a href="http://www.keepmedia.com/pubs/AFP/2004/10/21/617559">http://www.keepmedia.com/pubs/AFP/2004/10/21/617559</a> [hereinafter Children Likelier to Develop Schizophrenia] ("Children of older fathers face an enhanced risk of developing schizophrenia when they grow older .... More than 15 percent of cases may have been due to the fact that the patient had a father who was aged over 30 years at birth ....").

As the combination of advances in technology and the bioinformatics revolution unfolds, a person's genetic information will be accessible in greater and greater detail. Genetic liberty should be honored and genetic information protected, as personal property, from the dangers of unauthorized acquisition, use, or distribution.

A. Genetic Technology's Effect on Our View of Genetic Information

We need to look at the good things DNA has done ... I think some people are overwrought about their concerns. <sup>33</sup>

In California, police will be able in 2008 to take DNA samples from anyone arrested for a felony, whether the person is convicted or not  $\dots$  34

The future of genetic technology is bright. <sup>35</sup> The development of this technology raises several questions. Will the siren song of therapeutic advancement and utility in criminal investigation prove more powerful than the right of an individual to own or control **[\*620]** personal genetic information? <sup>36</sup> Will we be prisoners, slaves, or masters of our genetic information? Will we become a nation of genetic haves and have-nots? Furthermore, several biotech companies recently obtained exclusive rights to research and manipulate genetic material, including the patenting of human DNA sequences. <sup>37</sup> When will the rights of individuals in their genetic information catch up to the rights of corporations and entities to utilize this information?

In an oft-cited article quoted by the Court of Appeals of Maryland in State v. Raines, <sup>38</sup> Jeffrey S. Grand argued that genetic technology presents many grave dangers to personal privacy and security:

Although the intrusion of a buccal swab may be minimal in a physical sense, it certainly is great when the vast amount of personal and private information DNA contains is considered. As was recently explained:

"While the DNA profile is often referred to as a type of genetic "fingerprint,' this analogy is far too simplistic. Although current profiling methods utilize only limited amounts of genetic information, with the mapping of the human genome now underway, future DNA analysis may soon reveal an individual's medical history; proclivity toward certain diseases; and hereditary information such as race, physical, and behavioral traits. Thus, biological samples ... have the potential to reveal far more intimate information about the individual donor than a simple

<sup>&</sup>lt;sup>32</sup> See, e.g., Niedowski, supra note 6, at A8.

<sup>&</sup>lt;sup>33</sup> Hegeman, supra note 4, at 8A. Genetic samples, like the ones taken in the BTK investigation, "are evidence in a criminal investigation .... Under Kansas law, once they are no longer needed, a judge can decide what should be done with them." Id.

<sup>&</sup>lt;sup>34</sup> Id.

<sup>&</sup>lt;sup>35</sup> See, e.g., DNA Nabs 400 Crims, Herald Sun, (Melbourne, Australia) Apr. 28, 2003; DNA Tests Exclude Men Serving Life as Source of Evidence, Associate Press State & Local Wire, Apr. 29, 2003; Man Gets Life Term in 2 "Vicious' Rapes, Buffalo News, Apr. 26, 2003 (detailing the first ever local defendant convicted with DNA-linked evidence after the state's normal five-year statute of limitations); see also Leon R. Kass, Life, Liberty and the Defense of Dignity 121 (2002) [hereinafter Kass, Life].

<sup>&</sup>lt;sup>36</sup> See generally Barry Scheck, et al., Actual Innocence: Five Days to Execution and Other Dispatches from the Wrongly Convicted (2000) (chronicling the stories of ten wrongfully convicted inmates assisted by a pro bono civil rights group called "The Innocence Project").

<sup>&</sup>lt;sup>37</sup> For an example where human DNA sequences are a proper subject matter for protection under the patent regime, see <u>Amgen Inc. v. Hoechst Marion Roussel, Inc., 314 F.3d 1313, 1332 n.7 (Fed. Cir. 2003)</u>, in which the court notes that Amgen's patents expressly disclose the complete, albeit slightly incorrect, sequence of human genomic erythropoietin ("EPO") DNA and the encoded DNA. See also Donna M. Gitter, International Conflicts Over Patenting Human DNA Sequences in the United States and the European Union: An Argument for Compulsory Licensing and a Fair-Use Exemption, <u>76 N.Y.U. L. Rev. 1623, 1679-84 (2001)</u> (encouraging the U.S. Congress to enact compulsory licensing statutes and an experimental-use exemption for patents on human DNA sequences).

<sup>&</sup>lt;sup>38</sup> 857 A.2d 19 (Md. 2004).

fingerprint... . Unlike an individual's fingerprint, which use is limited to identification, information potentially contained **[\*621]** in a DNA profile may subject an individual to embarrassment, humiliation, public hostility, and even financial harm." <sup>39</sup>

This intimate information is increasingly imperiled in a world where genetic information is not protectible, increasingly accessible, and able to expose our genetic secrets forever.

#### B. DNA Is Forever

Some critics argue that genetic information, despite the promise and the hype, provides "magic-bullet results" in very few crimes. <sup>40</sup> This view, however, does not account for the virtual certainty that the ability to obtain and extract DNA evidence will progress over time. In the future, a tremendous amount of information will become available from minute amounts of genetic material, extracted over longer time horizons than currently feasible. <sup>41</sup> DNA samples exist in useful form for an indefinite period of time. <sup>42</sup> If a person does not own his genetic material, he can neither own nor protect his genetic identity, thus leaving it in peril indefinitely. <sup>43</sup> If no one owns something, then, by legal definition, no one can be guilty of stealing it. How can we best protect our genetic identity? The only way to protect genetic identity from theft is to create a legal property right in the genetic information that secures this identity. **[\*622]** 

C. The Human Genome Project and Beyond: The Bioinformatics Revolution

Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning. 44

The Human Genome Project was a comprehensive government effort to "map" the human genome. <sup>45</sup> The project finished years ahead of projections in part because Celera, a private company, competed with the HGP in a race to map the genome. The HGP provides a vast ocean of genomic data. This vast amount of genomic data, combined with other forms of data gathered regarding human composition and health care, is all part of the bioinformatics

<sup>&</sup>lt;sup>39</sup> <u>Id. at 62-63</u> (quoting Jeffrey S. Grand, The Blooding of America: Privacy and the DNA Dragnet, <u>23 Cardozo L. Rev. 2277,</u> 2288-89 (2002)) (emphasis added).

<sup>&</sup>lt;sup>40</sup> Edward Lazarus, Op-Ed, The Limits of DNA Justice; Testing Is No Substitute for a Fair Trial, Wash. Post, June 16, 2000, at A29.

<sup>&</sup>lt;sup>41</sup> See Geoffrey Christopher Rapp, Book Note, DNA's Dark Side, <u>110 Yale L.J. 163, 167 (2001)</u> ("Lazarus neglects to consider that DNA technology could advance to the point where a stray hair or a flake of dead skin could provide sufficient material for an identification. Still, the fact remains that DNA evidence, at the present time, is available for only a small number of those who might be wrongly convicted.").

<sup>&</sup>lt;sup>42</sup> Technically, heat, not time, causes DNA molecules to denature. However, time increases the likelihood that DNA molecules will be exposed to heat and ultraviolet light and thus begin to break down. See L. McNally et al., Evaluation of Deoxyribonucleic Acid (DNA) Isolated from Human Bloodstains Exposed to Ultraviolet Light, Heat, Humidity, and Soil Contamination, 34 J. Forensic Sci. 1059 (1989) (reporting that studies show heat, ultraviolet light, humidity, and soil contamination can work to degrade a DNA sample), cited in Rapp, supra note 41, at 169 n.30.

<sup>&</sup>lt;sup>43</sup> Justice Brandeis's influential dissent in <u>International News Service v. Associated Press, 248 U.S. 215, 255 (1918)</u> (Brandeis, J., dissenting) displayed a telling disdain for anything not "property in the strict sense" or not the exclusive tangible property right of another.

<sup>&</sup>lt;sup>44</sup> John Bartlett, Familiar Quotations 621 (Justin Kaplan ed., 16th ed. 1992) (quoting Winston Churchill's speech at Mansion House, London, Nov. 10, 1942).

<sup>&</sup>lt;sup>45</sup> Funded at a cost of three billion dollars and jointly operated by the National Institutes of Health and the Department of Energy, the Human Genome Project "is the largest coordinated effort in biology ever directed at a single goal." Comm. on Gov't Operations, Designing Genetic Information Policy: The Need for an Independent Policy Review of the Ethical, Legal, and Social Implications of the Human Genome Project, H.R. Rep. No. 102-478, at 3 (1992).

revolution. <sup>46</sup> This data must be carefully studied and analyzed to find meaning in this morass of information. <sup>47</sup> The HGP can help identify genetic relationships and reveal underlying causes for diseases. Some international efforts are underway to share information and resources regarding genetic material. <sup>48</sup> No one knows for sure what will come from this ocean of data; indeed some of it will contain our deepest genetic secrets and bear the potential to cause great harm to individuals in the form of genetic discrimination.

#### [\*623]

# D. The Dangers of the Misuse of Genetic Information

In Baton Rouge, La. [2003], police hunting a serial killer collected 1200 DNA samples. In Miami, police in 1994 gathered 2300 samples while investigating the killing of six prostitutes. <sup>49</sup>

By gathering a single hair left on an office chair, someone possesses the material to access the hair owner's genetic information. <sup>50</sup> If this person's information discloses propensities toward diseases or disorders (for example, a significant chance of having children afflicted with spina bifida), <sup>51</sup> this information could make individuals and their progeny permanently uninsurable. <sup>52</sup> The most important factor, by far, in determining access to health care is "whether an individual has public or private health insurance." <sup>53</sup> Furthermore, our genetic

<sup>&</sup>lt;sup>46</sup> Bioinformatics is defined as "the collection, classification, storage, and analysis of biochemical and biological information using computers especially as applied in molecular genetics and genomics." Webster's Third New International Dictionary (unabridged ed. 2002) [hereinafter Webster's Third].

<sup>&</sup>lt;sup>47</sup> The Human Genome Project Information website lists the studies that are the "next step" of "functional genomics," such as transcriptomics, proteomics, structural genomics, knockout studies, and comparative genomics. The Science Behind the Human Genome Project, <a href="http://www.ornl.gov/sci/techresources/Human">http://www.ornl.gov/sci/techresources/Human</a> Genome/project/info.shtml#posthgp [hereinafter Science Behind the Human Genome Project] (last visited Nov. 13, 2007).

<sup>&</sup>lt;sup>49</sup> Hegeman, supra note 4, at 8A.

<sup>&</sup>lt;sup>50</sup> The motion picture Gattaca explores a future of persons who are either "valid" (genetically engineered) or "in-valid" ("God-children" born without genetic engineering). Invalids who want to try to succeed in the world of the valids jealously guard every stray hair, eye lash, and skin cell because their genetic identity is contained within these human artifacts that human bodies continually leave behind. Gattaca (Columbia/TriStar Studios 1997).

<sup>&</sup>lt;sup>51</sup> Spina bifida is a genopathy that results in incomplete closure of the spine. In its most severe form, it can lead to muscle weakness, paralysis, and accumulation of fluid in the brain (hydrocephalus), which can result in blindness, seizures, and brain damage if left untreated. See Neural Tube Defect, 8 The New Encyclopedia Britannica 621 (15th ed. 2002). See generally Adrian Sandler, Living with Spina Bifida: A Guide for Families and Professionals (1997) (in-depth exploration of spina bifida).

<sup>&</sup>lt;sup>52</sup> It is possible that individuals will eventually have the opportunity to engineer their own genetic material and that of their children and will face the choice of genetic abortion or designing children who are insurable. See generally Francis Fukuyama, Our Posthuman Future: Consequences of the Biotechnology Revolution 72-83 (2002); Kass, Life, supra note 35, at 121; Leon R. Kass, Toward a More Natural Science 1-3 (1988) [hereinafter Kass, Natural Science].

<sup>&</sup>lt;sup>53</sup> Maxwell J. Mehlman & Jeffrey R. Botkin, Access to the Genome: The Challenge to Equality 62 (1998). In Chapter 5, this work identifies the perils surrounding "Access to Genetic Technologies," including: supply shortages, insurance coverage, coverage of genetic testing, coverage of genetic testing, coverage of genetic enhancement, and access to genetic technologies based on ability to pay. *Id. at* 55-87.

information is, with increasing frequency, compiled and stored in databases. This valuable information must be properly protected, and violators of the information punished. <sup>54</sup>

#### [\*624]

#### 1. Insurance Discrimination

Unprotected genetic information fosters genetic discrimination, especially in insurance and employment contexts. <sup>55</sup> For example, Theresa E. Morelli's insurance company cancelled her policy when it learned her father might have Huntington's Disease. <sup>56</sup> Her physician provided this information about her father to the underwriter - without Ms. Morelli's knowledge or consent. <sup>57</sup> The private Council for Responsible Genetics claims that hundreds of similar genetic discrimination cases have been documented. <sup>58</sup>

#### 2. Workplace Discrimination

There is also great danger of genetic discrimination in the workplace. For example, the Equal Employment Opportunity Commission ("EEOC") filed suit against Burlington Northern Santa Fe Railway for secretly testing for a rare genetic condition causing carpel tunnel syndrome. <sup>59</sup> The company used the same screening to look for genetic proclivities to diabetes and alcoholism. One employee who refused to be tested was threatened with termination. Cases like this prompted calls for federal legislation entirely banning genetic testing in the workplace.

A related problem, and one of the principal dangers of the misuse of genetic information, lies in the labeling of predispositions toward disease as "preexisting conditions," enabling underwriters or employers to deny or terminate insurance coverage or employment. [\*625] This danger is particularly acute in private insurance regimes. <sup>61</sup> The

See Diedtra Henderson, FDA Approves Use of Chip in Patients, Associated Press, Oct. 13, 2004 ("The Food and Drug Administration on Wednesday approved an implantable computer chip that can pass a patient's medical details to doctors [and others] with scanners and access to the patient."); Ryan Singel, Senate Wants Database Dragnet, Wired News, Oct. 6, 2004, <a href="http://www.wired.com/news/privacy/0,1848,65242,00.html">http://www.wired.com/news/privacy/0,1848,65242,00.html</a> ("The Senate could pass a bill as early as Wednesday evening that would let government counter-terrorist investigators instantly query a massive system of interconnected commercial and government databases that hold billions of records on Americans..... [Critics worry that] "if someone transfers your ... medical history, you have no way of knowing ....").

<sup>&</sup>lt;sup>55</sup> Elaine Draper, The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information, <u>20</u> <u>Berkeley J. Emp. & Lab. L. 286, 311 (1999)</u>.

<sup>&</sup>lt;sup>56</sup> Theresa E. Morelli, Genetic Discrimination by Insurers: Legal Protections Needed from Abuse of Biotechnology, 9 HealthSpan 8, 8 (1992).

<sup>&</sup>lt;sup>57</sup> Id.

<sup>&</sup>lt;sup>58</sup> Council for Responsible Genetics, Genetic Discrimination: A Position Paper Presented by the Council for Responsible Genetics (2001), <a href="http://www.gene-watch.org/educational/genetic">http://www.gene-watch.org/educational/genetic</a> discrimination.pdf.

<sup>&</sup>lt;sup>59</sup> William R. Corbett, The Need for a Revitalized Common Law of the Workplace, <u>69 Brook. L. Rev. 91, 107 (2003)</u>. The EEOC sued Burlington Northern Santa Fe Railway for genetic testing of employees, alleging a violation of the Americans with Disabilities Act. The case settled for \$ 2.2 million. Id.

<sup>&</sup>lt;sup>60</sup> See, e.g., Jennifer Krumm, Genetic Discrimination: Why Congress Must Ban Genetic Testing in the Workplace, 23 J. Legal Med. 491, 515-16 (2002).

<sup>&</sup>lt;sup>61</sup> Government insurance regimes like the Employment Retirement Income Security Act ("ERISA") generally discourage genetic discrimination through legislation like the Health Insurance Portability and Accountability Act ("HIPAA"). See infra Part II.A.1.

nature of genetic information is such that if a parent is uninsurable, his progeny may be uninsurable in perpetuity - at least until either the law protects us, or science can change our genes <sup>62</sup> or cure the genopathy. <sup>63</sup>

#### 3. Other Discrimination and Dangers

In addition to insurance and employment discrimination, there are other dangers that can arise from the misuse of genetic information. <sup>64</sup> The power of DNA evidence in criminal investigations may place many of our most precious liberties in jeopardy. <sup>65</sup> There is great peril of community discrimination and stigma regarding a person's genetic identity. <sup>66</sup> Stereotypes and generalizations regarding groups of people can be utilized to deny them employment or [\*626] insurance coverage. <sup>67</sup> The exploitation of genetic information also raises the specters of genetic monopolies <sup>68</sup> and "biopiracy." <sup>69</sup>

E. The Special Problems Presented by Biometric Data

In a unique arrangement, former Harvard Medical School professor Kari Stefansson has secured the exclusive right to create a genetic database from the health records of Iceland's entire population. Stefansson has already founded his own company, deCODE Genetics, in order to mine this genetic database and isolate the genes believed to cause 12 diseases. He has also entered into a \$ 200-\$ 300 million contract with the Swiss pharmaceutical company Hoffman-LaRoche to develop and market any drugs that may result from this research. All that Icelanders are to receive in exchange are the rights to obtain any drugs developed from this research for free during the patent period.

Id. (citing Martin Enserink, Physicians Wary of Scheme to Pool Icelanders' Genetic Data, 281 Science 890 (Aug. 14, 1998).

<sup>&</sup>lt;sup>62</sup> It is now possible to alter an individual's genetic makeup after birth. According to Mark Hall: "At the end of 1994, there were over 100 approved clinical protocols offering gene therapy - therapeutic interventions that alter the existing genetic structure in patients ... . These are still experimental protocols, but at some point they will lead to generally approved treatments that will be widely available." Mark A. Hall et al., Health Care Law and Ethics in a Nutshell 429 (2d ed. 1999).

<sup>63</sup> Genopathy is "a disease resulting from a genetic defect." King & Stansfield, supra note 8, at 141.

<sup>&</sup>lt;sup>64</sup> The ways in which sensitive data can be taken and easily misused and disseminated are particularly troubling. See, e.g., Eric Dash, Lost Credit Data Improperly Kept, Company Admits, N.Y. Times, June 20, 2005, at A1. ("The chief of the credit card processing company whose computer system was penetrated by data thieves, exposing 40 million cardholders to risk of fraud, acknowledged that the company should not have been retaining those records.").

<sup>&</sup>lt;sup>65</sup> It is not difficult to see how the siren song of DNA evidence may contribute to the erosion of Fourth Amendment limits on searches and seizures. See Rapp, supra note 41, at 168, 170 (2001) (reviewing Scheck et al., supra note 36) (arguing that in addition to leading to the "flexification" of criminal procedure protections, DNA evidence is dangerous because juries may begin to overvalue it).

<sup>&</sup>lt;sup>66</sup> Without a clear understanding of the consequences of genetic research in terms of individual and community-wide discrimination and stigmatization, genetic databases raise concerns about the protection of genetic information." Alice Hsieh, Note, A Nation's Genes for a Cure to Cancer: Evolving Ethical, Social and Legal Issues Regarding Population Genetic Databases, <u>37 Colum. J.L. & Soc. Probs.</u> 359, 359 (2004).

<sup>&</sup>lt;sup>67</sup> World Health Organization Advisory Committee on Health Research, Genomics and World Health 157 (2002), available at <a href="http://www.who.int/gb/ebwha/pdf">http://www.who.int/gb/ebwha/pdf</a> files/EB112/eeb1124.pdf, cited in Hsieh, supra note 66, at 367.

<sup>&</sup>lt;sup>68</sup> See Radhika Rao, Property, Privacy, and the Human Body, <u>80 B.U. L. Rev. 359, 370 n.30 (2000)</u>. Regarding genetic monopolies, Rao writes, "Iceland, for example, recently sold the genetic records of its entire population to one private company - an event that critics contend may lead to the formation of genetic monopolies." Id. (emphasis added).

<sup>&</sup>lt;sup>69</sup> Id. (noting criticisms that "DNA prospectors ... are committing a new offense ... called "bio-piracy,' [by] exploiting remote peoples for their precious DNA, which could lead to big-money drug patents or even a Nobel prize" (quoting Mary W. Walsh, A Big Fish in a Small Gene Pool, L.A. Times, June 5, 1998, at B3) (emphasis added)). Rao continues:

The notion of privacy is particularly poor at protecting that which is not intuitively thought of as hidden or private. This is a potential Achilles heel in a privacy regime because much of our genetic information will not be private or hidden in any sense. Biometric data illustrate this conundrum. Biometric data include information related to genetic information. <sup>70</sup> Some of this personal information, such as race or birth date, cannot practically be kept a secret. These are good examples of information not necessarily genetic, but of a class related to genetic information and vulnerable to exploitation for purposes of discrimination. Biometric data, data stored as a result of medical diagnosis and treatment, and even that given to obtain a driver's license, can be easily gathered from observation or public databases or can be stolen from private databases, and may reveal one's propensities to develop certain diseases or disorders over time. <sup>71</sup> [\*627] For example, there is significant correlation between schizophrenia and birth date. <sup>72</sup> Multiple Sclerosis is correlated to people with birth dates in April, May, and June. <sup>73</sup> There is a higher incidence of epilepsy in those with birthdays between December and March. <sup>74</sup> Age can indicate predisposition to disease as well. <sup>75</sup>

Most genetic information is easier to keep secret than data that are merely related to genetic information, such as race, birth date, or height. Information on the genome or proteome level can only be determined from genetic testing. If information like "birth date" shows predisposition toward certain diseases, can this be categorized as genetic information, and if so, is it protectible information? Given that this information is easily obtained, a question arises: Is it unjust to use this information to influence employment or insurance decisions?

#### II. Regulation of Genetic Information: Protecting Genetic Identity

Both state and federal legislation are beginning to protect genetic information. The long-term success of this legislation depends on what information is protected and how it is protected. Many states already protect individuals from identity theft. <sup>76</sup> We protect the identities of individuals, in part because we recognize that it has real economic value, and, more importantly, because it is undeniably theirs. If a social security number and other elements of an individual's "identity" are protectible, how much more important is the information that determines our biological identity - our genetic material and code?

After examining the state of American regulation of genetic information, one might be tempted to claim that this note cries wolf. Almost all states already protect genetic information in one form or another, and federal regimes protect against some discrimination as well. Current state and federal legislation, however, leave [\*628] individuals vulnerable. Current law, with a few exceptions noted below, either does not protect genetic information or treats genetic data under a privacy regime, rather than as personal property. The rest of this note is devoted to contrasting these two different approaches to genetic liberty in order to show that the law must begin to treat genetic information as property in order to fully protect genetic liberty.

A main point of this note is that current legislation itself is vulnerable because privacy rights provide a less substantial edifice upon which to build a scheme of protection than would property rights. For example, without property protection (or cobbled-together positive law in the name of "privacy") there is no individual cause of action

<sup>&</sup>lt;sup>70</sup> Biometrics is defined as "the statistical study of biological observations and phenomena." Webster's Third, supra note 46. This note considers biometric information to be similar enough to genetic information to be included within the concept.

<sup>&</sup>lt;sup>71</sup> See Niedowski, supra note 5, at A8 ("Our birth month may predispose us to certain diseases later in life.").

<sup>&</sup>lt;sup>72</sup> Seasonal birth patterns have been most firmly established in schizophrenia patients." Id. Studies have shown that schizophrenia is more common among those born in late winter or early spring. Id.

<sup>&</sup>lt;sup>73</sup> Id.

<sup>&</sup>lt;sup>74</sup> Id.

<sup>&</sup>lt;sup>75</sup> See Children Likelier to Develop Schizophrenia, supra note 31.

<sup>&</sup>lt;sup>76</sup> See, e.g., <u>Cal. Bus. & Prof. Code</u> §350 (West 2003) (detailing California's creation of an "Office of Privacy Protection" to "investigate and assist in the prosecution of identity theft and other privacy-related crimes").

against the thief (and no thief, for there is nothing to be stolen) who takes our information from a population genetic database.

This problem raises several issues; for instance, whether population genetic databases are protectible in light of Feist Publications, Inc. v. Rural Telephone Service. <sup>77</sup> The Court in Feist held that data compilations, similar to the databases that are sure to hold our genetic information, are often not considered property and thus are unprotectible under copyright law - in these databases no one can "own" this information. <sup>78</sup> If no one can own the information, another question that arises is whether a "personal account model" adequately serves the needs of health care professionals, employers, insurers, relatives, and the community with the knowledge that patient information is generally kept confidential unless there is a strong reason for disclosure. Or, does a "joint account model" adequately address the interests of individuals and their relatives? <sup>79</sup> Although beyond the scope of this note, the protection of genetic information touches on other important issues including eugenics and genetic abortion. <sup>80</sup>

#### [\*629]

A. Federal and State Legislation Regulating the Use of Genetic Information

#### 1. Federal Regulation

Federal regulation of genetic information is slow in coming. <sup>81</sup> "Although Congress considered fourteen bills protecting genetic information in 1996, and an additional seven bills by May of the following year, federal legislation precluding improper use of this sensitive information has consistently failed." <sup>82</sup> A notable attempt at federal protection and regulation of genetic information came in the form of the February 8, 2000, Clinton executive order that prohibited any hiring or promoting, in any federal department or agency, based upon genetic information. <sup>83</sup> Existing federal anti-discrimination law currently provides some of the only viable protection of genetic information from misuse and includes the Americans with Disabilities Act ("ADA"), the Employee Retirement Income Security Act ("ERISA"), the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), <sup>84</sup> (and the first-ever

<sup>&</sup>lt;sup>77</sup> 499 U.S. 340 (1991).

<sup>78</sup> Id. at 363-64.

<sup>&</sup>lt;sup>79</sup> This familial joint account model extends the benefits of genetic testing to one's whole family and emphasizes that the sharing of information should be routine.

<sup>&</sup>lt;sup>80</sup> Do parental rights continue to trump the rights of the unborn regarding genetic decision making? C.S. Lewis described the impact of decision making by parents where "there is a paradoxical, negative sense in which all possible future generations are the patients or subjects of a power wielded by those already alive.... From this point of view, what we call Man's power over Nature turns out to be a power exercised by some men over other men with Nature as its instrument." C.S. Lewis, The Abolition of Man 55 (HarperCollins 2001) (1944). "In reality, of course, if 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." *Id. at 57*.

<sup>&</sup>lt;sup>81</sup> No federal legislation has been passed relating to genetic discrimination in individual insurance coverage or to genetic discrimination in the workplace." Human Genome Project Information, Genetics Privacy and Legislation, <a href="http://www.ornl.gov/sci/techresources/Human">http://www.ornl.gov/sci/techresources/Human</a> Genome/elsi/legislat.shtml (last visited Nov. 13, 2006) (emphasis omitted).

<sup>&</sup>lt;sup>82</sup> Sheri Mezoff, Note, Forcing a Square Peg into a Round Hole: The Negative Ramifications of Misaligned Protection for Predisposed Individuals Under the ADA, <u>85 B.U. L. Rev. 323, 324-25 (2005)</u>. See also Michael Baram, The Laws of Genetics, 105 Envtl. Health Persp. 488, 489-91 (1997); Corbett, supra note 59, at 94. Alternatively, protective legislation has successfully passed on a state level. Baram, supra, at 82.

<sup>83</sup> Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000).

<sup>84</sup> See Ruebner & Reis, supra note 29, at 560-63.

patients' medical privacy standards promulgated in 2000 as a regulation under that statute), and Title VII of the Civil Rights Act of 1964. <sup>85</sup> The most significant of the genetic information protection bills introduced in Congress is the Genetic Information Nondiscrimination Act of 2003. In its latest incarnation as the Genetic Information Nondiscrimination Act of 2005, sponsored by Senator Olympia J. Snowe, it was introduced to the 109th Senate on February 7, 2005, and passed, as amended, ten days later. <sup>86</sup>

### [\*630]

a. The Genetic Information Nondiscrimination Act of 2005

An act to prohibit discrimination on the basis of genetic information with respect to health insurance and employment. <sup>87</sup>

On February 7, 2005, GINA was introduced to the Senate. <sup>88</sup> GINA adopts a "privacy" <sup>89</sup> rationale and does not explicitly acknowledge genetic information as the property of the individual. Despite this, Senator Pete V. Domenici summed up many of the important issues surrounding protection of genetic information:

#### [\*631]

85 For a comprehensive list of federal genome related legislation, see Genetics Privacy and Legislation, supra note 81.

- <sup>88</sup> Id. (encouraging individuals to seek genetic counseling and treatment without fear of discrimination resulting from the resulting disclosure of genetic information). GINA outlines the significant promise of advances in our understanding of the human genome while warning of the dangers related to the misuse of genetic information. Section 2 of the bill makes the following findings:
- (2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic "defects" such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions.... By 1981, a majority of States adopted sterilization laws to "correct" apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.
- (3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender....
- (4) Congress has been informed of examples of genetic discrimination in the workplace. These include the use of preemployment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case <u>Norman-Bloodsaw v. Lawrence Berkeley Laboratory (135 F.3d 1260, 1269 (9th Cir. 1998))</u>. Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.
- (5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections.... The existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.
- Id. §2 (emphases added).
- <sup>89</sup> Id. §104 (dealing with the "Privacy and Confidentiality" of genetic information, "a group health plan, a health insurance issuer, or issuer of a medicare supplemental policy shall not use or disclose genetic information ... for purposes of underwriting, determinations of eligibility to enroll, premium rating, or the creation, renewal or replacement of a plan, contract or coverage for health insurance or health benefits").

<sup>86</sup> Genetic Information Nondiscrimination Act, supra note 9.

<sup>87</sup> ld.

The genome map has brought a promise of improved health through revolutionary new treatments for illness and disease. The ultimate result of mapping the human genome is a complete genetic blueprint, a blueprint containing the most personal and most private information that any human being can have. We will now have a wealth of knowledge of how our countless individual traits are determined. And perhaps more important, we will have fundamental knowledge about the genes that can cause sickness and sometimes even death.

Our personal and unique genetic information is the essence of our individuality. Our genetic blueprint is unique in each of us. However, as genetic testing becomes a more frequently used tool, we now must begin to address the ethical and legal issues regarding discrimination on the basis of genetic information. Questions regarding privacy and confidentiality, ownership and control, and consent for disclosure and use of genetic information need to be carefully considered.

An unintended consequence of this new scientific revolution is the abuses that have arisen as a result of our gathering genetic information. Healthy people are being denied employment or health insurance because of their genetic information. By addressing the issue of nondiscrimination, we are affirming the right of an individual to have a measure of control over his or her personal genetic information.

Genetic information only indicates a potential susceptibility to future illness. In fact, many individuals identified as having a hereditary condition are, indeed, healthy. Some people who test positive for genetic mutations associated with certain conditions may never develop those conditions at all. Genetic information does not necessarily diagnose disease. Yet many people in our society have been discriminated against because other people had access to information about their genes, and made determinations based on this information that the individual was too risky to ensure or unsafe to employ.

... The Genetic Information Nondiscrimination Act is an important first step toward protecting access for all Americans to employment and health services regardless of their genetic inheritance. There is simply no place in the health insurance or the **[\*632]** employment sector for discrimination based solely upon genetic information. <sup>90</sup>

Senator Michael B. Enzi of Wyoming extolled the virtue of the bill in "hyperbolic" language, claiming that it fulfilled the "promise of genomics." <sup>91</sup> Despite the hyperbole, GINA is a significant step in the direction of protecting genetic information.

# 2. State Regulation 92

Currently, states regulate genetic information in many disparate forms. <sup>93</sup> Only Pennsylvania lacks a statute proscribing the misuse of genetic information. <sup>94</sup> Genetic information is protected on the state level by an incomplete "patchwork" of legislation. <sup>95</sup>

Americans must recognize that they have a civic responsibility not only to care for their own health, but to participate in the research yet to come ... . All note[] the remarkable "explosion of knowledge" and the "great strides" in healthcare that have resulted from research already performed... . While the science of human genomics has ushered in a new era of vast potential, that promise has not yet been fully realized. There is much that remains to be done to "unleash the power" of this science to change permanently the practice of healthcare for the better... . We must work to foster a culture of enlightened self-interest in the American people, underscoring their altruistic motivation to do what's right. Finally, we have a responsibility to encourage our fellow citizens to participate fully in their own healthcare by working with their providers to incorporate advances in science into their personal health plans as quickly as possible.

Id. at S1596-97 (statement of Sen. Enzi).

<sup>90 151</sup> Cong. Rec. S1595, 1595 (daily ed. Feb. 17, 2005) (statement of Sen. Domenici) (emphases added).

<sup>91</sup> Senator Enzi of Wyoming further stated that:

<sup>92</sup> Several state genetics reports are accessible through the web portal for Genetics Privacy and Legislation, supra note 81.

<sup>&</sup>lt;sup>93</sup> Some states treat genomic issues more comprehensively than others. The National Human Genome Research Institute ("NHGRI") Policy and Legislation Database lists the three Alaska statutes and the fifty-one California statutes covering diverse

### [\*633]

a. The Genetic Property Regimes: Colorado, Georgia, and Louisiana

Three states explicitly protect genetic information as property: Colorado, <sup>96</sup> Georgia, <sup>97</sup> and Louisiana. <sup>98</sup> For example, Colorado statutes explicitly recognize genetic information as personal property: "Genetic information is the unique property of the individual to whom the information pertains." <sup>99</sup> A majority of the remaining states that protect genetic information use privacy rationales to justify their legislation. Adopting a property rationale would allow these states the future flexibility to better regulate even the possession of someone else's genetic information, an option not available under a privacy regime.

As mentioned before, it is unlikely that many forms of biometric data are protected at all, including information derived from protected genetic information. One primary difficulty haunting any legislation is that insurers can discriminate based upon genetic information depending upon which states' laws govern them. <sup>100</sup> Different states deal with these issues in a variety of ways.

# [\*634]

b. The Privacy Regimes: California and Michigan

Currently, California forbids discrimination based upon the "genetic characteristics" and "genetic information" of individuals in a number of contexts, including employment, insurance, <sup>101</sup> and **[\*635]** adoption. <sup>102</sup> The California

genomic issues such as genetic information and discrimination, genetic testing and screening, cloning, and stem cell research (Texas, meanwhile, is listed with thirty-one discrete statutory provisions). NIH NHGRI Policy and Legislation Database, <a href="http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. For an example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. An example of New York's laws, see <a href="https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm">https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm</a> [hereinafter NIH NHGRI]. An example of New York's la

- 94 See NIH NHGRI, supra note 93.
- <sup>95</sup> Mezoff, supra note 82, at 323-24 ("Judicial decisions on such matters [protection of individuals from discrimination based upon genetic information] are case-specific and result in a bewildering patchwork of rights and duties across the United States." (quoting Baram, supra note 82, at 105)). See also Nicoll, supra note 29, at 774 (arguing that current legislation protecting individuals from genetic discrimination particularly in New York and the area of long-term insurance must evolve to decrease discrimination because Medicaid is insufficient to cover everyone).
- <sup>96</sup> Colo. Rev. Stat. Ann. §10-3-1104.7(1)(a) (West 1999 & Supp. 2004) (The Colorado insurance statute regarding unfair competition and deceptive practices declares that "genetic information is the unique property of the individual to whom the information pertains.").
- <sup>97</sup> <u>Ga. Code Ann. §33-54-1</u> (2005). Using similar language to the Colorado statute, the Georgia insurance statute, regarding genetic testing "finds and declares that ... genetic information is the unique property of the individual tested." Id.
- <sup>98</sup> La. Rev. Stat. Ann. §22:213.7 (2004) (declaring that "an insured's or enrollee's genetic information is the property of the insured or enrollee").
- 99 Colo. Rev. Stat. Ann. §10-3-1104.7(1)(a).
- <sup>100</sup> See Genetics and Life, Disability and Long-Term Care Insurance, National Conference of State Legislatures (2003), <a href="http://www.ncsl.org/programs/health/genetics/ndislife.htm">http://www.ncsl.org/programs/health/genetics/ndislife.htm</a> (displaying a chart detailing state nondiscrimination legislation).
- See NIH NHGRI, supra note 93, for detailed summaries of the following California statutes: <u>Cal. Civ. Code §56.265</u> (West Supp. 2005) (mandating that insurers maintain the confidentiality of genetic information); <u>Cal. Gov't Code §12926(h)(2)</u> (West Supp. 2005) (including genetic characteristics within the definition of medical condition); id. §12940(a) (prohibiting employment discrimination, including the requirement of tests, on the basis of a medical condition); **Cal. Health & Safety Code §1357.03(f)(6)** (West 2000) (prohibiting discrimination on the basis of genetic information by small employer health plans); id. §1357.52 (prohibiting health care service plan eligibility exclusions based on genetic information, with some exceptions); id.

§1367.7 (requiring group health care service plan contracts that offer maternity coverage to also provide prenatal diagnosis of genetic disorders); id. §§1374.7, 1374.9 (prohibiting discrimination by health plans in enrollment or premiums on the basis of genetic characteristics and providing penalties for discrimination on the basis of genetic characteristics, respectively); Cal. Health & Safety Code §1399.804(c) (West Supp. 2005) (prohibiting health plans from encouraging individuals to refrain from filing applications for coverage based on genetic information); id. §1399.804(d) ("No plan shall, directly or indirectly, enter into any contract, agreement, or arrangement with a solicitor that provides for or results in the compensation paid to a solicitor for the sale of a health care service plan contract to be varied because of ... genetic information ... ."); Cal. Health & Safety Code §103825 (West 1996) (establishing a statewide birth defects monitoring program; the term "birth defect" is defined to include any medical problem of organ structure, function, or chemistry of possible genetic or prenatal origin); id. §124975 (presenting the Legislature's findings related to heredity disorders and requiring that screening programs for heredity disorders comply with the Hereditary Disorders Act §27); Cal. Health & Safety Code §§124980-124981 (West 1996 & Supp. 2005) (requiring the State Director of Health Services to create necessary regulations and standards for hereditary disorders programs, including consent for testing, the confidentiality of information, the licensing of master level genetic counselors, and listing the minimum licensing requirements to use the title genetic counselor, respectively); Cal. Health & Safety Code §124995 (West 1996) (requiring prenatal testing programs for newborns under §\$125050-125065 to comply with the Hereditary Disorders Act); Cal. Health & Safety Code §§125000-125001 (West 1996 & Supp. 2005) (establishing a genetic disease unit to coordinate genetic disease programs and to promote information, testing, and counseling services, including the testing of pregnant women); Cal. Health & Safety Code §125025 (West 1996) (stating the policy of the State to detect sickle cell anemia and providing that the State Department of Health Services has the responsibility to designate needed tests and regulations); id. §125030 (granting the power to test identified segments of the population for sickle cell anemia); id. §125050 (requiring State Department of Health Services to administer a statewide program for the prenatal testing for genetic disorders and birth defects); id. §125055 (listing responsibilities for the State Department of Health Services related to a statewide program for the prenatal testing for genetic disorders and birth defects); id. §125060 (making participation in a statewide program for the prenatal testing for genetic disorders and birth defects voluntary); id. §125065 (requiring prenatal diagnosis centers to meet standards developed by the State Department of Health Services and to accept patients from certain State-funded or State-administered programs); Cal. Health & Safety Code §125070 (West 1996 & Supp. 2005) (restricting the use of maternal serum-alpha fetoprotein screening test for prenatal detection of neural tube defects until the State Department of Health Services develops regulations); Cal. Health & Safety Code §125110 (West 1996) (refusing to apply the Maternal and Child Health Program Act if a pregnant woman objects to the test required by that act based on her religious beliefs or practices); Cal. Health & Safety Code §127660 (West Supp. 2005) (presenting legislative request to the University of California for a written analysis that examines the public health, medical, and economic effects of mandating benefits, including genetic tests for certain populations); Cal. Ins. Code §742.405 (West Supp. 2005) (prohibiting discrimination by multiple employer welfare arrangements against subscribers or applicants based on genetic characteristics possibly associated with a disability and prohibiting these arrangements from seeking genetic information for non-therapeutic purposes); id. §742.407 (prohibiting multiple-employer welfare arrangements from disclosing individually identifiable genetic test results to third parties without written authorization and providing civil penalties for violations); id. §10123.3(a) (prohibiting discrimination by self-insured employee welfare benefit plans on the basis of genetic characteristics); id. §10123.31 (describing administrative penalties for discrimination based on genetic characteristics by self-insured employee welfare benefit plans); id. §10123.35 (providing penalties for the unauthorized disclosure of genetic test results by self-insured employee welfare benefit plans); id. §10123.9 (requiring group disability insurance policies that offer maternity coverage to also offer coverage for prenatal diagnosis of genetic disorders for high-risk pregnancies); id. §§10140(b)-(d) (prohibiting discrimination on the basis of genetic characteristics by life or disability insurers); id. §10140.1 (prohibiting unauthorized disclosure of genetic testing results by life or disability insurers); id. §10140.5 (providing penalties for discrimination on the basis of genetic characteristics by life or disability insurers); id. §10143 (prohibiting life and disability insurers from refusing to sell a policy based solely on the fact that an individual carries a gene associated with a disability in that person's offspring); id. §§10146-10149.1 (prohibiting discrimination on the basis of genetic characteristics and unauthorized disclosure of genetic testing results in the life and disability income insurance contexts); id. §10198.9 (prohibiting disability insurers from excluding enrollees based on genetic information, with some exceptions); id. §10233.1 (prohibiting long-term care insurers from requiring genetic testing for underwriting or insurability purposes); id. §10705(j) ("[A] disability insurer may not exclude any eligible employee or dependent who would otherwise be entitled to health care services on the basis of any ... genetic information ...."); id. §§10901.2(c)-(d) (prohibiting insurance carriers from discouraging eligible applicants from applying based on their genetic information and prohibiting a carrier from entering "into any contract, agreement, or arrangement with an agent or broker that provides for or results in the compensation paid to a solicitor for the sale of a health benefit plan design to be varied because of ... genetic information"). See also Faigus, supra note 6, at 299.

<sup>102</sup> See <u>Cal. Fam. Code §8706</u> (West 2004) (requiring a written report of a child's medical background, including the attainable medical information of the child's biological parents, to be "submitted to the prospective adoptive parents" and detailing

legislation, rather, does not explicitly recognize genetic information as property, but protects it through privacy conceptualizations; for example, by protecting private and sensitive medical and genetic information. <sup>103</sup>

[\*636] Currently, Michigan protects genetic information without using the word "privacy," and also does not explicitly protect it as an individual's property. 104

III. The Best Solution: Protecting Genetic Information as Genetic Property

In the profoundest sense there are no rights but property rights. <sup>105</sup>

This part of the note examines the use of genetic property rights by first looking at property rights in genetic information and the history of property rights in the dead. Arguments for the dignity and autonomy in the property of the person are then explored. From there the note proceeds to examine which particular "bundle of sticks" of property rights are implicated by genetic information as well as the special problems created by the protection of genetic information as property. The note then defends the choice of a [\*637] property regime to protect genetic information and explores the historic bias toward recognizing only the tangible as property. The next parts explore the nature of property as both a right and a thing, and the role of positive law. Subsequent parts explore the author's chosen solution: the classification of genetic information as tangi non possunt property. Next, quasi property and intellectual property regimes are explored as possible mechanisms to protect genetic information. Also, hypothetical cases are examined under different approaches to genetic information

A. Using Property Rights to Protect Genetic Information

#### 1. Property in Genetic Information

procedure for storing and conducting DNA tests on blood samples freely given by child's biological parents); id. §§8817, 8909 (mandating the written report detailed in section 8706 to be made by the department or delegated county adoption agency as part of the study required by section 8806 and discussing birth parent's blood samples for future DNA testing and DNA storage for both independent and intercounty adoptions, respectively); id. §9202.5 (restricting access to the blood samples of birth parents stored pursuant to the preceeding sections).

<sup>103</sup> See Cal. Const. art. I, §1 (West 2002). While the text itself does not mention genetic information, it does expressly protect "privacy" generally as an "inalienable right[]." Id.

<sup>104</sup> See, e.g., <u>Mich. Comp. Laws Ann. §37.1201(d)</u> (West 2001) (defining "genetic information"); id. §37.1202(b) (an employer may not "discharge or otherwise discriminate against an individual ... because of a disability or genetic information that is unrelated to the individual's ability to perform the duties of a particular job or position"); <u>Mich. Comp. Laws Ann. §500.3407b</u> (West 2002) (prohibiting the requirement of genetic testing as a condition of insurance).

<sup>105</sup> Murray N. Rothbard, Power and Market 238 (2d ed. 1977). Additionally, the late Chief Justice Rehnquist, even prior to his ascent to the position of Chief Justice of the United States, understood property rights, and their importance, as follows:

Obviously, however, a "legitimate" expectation of privacy by definition means more than a subjective expectation of not being discovered.... Legitimation of expectations of privacy by law must have a source outside of the Fourth Amendment, either by reference to concepts of real or personal property law or to understandings that are recognized and permitted by society. One of the main rights attaching to property is the right to exclude others ... and one who owns or lawfully possesses or controls property will in all likelihood have a legitimate expectation of privacy by virtue of this right to exclude. Expectations of privacy protected by the Fourth Amendment, of course, need not be based on a common-law interest in real or personal property, or on the invasion of such an interest.... But by focusing on legitimate expectations of privacy in Fourth Amendment jurisprudence, the Court has not altogether abandoned use of property concepts in determining the presence or absence of the privacy interests protected by that Amendment. No better demonstration of this proposition exists than the decision in Alderman v. United States ... where the Court held that an individual's property interest in his own home was so great as to allow him to object to electronic surveillance of conversations emanating from his home, even though he himself was not a party to the conversations. On the other hand, even a property interest in premises may not be sufficient to establish a legitimate expectation of privacy with respect to particular items located on the premises or activity conducted thereon.

Much is written on the protection of genetic information as property. <sup>106</sup> There are categories in which genetic information could be placed and thus be protected as personal property, including quasi property, jura in re propria, <sup>107</sup> or "quasi in rem property." <sup>108</sup> Genetic information is best protected as an incorporeal thing (tangi non possunt) - "the subject matter of incorporeal ownership: any proprietary right apart from the right of full dominion over a material object." <sup>109</sup>

### [\*638]

2. The Nature of Property and the Tangible Property Bias

[Property] embraces every thing to which a man may attach a value and have a right ... . 110

There is a bias in our culture in favor of thinking of property only as that which is tangible. We cannot properly protect genetic information as personal property unless this bias is overcome. As this note will show, property rights are recognized as fundamental rights. <sup>111</sup> Thus, genetic information is best protected as personal property. This

See, e.g., Barrad, supra note 29, at 1053-80 (examining a different property rights theory justifications for genetic information); Mary J. Hildebrand et al., Toward a Unified Approach to Protection of Genetic Information, 22 Biotechnology L. Rep. 602, 604-06 (2003) (reviewing approaches to protecting genetic information that emphasize property rights); Rao, supra note 68 ("Of course, property is not limited to the category of tangible things; individuals may also possess property rights in their ideas and other intangible assets. Indeed, a similar division between privacy and property theories also appears with respect to intangible assets in the human body."); Symposium, Probing the Human Genome, supra note 29, at 73-77 (patent lawyer Edmund Pitcher discussing the problems with calling patents for genetic information "ownership" rights and implicitly suggesting the need for property right protection of such information).

<sup>107</sup> Jura in re propria is an in rem proprietary right that is not classified as corporeal property. See Black's Law Dictionary, supra note 3, at 1253 ("Incorporeal property is traditionally broken down into two classes: (1) jura in re aliena (encumbrances), whether over material or immaterial things, examples being leases, mortgages, and servitudes; and (2) jura in re propria (full ownership over an immaterial thing), examples being patents, copyrights, and trademarks.") (emphasis added).

<sup>108</sup> See supra note 25 (author's definition of quasi in rem property).

<sup>109</sup> See author's discussion of tangi non possunt, supra note 26. See also La. Civ. Code Ann. art. 470 (1980) ("Rights and actions that apply to immovable things are incorporeal immovables. Immovables of this kind are such as personal servitudes established on immovables, predial servitudes, mineral rights, and petitory or possessory actions.").

<sup>110</sup> James Madison, Property (1792), reprinted in James Madison: Writings 515 (Jack N. Rakove ed., 1999). Madison also wrote that:

[A] man has property in his opinions and the free communication of them.

He has a property of peculiar value in his religious opinions, and in the profession and practice dictated by them.

He has property very dear to him in the safety and liberty of his person. He has an equal property in the free use of his faculties and free choice of the objects on which to employ them.

In a word, as a man is said to have a right to his property, he may be equally said to have a property in his rights.

Id. (emphasis added).

111 See infra text accompanying note 173. See also Cleaver v. Bd. of Adjustment, 200 A.2d 408, 411 (Pa. 1964):

The Constitution of the United States in the Fifth Amendment and in the Fourteenth Amendment ... ordain and guarantee the right of private property. Article I, §1, of the Constitution of Pennsylvania provides: "All men ... have certain inherent and indefeasible rights, among which are those of enjoying and defending life and liberty, of acquiring possession and protecting property.

approach is adopted by the leading group of bioethicists who drafted the Genetic Privacy Act ("GPA"), <sup>112</sup> which declares that an individual's "identifiable DNA" is the property of the individual. Colorado, Georgia, and Louisiana enacted legislation or drafted bills that use rationales similar to the GPA's property model to protect genetic information. "They declare that genetic information (and less commonly genetic samples) are the "unique' or "exclusive' property of the individual to whom the information pertains." <sup>113</sup> The [\*639] strong ties that bind a person to his genetic information and the serious harms possible through its misuse should give rise to strong prima facie rights such as those typically associated with property ownership in the common law system. <sup>114</sup>

#### a. What Property Is

Property scholar John E. Cribbet famously asserted that the question, "What is property?" is "unanswerable." <sup>115</sup> John G. Sprankling observes that the difficulty in defining property arises from the notion that ordinary people tend to think of property as things, while lawyers view property as rights. <sup>116</sup> On the contrary, ordinary people seem to have an intuitive understanding of property and ownership that encompasses both the tangible and the intangible. <sup>117</sup> Sprankling quotes Thomas C. Grey, who claims that "most people share an understanding that property means: "things that are owned by persons." <sup>118</sup> This understanding does not necessarily exclude the more nuanced notion of property that most people share: something that is owned or controlled, tangible or intangible, in whole or part, by someone. It is not the common man who struggles with the concept of intangible property rights but lawyers, legislators, and judges.

#### [\*640]

The right of private property, together with the right of freedom of speech, freedom of religion, and freedom of the press are the Hallmarks of western civilization. These Basic Freedoms constitute the fundamental differences which distinguish - and create the great unpassable gulf which divides - western civilization and free peoples, from Communists and from other peoples who are ruled by a despotic dictator.

- <sup>112</sup> See supra note 47.
- <sup>113</sup> Sonia M. Suter, Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy, <u>72 Geo. Wash. L.</u> <u>Rev. 737, 744 (2004)</u> (footnotes omitted).
- <sup>114</sup> Regarding common law descriptions of property, one scholar notes:

In our system, a full property right usually gives an owner the right to obtain monetary relief, as well as the right to obtain injunctions. Further, these rights are usually assertable against any intentional boundary crossing, regardless of whether the owner has suffered any loss from the unconsented intrusion or whether the intruder had every reasonable ground for believing his conduct was not wrongful.

Wendy J. Gordon, On Owning Information: Intellectual Property and the Restitutionary Impulse, <u>78 Va. L. Rev. 149, 166 n.61</u> (1992).

- <sup>115</sup> John Edward Cribbet, Concepts in Transition: The Search for a New Definition of Property, <u>1986 U. III. L. Rev. 1, 1</u>.
- <sup>116</sup> Sprankling, supra note 23, at 1.
- 117 See, e.g., B.L. Rayner, Life of Jefferson 356 (1834) (remark to Baron von Humboldt, 1807: "When a man assumes a public trust, he should consider himself as public property."); Cole Porter, My Heart Belongs to Daddy, on The Very Best of Cole Porter (Hip-O Records 2004); Barbara Streisand, My Heart Belongs to Me, on Streisand Superman (Sony 1990); Jodeci, My Heart Belongs To You, on Back to the Future: The Very Best of Jodeci (Universal 2005); William S. Gilbert & Arthur Sullivan, H.M.S. Pinafore act 2 (1878) ("But in spite of all temptations / To belong to other nations, / He remains an Englishman!"); The Oxford Dictionary Of Quotations 322 (5th ed. 1999) ("He was uniformly of an opinion which, though not a popular one, he was ready to aver, that the right of governing was not property but a trust.") (quoting J.L. Hammond, Charles James Fox (1903)).
- <sup>118</sup> Sprankling, supra note 23, at 1 (quoting Thomas C. Grey, The Disintegration of Property, in Nomos XXII at 69 (J. Roland Pennock & John W. Chapman eds., 1980)).

#### b. Genetic Information: Tangi non Possunt - as if It Were a Thing - and a Right

An ideal mechanism to protect genetic information is to treat it as both a thing and a right. Unlike genetic information, genetic material is tangible personal property, in that it is "corporeal" and "perceptible to the senses." <sup>119</sup> Genetic information is intangible property. <sup>120</sup> Genetic information, as a right, also belongs to the jura in re propria class of incorporeal property. <sup>121</sup> Throughout history, property was conceptualized primarily as in rem, as seen in the definitions throughout this note. <sup>122</sup> The time has come to recognize property rights in genetic information as tangi non possunt - intangible but important personal property. <sup>123</sup> The concept of ownership is inextricably tied to control. If it is property, even quasi property, and it is not owned by one person, then it is subject to another person's control.

### c. Property as Right or Property as Thing

Black's Law Dictionary expresses ambivalence in its definition of "property." The primary definition of "property" is "the right to possess, use, and enjoy a determinate thing (either a tract of land or a chattel): the right of ownership." <sup>124</sup> The secondary Black's definition of "property" is "any external thing over which the rights of possession, use and enjoyment are exercised." <sup>125</sup> The primary definition may consciously cover the concepts of intangible property or property in something, but it is less than clear. Some things are neither determinate things, as required by the first definition, nor are they "external things," as required by the secondary definition. <sup>126</sup> Sprankling endorses a definition of "property" as composed of "two parts: (1) rights among people (2) that concern things." <sup>127</sup> Sprankling [\*641] describes intangible personal property as "rights in intangible, invisible things" like "stocks, bonds," intellectual property, "debts, franchises, licenses, and other contract rights" - a "seemingly endless" list that is "evolving rapidly." <sup>128</sup> This list should include genetic information as described in this note.

### d. Property as Positive Law: Nothing Else

Another option is to recognize property as whatever we make it to be through the force of positive law. The concept of property from the perspective of legal positivism, that "property rights, in short, are defined by law," 129 is certainly true, at least in a limited sense. Jeremy Bentham claimed: "Property and law are born together, and die together. Before laws were made there was no property; take away laws, and property ceases." 130 Individuals,

<sup>119</sup> Black's Law Dictionary, supra note 3, at 1253-54.

<sup>&</sup>lt;sup>120</sup> Intangible property is "property that lacks a physical existence. Examples include stock options and business goodwill." Id. at 1253.

<sup>&</sup>lt;sup>121</sup> Id. (defining "jura in re propria").

<sup>&</sup>lt;sup>122</sup> The Law of Property is, "the category of law dealing with proprietary rights in rem, such as personal servitudes, predial servitudes, and rights of real security." Id. at 903.

<sup>&</sup>lt;sup>123</sup> See supra note 26 and accompanying text.

<sup>124</sup> Black's Law Dictionary, supra note 3, at 1252.

<sup>&</sup>lt;sup>125</sup> Id.

<sup>126</sup> Id. at 1252-53.

<sup>&</sup>lt;sup>127</sup> Sprankling, supra note 23, at 2 (the term "rights" is thoughtfully changed to "relationships" a few pages later in his book, an insight attributed to Wesley Newcomb Hohfeld, Some Fundamental Legal Conceptualizations as Applied in Judicial Reasoning, 23 Yale L.J. 16 (1913)).

<sup>&</sup>lt;sup>128</sup> Id. at 9.

<sup>&</sup>lt;sup>129</sup> Id. at 3.

<sup>&</sup>lt;sup>130</sup> Jeremy Bentham, The Theory of Legislation 69 (Oceana Publ'ns, Inc. 1975) (1690), quoted in Sprankling, supra note 23, at 2.

however, have always understood that certain things, such as their bodies and homes, are theirs in a way that cannot be justly abrogated by law and that they exist independently from the positive law.

3. Two Other Property Regimes: Quasi Property and Intellectual Property

#### a. Quasi Property

There are other methods besides "property" and "privacy" to protect genetic information, including quasi property. Quasi property is property that is to be treated as if it were a tangible thing, so as to fit within accepted conceptualizations of property rights. Curiously, although the phrase is commonly cited in case law and scholarly commentary, Black's Law Dictionary does not define "quasi property." <sup>131</sup>

Arguments for quasi property rights include the idea that our increasingly complex world demands ownership regimes that are **[\*642]** more complex and nuanced than the current proprietary and in rem-dominated notions of property. One argument against quasi property rights is the idea that full property rights in genetic information violate concepts of dignity of the human body, <sup>132</sup> and the limited rights provided by privacy regimes better protect the information while preserving human dignity.

Two examples of quasi property are illustrative of the function served by these rights. In the landmark intellectual property case International News Service v. Associated Press, <sup>133</sup> the Supreme Court granted a "quasi property" right in reported news that was gathered. The right lasted at least as long as was necessary to process the information gathered. <sup>134</sup> Another example is that next-of-kin have quasi property rights in the bodies of the deceased for purposes of burial, including custody, internment, and disposition of corpses. <sup>135</sup>

Nothing is yours or adequately controlled by you unless you own it; it "cannot be stolen" unless you have a legitimate property right in it. <sup>136</sup> However, this does not mean that the full complement of property rights must be granted. Individuals can be granted a limited property right, not necessarily the full "bundle of sticks." For example, an individual may not retain the right to alienate his genetic information. Protection of genetic information must include even the matter left behind - hair, fingernails, blood, skin - to prohibit its [\*643] misuse. Under a property regime, this material can be disposed of if obtained, but cannot be misused. Perhaps recognizing "qualified

<sup>&</sup>lt;sup>131</sup> See, e.g., <u>Bonito Boats, Inc. v. Thunder Craft Boats, Inc., 489 U.S. 141, 157 (1989)</u>; <u>KVOS, Inc. v. Associated Press, 299 U.S. 269, 276 (1936)</u>; <u>Int'l News Serv. v. Associated Press, 248 U.S. 215, 236, 242 (1918)</u>.

<sup>&</sup>lt;sup>132</sup> See generally Fukuyama, supra note 52, at 148-77 (presenting a secular vision of special moral status and dignity for humans and what it means to be human in his chapter entitled "Human Dignity"); Kass, Life, supra note 52; Kass, Natural Science, supra note 52; Barry Brown, The Case for Caution - Being Protective of Human Dignity in the Face of Corporate Forces Taking Title to Our DNA, *29 J.L. Med. & Ethics 166 (2001)*. See also Danforth, supra note 6, at 179.

<sup>&</sup>lt;sup>133</sup> 248 U.S. 215 (1918).

<sup>134</sup> Id. at 242.

<sup>135</sup> See <u>Cohen v. Groman Mortuary, Inc., 41 Cal. Rptr. 481 (Cal. Dist. Ct. App. 1964)</u>, disapproved on other grounds by <u>Christensen v. Superior Court, 820 P.2d 181 (Cal. 1991)</u>. See also <u>Newman v. Sathyavaglswaran, 287 F.3d 786, 796-97 (9th Cir. 2002)</u> (holding that the State of California violated the property rights parents held in the bodies of their deceased children, rooted in the Due Process Clause of the Fourteenth Amendment, when the State removed the corneas of the deceased children without the parents' permission); <u>Brotherton v. Cleveland, 173 F.3d 552, 555 (6th Cir. 1999)</u> (permitting widowed plaintiff to pursue civil claim against a physician for nonconsensual removal of her deceased husband's corneas); Michele Goodwin, Altruism's Limits: Law, Capacity, and Organ Commodification, **56 Rutgers L. Rev. 305, 319-20 (2004)**.

<sup>&</sup>lt;sup>136</sup> Murray v. Nat'l Broad. Co., 844 F.2d 988, 993 (2d Cir. 1988), abrogated on other grounds by Nadel v. Play-By-Play Toys & Novelties, Inc., 208 F.3d 368 (2d Cir. 2000) ("Ideas that reflect "genuine novelty and invention' are fully protected against unauthorized use. But those ideas that are not novel "are in the public domain and may freely be used by anyone with impunity.' Since such non-novel ideas are not protectible as property, they cannot be stolen.") (citations omitted).

property" rights in genetic information will satisfy those fearful of granting fuller property rights, while allowing individuals to control their genetic material and information. This would entail creating a special interest in genetic information like the limited right to control its use extinguished by the death of the individual. <sup>137</sup>

# b. Intellectual Property

[The] peculiar character [of an idea] is that no one possesses the less, because every other possesses the whole of it. He who receives an idea from me, receives instruction himself without lessening mine; as he who lights his taper at mine, receives light without darkening me. <sup>138</sup>

Property rights can be viewed as a continuum with intangible on one side and tangible on the other. Property can also be fungible <sup>139</sup> or non-fungible, and subject to rivalrous use, or not. <sup>140</sup> Standard property regimes best protect and are most suitable for property that is (1) tangible, (2) not fungible, and (3) subject to rivalrous use. Intellectual property regimes, the subject of the next part, are particularly adept at handling property that is intangible, fungible, and subject to non-rivalrous use.

Intellectual property is used to recognize and protect some forms of intangible property and thus has some intuitive appeal as a possible protection regime for genetic information. One of the touchstones of intellectual property is that it does not protect ideas but the particular expression of ideas. <sup>141</sup> Thus, facts, data, and **[\*644]** information - without a minimal amount of creativity - are not protectible as intellectual property. Also, unlike most tangible property, some property, including most intellectual property, is not diminished by another "possessing" it; it is subject to non-rivalrous use. <sup>142</sup> Some property, like real estate, is tangible and not fungible. <sup>143</sup> Property like a common U.S. quarter is tangible, fungible, and not subject to rivalrous use. Only one person can use it at a time, and if it is used or taken, the taker possesses one more quarter and the giver one less. Genetic information has both fungible and non-fungible properties - it can be taken from an individual, and the individual still has his full

<sup>&</sup>lt;sup>137</sup> Qualified property" is "[a] temporary or special interest in a thing (such as a right to possess it), subject to being totally extinguished by the occurrence of a specified contingency over which the qualified owner has no control." Black's Law Dictionary, supra note 3, at 1254. A central problem with using the "qualified property" approach centers on defining the property rights a deceased individual has in his genetic information; the problem is that the misuse of his genetic information can harm his descendants - in the same way such misuse could harm him during his life - even after he has died.

<sup>&</sup>lt;sup>138</sup> Letter from Jefferson, supra note 1, at 1291. Placed in the context of the misuse of genetic information, Jefferson's words are dangerously naive.

<sup>&</sup>lt;sup>139</sup> Fungible goods "are interchangeable with one another; goods that, by nature or trade usage, are the equivalent of any other like unit, such as coffee or grain." Black's Law Dictionary, supra note 3, at 714.

<sup>&</sup>lt;sup>140</sup> See Letter from Jefferson, supra note 1, at 1291.

<sup>141</sup> See <u>Baker v. Selden, 101 U.S. 99, 107 (1879)</u> (holding that a copyright in Selden's book, containing a novel accounting scheme and forms to use, extended only to the exact contents of the book itself - not to the ideas in the book; others were free to use his ideas and modify his system and forms under the copyright regime). The dichotomy between idea and expression, used to determine what information is protectible, pervades all intellectual property regimes to various degrees. This dichotomy is most clearly articulated in the copyright regime. See <u>17 U.S.C. §102(b)</u> (2000) ("In no case does copyright protection ... extend to any idea.").

<sup>&</sup>lt;sup>142</sup> See <u>Cheney Bros. v. Doris Silk Corp., 35 F.2d 279, 280 (2d Cir. 1929)</u> ("In the absence of some recognized right at common law, or under the statutes ... a man's property is limited to the chattels which embody his invention.").

<sup>&</sup>lt;sup>143</sup> <u>Balaber-Strauss v. Markowitz, 191 B.R. 564, 573 (Bankr. S.D.N.Y. 1995)</u> ("Real estate is unique and bears no resemblance to a fungible commodity ....").

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component of genetic information; however, depending on what is done with this information, the person may suffer significant loss. <sup>144</sup>

Without precedent, such as a statute or a common law right, American courts display hostility toward granting property rights for the intangible or ephemeral - especially regarding intellectual property. <sup>145</sup> Much of this hostility comes from "the traditional judicial reluctance to recognize ideas as property at all, reflecting a societal mindset that equated property with interests in land and other tangible objects." <sup>146</sup> American courts grow increasingly reluctant to grant property rights to the extent that the rights in question are [\*645] categorized as intangible. <sup>147</sup> Courts are also hostile toward granting property rights to anything vague.

A few states recognize common law property rights in some ideas, for example, an original idea submitted for a Reader's Digest magazine article. <sup>149</sup> If an idea for a magazine article is recognized as valuable property, certainly the genetic information that comprises a large part of our genetic destiny, and subjects us to significant harm if misused, is protectible as a property right.

Unless sui generis legislation <sup>150</sup> is utilized to protect genetic information, all of the traditional intellectual property regime models, such as patent, <sup>151</sup> copyright, <sup>152</sup> trademark, <sup>153</sup> trade secret, <sup>154</sup> and unfair **[\*646]** competition

<sup>&</sup>lt;sup>144</sup> See Robert P. Merges et al., Intellectual Property in the New Technological Age 7 (3d ed. 2003) (discussing fungible and instrumental use of property).

<sup>&</sup>lt;sup>145</sup> See <u>Cheney Bros.</u>, <u>35 F.2d at 280</u> (holding that without a right recognized at common law or under statutes, a person's property rights are limited to those chattels which embody the person's "invention"). But see Janice M. Mueller, Public Access Versus Proprietary Rights in Genomic Information: What Is the Proper Role of Intellectual Property Rights?, <u>6 J. Health Care L.</u> & Pol'y 222 (2003).

<sup>146</sup> Sprankling, supra note 23, at 73-74.

<sup>&</sup>lt;sup>147</sup> Courts often seem to implicitly embrace this reasoning. For an example of a case where a court made this reasoning explicit, see <u>Burten v. Milton Bradley Co., 592 F. Supp. 1021, 1031 (D.R.I. 1984)</u> ("Ideas are the most intangible of property rights, and their lineage is uniquely difficult to trace.") (emphasis added).

<sup>&</sup>lt;sup>148</sup> See, e.g., <u>Hamilton Nat. Bank v. Belt, 210 F.2d 706, 708 (D.C. Cir. 1953)</u> ("The law shies away from according protection to vagueness ....").

<sup>&</sup>lt;sup>149</sup> See <u>Seymore v. Reader's Digest Ass'n, 493 F. Supp. 257, 265 (S.D.N.Y. 1980)</u>.

The protection given to genetic information could resemble the intellectual property protection given to semiconductor chips. See generally 17 U.S.C. §§901-914 (2000). In the alternative, the protection could resemble that given to boat hulls. See, e.g., Bonito Boats, Inc. v. Thunder Craft Boats, Inc., 489 U.S. 141, 156 (1989). Both of these approaches fall outside of traditional intellectual property protection regimes.

<sup>&</sup>lt;sup>151</sup> A patent grants "the right to exclude others from making, using, marketing, selling, offering for sale, or importing an invention for a specified period (twenty years from the date of filing), granted by the federal government to the inventor if the device or process is novel, useful, and nonobvious." Black's Law Dictionary, supra note 3, at 1156. Genetic information has no inventor, cannot be called an invention, and cannot meet, at minimum, the novelty, utility, and disclosure prongs. But see Mueller, supra note 145.

<sup>&</sup>lt;sup>152</sup> Copyright is "the right to copy; specifically, a property right in an original work of authorship ... fixed in any tangible medium of expression ... ." Black's Law Dictionary, supra note 20, at 361. Genetic information fails the originality and authorship prongs of copyrightability and runs afoul of the idea/tangible medium of expression dichotomy, making it unprotectible under the copyright regime.

<sup>&</sup>lt;sup>153</sup> A trademark is "[a] word, phrase, logo, or other graphic symbol used by a manufacturer or seller to distinguish its product or products from those of others. The main purpose of a trademark is to designate the source of goods or services. In effect, the trademark is the commercial substitute for one's signature." Id. at 1530.

<sup>155</sup> are fatally flawed. <sup>156</sup> At the very least, genetic information lacks the necessary elements of creativity and commercial value. But there is an interesting analogy to be gleaned regarding patents.

By limiting the biotechnology patent exemption of 287(c), the restrictions on diagnostic testing, as in the case of Canavan Disease, would be loosened to the benefit of patients. The precise extent of this loosening would have to be worked out in the political process. For example, a Congressional majority might want to impose stricter restrictions on parents' access to fetal genetic information than it would on individuals' access to their own "personal" genetic information. Even if the legislative process, subject to judicial review, were to maintain relatively tight restrictions on access to genetic testing, it is better that those restrictions be controlled by the policy choices of publicly accountable representatives, rather than the individual actions of private parties. <sup>157</sup>

Another possibility is that data compilations are generally protectible under copyright regimes and thus can be protected under property and intellectual property regimes. <sup>158</sup> Data compilations that **[\*647]** are not protectible

#### <sup>154</sup> A trade secret is:

- 1. A formula, process, device, or other business information that is kept confidential to maintain an advantage over competitors; information including a formula, pattern, compilation, program, device, method, technique, or process that (1) derives independent economic value, actual or potential, from not being generally known or readily ascertainable by others who can obtain economic value from its disclosure or use, and (2) is the subject of reasonable efforts, under the circumstances, to maintain its secrecy.
- Id. at 1533. See also <u>Ruckelshaus v. Monsanto Co., 467 U.S. 986, 1003 (1984)</u> ("Although this Court never has squarely addressed the question whether a person can have a property interest in a trade secret, which is admittedly intangible, the Court has found other kinds of intangible interests [like liens and contracts] to be property for purposes of the Fifth Amendment's Taking Clause.").
- <sup>155</sup> Unfair competition is:
- 1. Dishonest or fraudulent rivalry in trade and commerce; esp., the practice of endeavoring to pass off one's own goods or products in the market for those of another by means of imitating or counterfeiting the name, brand, size, shape, or other distinctive characteristic of the article or its packaging... 2. The body of law encompassing various business and privacy torts, all generally based on deceitful trade practices, including passing off, false advertising, commercial disparagement, and misappropriation.

Black's Law Dictionary, supra note 3, at 1563-64. This doctrine of unfair competition developed out of the basic idea that dealings founded upon deceit are legally iniquitous. Id. at 1564.

- <sup>156</sup> Genetic information also lacks the "creative" aspect required in most intellectual property regimes, giving property rights to people who create something with their minds. See <u>Feist Publ'ns v. Rural Tel. Serv., 499 U.S. 340, 364 (1991)</u> (holding that for a work to be copyrightable, it must meet a threshold of originality).
- <sup>157</sup> Gregory P. Lekovic, Genetic Diagnosis and Intellectual Property Rights: A Proposal to Amend "The Physician Immunity Statute", <u>4 Yale J. Health Pol'y L. & Ethics 275, 298 (2004)</u> (emphasis added).
- Feist, 499 U.S. at 345, 357, 363-64 (holding that data compilations that involve originality or "some minimal degree of creativity" in the "selection, coordination, or arrangement" of information may qualify for copyright protection the alphabetical arrangement of phone company customers is not sufficiently original for copyright protection and thus not worthy of protection). A principled argument, despite the Supreme Court's hostility to the idea, can be made that enough labor mixed with the "natural" state of the data creates a protectible interest in the compilation or arrangement what this author calls "sweat of the brain." John Locke proposed a theory of property in which labor over a previously unowned piece of property (intellectual or physical) can vest ownership rights in the laborer. John Locke, Two Treatises of Government 27-28 (Prometheus Books 1986) (1690). The sweat of the brow theory also commands as adherents a number of venerable court decisions and some modern commentators. See, e.g., Int'l News Serv. v. Associated Press, 248 U.S. 215, 236 (1918); Blunt v. Patten, 3 F. Cas. 763, 765 (C.C.S.D.N.Y. 1828) (No. 1580); Robert C. Denicola, Copyright in Collections of Facts: A Theory of the Protection of Nonfiction Literary Works, 81 Colum. L. Rev. 516 (1981); Merges et al., supra note 144, at 328. Recently, the trespass doctrine was used in the protection of data compilations. eBay, Inc. v. Bidder's Edge, Inc., 100 F. Supp. 2d 1058 (N.D. Cal. 2000); CompuServe v.

under the copyright regime are "freely copied." <sup>159</sup> This exposes genetic data to unacceptable risk. This hole in intellectual property protection leaves genetic information in databases vulnerable. <sup>160</sup>

The nature of the sui generis legislation necessary to protect genetic information as intellectual property makes it a square peg in a round hole, and the property regime as it currently exists provides a more efficient mechanism of protection.

- 4. Some Historical Perspective Regarding Property in the Human Body
- a. Property in the Dead

To better understand the arguments put forth in this note, it is useful to understand some of the history related to property rights in the human body. In the past, property rights in the human body centered on interest in the dead corpse, "decent internment," and "acceptable disposition" of bodies. <sup>161</sup> This reflects a bias in that property is often thought of as a determinate or tangible thing - in rem. <sup>162</sup> This narrow view is neither necessary nor sufficient to protect **[\*648]** an individual's genetic information. One popular dictionary captures the point this note tries to make about the nature of intangible property, but only if the first two given meanings of "property" are combined: (1) "a quality or trait belonging and especially peculiar to an individual or thing" and (2) "the exclusive right to possess, enjoy, and dispose of a thing." <sup>163</sup> The law already recognizes property interests that extend beyond an in rem

<u>Cyber Promotions</u>, 962 F. Supp. 1015, 1022 (S.D. Ohio 1997) (stating that "trespassers" may be liable for injury to property "even though it is not physically damaged by defendant's conduct").

- 159 Feist, 499 U.S. at 357-59.
- <sup>160</sup> Id. at 340.
- <sup>161</sup> Erik B. Seeney, Note, Moore 10 Years Later Still Trying to Fill the Gap: Creating a Personal Property Right in Genetic Material, <u>32 New Eng. L. Rev. 1131, 1131-32 (1998)</u> (quoting William Boulier, Note, Sperm, Spleens, and Other Valuables: The Need to Recognize Property Rights in Human Body Parts, <u>23 Hofstra L. Rev. 693, 705, 707 (1995)</u>). Courts have considered certain parts of the human body, such as blood plasma, to be tangible property. See, e.g., <u>United States v. Garber, 607 F.2d 92, 97 (5th Cir. 1979)</u>.
- <sup>162</sup> Property is:
- 1. The right to possess, use, and enjoy a determinate thing (either a tract of land or a chattel); the right of ownership <the institution of private property is protected from undue governmental interference>. Also termed bundle of rights. 2. Any external thing over which the rights of possession, use, and enjoyment are exercised <the airport is city property>....

Black's Law Dictionary, supra note 3, at 1252 (emphasis omitted) (footnotes omitted). Black's Law Dictionary contains this passage after the definition of property:

"In its widest sense, property includes all a person's legal rights, of whatever description. A man's property is all that is his in law. This usage, however, is obsolete at the present day, though it is common enough in the older books.... In a second and narrower sense, property includes not all a person's rights, but only his proprietary as opposed to his personal rights. The former constitute his estate or property, while the latter constitute his status or personal condition. In this sense a man's land, chattels, shares, and the debts due to him are his property; but not his life or liberty or reputation.... In a third application, which is that adopted [here], the term includes not even all proprietary rights, but only those which are both proprietary and in rem. The law of property is the law of proprietary rights in personam being distinguished from it as the law of obligations. According to this usage a freehold or leasehold estate in land, or a patent or copyright, is property; but a debt or the benefit of a contract is not.... Finally, in the narrowest use of the term, it includes nothing more than corporeal property - that is to say, the right of ownership in a material object, or that object itself."

Id. at 1252-53 (quoting John Salmond, Jurisprudence 423-24 (Glanville L. Williams ed., 10th ed. 1947)). See also <u>63C Am. Jur.</u> <u>2d Property §1</u> (1997) (discussing property as a right or interest in an "object" or "thing") (citing <u>United States v. General Motors Corp.</u>, 323 U.S. 373, 378 (1945)).

conceptualization, including intangible property and intellectual property. The law should recognize such a right in genetic information.

# b. Autonomy in the Property of the Person

Property rights in the human body are fundamental natural rights. The Supreme Court, in Union Pacific Railway Co. v. [\*649] Botsford, <sup>164</sup> acknowledged that: "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others ....." <sup>165</sup> Of course, people also have the right to exclude others from their bodies. <sup>166</sup> Individual autonomy regarding a person's body has long been greatly valued. <sup>167</sup> People have an interest in their bodies, an interest that makes assault and other wrongs against the person actionable. <sup>168</sup> When an individual does not control and own personal genetic information, under the law someone else can control and misuse it to the extent [\*650] they obtain access to the information. These rights and interests can be properly characterized as personal property rights.

<sup>163</sup> Property," as defined in Merriam-Webster; "Property" has its etymology in Middle English proprete, from Middle French proprete, from Latin proprietat-, proprietas, from proprius own. Merriam-Webster's Collegiate Dictionary 933 (10th ed. 2001). Other entries include: "property right ... a legal right or interest in or against specific property"; and "personal property: property other than real property consisting of things temporary or movable." Id.

164 141 U.S. 250 (1891). See Barrad, supra note 29, at 1053 n.79, for a list of some very useful property right resources.

Botsford, 141 U.S. at 251. In referencing this passage, the Court in Cruzan v. Dir., Mo. Dept. of Health, 497 U.S. 261, 269 (1990) noted, "this notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment."

This fundamental "property" now includes previously unprotected relationships like husband and wife. See <u>Cal. Penal Code</u> §262 (West 1999) (describing the circumstances by which a person's spouse is guilty of rape).

<sup>167</sup> See generally David Boaz, Libertarianism: A Primer 295 (1997). While Boaz's line of reasoning is not necessarily libertarian, he briefly ties together the historical, philosophical arc that individuals have property rights in their own persons by identifying a linage of thinkers including: Plato; the authors of the Magna Carta (security from illegal interference to person and property); Magdeburg law; King Andrew II and the Golden Bull; Aguinas; Roger Bacon; the School of Salamanica (16th cent.); circa 1649 Netherlands and commercial freedom; Hugo Grotius; Samuel Pufendorf; the Levelers (self-ownership and natural rights); Richard Overton's An Arrow Against All Tyrants ("self-propriety," self-ownership and thus rights to life, liberty, and property); the Glorious Revolution and John Locke (Second Treatise of Government) (often writing in response to Sir Robert Filmer's works); the Scottish Enlightenment (Adam Smith and David Hume); Mary Wollstonecraft (female rights in their bodies); Jeremy Bentham; John Stuart Mill (On Liberty); Kant (individual autonomy); American abolitionists, including Lysander Spooner (natural rights argument against slavery) and Frederick Douglass (self-ownership and natural rights); the "Austrian School" (Mises and Hayack); Milton Friedman (Capitalism and Freedom); and modern Law and Economics arguments. But see Plato, Laws, Bk. VI (Thomas L. Pangle trans.), in The Laws of Plato 165 (Basic Books, Inc. 1980) ("It's obvious that the human animal is a difficult possession ... . Those will more easily serve as slaves who aren't compatriots and whose languages are as discordant as possible ...."); Aristotle, Politics, Bk. 1, Ch. 3, in The Basic Works of Aristotle 1131 (Richard McKeon, ed., Random House 1941) ("Instruments are of various sorts; some are living, others lifeless ... . And so in the arrangement of the family, a slave is a living possession, and property a number of such instruments ....") (emphasis added). While the Thirteenth Amendment formally abolished slavery in the United States following the Civil War by eliminating the right of personal property in the body of another, U.S. Const. amend. XIII, §1, if we cannot control our genetic property, we run the risk of becoming slaves to those that use and misuse our genetic property.

<sup>168</sup> At common law, even the touching of one person by another without consent and without legal justification was a battery. W. Keeton et al., Prosser & Keeton on Law of Torts 39-42 (5th ed. 1984).

Currently, laws generally allow (1) the taking of both genetic information <sup>169</sup> and some genetic material from the "owner," and (2) its use to make a profit without the permission of the owner and without allowing the owner to refuse, or at least participate in a fair share of the profits. <sup>170</sup> The right to exclude is an appropriate defense against those who use an individual's genetic material and information to deny the person insurance or generate profits for themselves.

c. A Fundamental Right, but a Limited "Bundle of Sticks"

Genetic liberty must at least include the right to control the use of genetic information (including some form of "ownership") and the right to exclude others from use and control. Property rights are among the oldest recognized legal rights <sup>171</sup> and are enshrined in the **[\*651]** United States Constitution. <sup>172</sup> An early pronouncement from the Supreme Court on property rights declared "the right of the citizens to the free enjoyment of their property" to be a "great and fundamental principle of a republican government." <sup>173</sup> The right to use and control the disposition of genetic information is a fundamental natural right. <sup>174</sup> Law and Economics scholars argue (correctly, as far as the

<sup>169</sup> For example, the common law definition of larceny requires a taking, without the permission of the owner, and carrying away of the tangible personal property of another with the intent to permanently deprive the owner. Of course there is also no "owner" to take the property away from without recognizing property rights in genetic information. Modern statutes have recognized through common law the theft of some intangible property like gas and electrical power.

<sup>170</sup> See, e.g., *Moore v. Regents of the Univ. of Cal., 793 P.2d 479 (Cal. 1990)* (holding that individuals do not retain property and ownership interests in their bodies' cells after the cells have been removed from their bodies, that individuals lack standing to sue on a theory of conversion with respect to their cells, and that Plaintiff did not retain the right to exclude others from using or misusing his body parts). See also Danforth, supra note 7, where she contends:

Research with human cells that results in significant economic gain for the researcher and no gain for the patient offends the traditional mores of our society in a manner impossible to quantify. Such research tends to treat the human body as a commodity - a means to a profitable end. The dignity and sanctity with which we regard the human whole, body as well as mind and soul, are absent when we allow researchers to further their own interests without the patient's participation by using a patient's cells as the basis for a marketable product.

Id. at 190 (footnote omitted).

<sup>171</sup> See, e.g., Jeremy Bentham, The Theory of Legislation 69 (Oceana Publ'ns Inc. 1975) (1802), quoted in William B. Stoebuck & Dale A. Whitman, The Law of Property 1 (3d ed. 2000) ("There have been from the beginning, and there always will be, circumstances in which a man may secure himself, by his own means, in the enjoyment of certain things.") (emphasis added); Proverbs 31:16-18 (detailing property that "she picks" with "her earnings" and also acknowledging the "success of her dealings"); Stoebuck & Whitman, supra, at v ("Who can conceive of a society of any complexity that does not enforce a system of rights and duties respecting things?"); The Oldest Code of Laws in the World: The Code of Laws Promulgated by Hammurabi, King of Babylon 2-3 (C.H.W. Johns trans., The Lawbook Exchange 2000) (n.d.) ("If a man has stolen the goods of temple or palace, that man shall be killed, and he who has received the stolen thing from his hand shall be put to death.").

U.S. Const. amend. V ("Nor shall any person ... be deprived of life, liberty, or property, without due process of law; nor shall private property be taken for public use, without just compensation"); U.S. Const. amend. XIV, §1 ("No State shall ... deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.").

<sup>173</sup> Terrett v. Taylor, 13 U.S. (9 Cranch) 43, 50-51 (1815).

The author consciously uses the phrase "natural right" instead of "human right" to avoid the positive law related aspects of "human right" and the implications of unlimited human autonomy that often accompany concepts of human rights - including the denial of accompanying duties and rights. The Supreme Court acknowledges a constitutionally independent source of property interests (although only in state law, not natural law): "Property interests, of course, are not created by the Constitution. Rather, they are created and their dimensions are defined by existing rules or understandings that stem from an independent source such as state law ...." Bd. of Regents of State Colls. v. Roth, 408 U.S. 564, 577 (1972).

argument extends) that the "legal protection of property rights creates incentives to exploit resources efficiently."

In the profoundest sense, there are no rights but property rights.... There are several senses in which this is true. In the first place, each individual, as a natural fact, is the owner of himself, the ruler of his own person. The "human" rights of the person that are defended in the purely free-market society are, in effect, each man's property right in his own being, and from this property right stems his right to the material goods that he has produced.

In the second place, alleged "human rights" can be boiled down to property rights ... . Take, for example, the "human right" of free speech. Freedom of speech is supposed to mean the right of everyone to say whatever he likes. But the neglected question is: Where? Where does a man have this right? He certainly does not have it on property on which he is trespassing. In short, he has this right only either on his own property or on the property of someone who has agreed ... to allow him on the premises. In fact, then, there is no such thing as a separate "right to free speech"; there is only a [\*652] man's property right: the right to do as he wills with his own or to make voluntary agreements with other property owners. <sup>176</sup>

If this fundamental right is further conceptualized as a "bundle of sticks," <sup>177</sup> then what sticks form the "bundle" for intangible property in our own genetic information? <sup>178</sup>

The entire "bundle" of property rights includes, but is not limited to, possession, use, enjoyment, ownership, alienation, and exclusion. <sup>179</sup> Courts further recognize that property also consists of a "bundle of interrelated interests" including "rights, duties, claims, exemptions, and immunities." <sup>180</sup> At the very least, an individual must have the right to (1) use the individual's genetic information, (2) exclude others from its use, and (3) "own" the individual's genetic information to the extent that the individual controls the genetic information. At a minimum, there is a necessity for a cause of action to redress the wrongful appropriation of genetic information. Most people

OSTERREICHISCHES GENTECHNIKGESETZ [Austrian Law on Genetic Engineering], §67 (1994). Other European countries also have laws forbidding the use of genetic data even when the data are disclosed voluntarily; see the Belgian Insurance Act of 1992, the Danish Insurance Act of 1997 (preventing insurance companies from using genetic information), and the Norwegian Law on the Medical Use of Biotechnology of 1998 (preventing both insurance companies and employers from using genetic information).

Id. at 247 n.67 (emphasis added).

<sup>&</sup>lt;sup>175</sup> Richard A. Posner, Economic Analysis of Law 32 (6th ed. 2003) (1972). Stoebuck & Whitman, supra note 171, at 3 (listing the "three criteria of an efficient system of property rights" as 1) universality, 2) exclusivity, and 3) transferability). Stoebuck lists five "theories" as justification for "private" property: 1) occupation [or possession], 2) labor, 3) contract, 4) natural rights, 5) social utility. Id. at 2.

<sup>&</sup>lt;sup>176</sup> Rothbard, supra note 105, at 238-39 (emphasis added).

<sup>&</sup>lt;sup>177</sup> A common idiom describes property as a "bundle of sticks' - a collection of individual rights which, in certain combinations, constitute property." *United States v. Craft, 535 U.S. 274, 278 (2002)*; see Benjamin N. Cardozo, The Paradoxes of Legal Science 129 (The Lawbook Exchange, Ltd., 2000) (1928).

<sup>&</sup>lt;sup>178</sup> An interesting question is posed by those wanting to disclose genetic information voluntarily. See Jerry Kang & Benedikt Buchner, Privacy in Atlantis, <u>18 Harv. J.L. & Tech. 229 (2004)</u>, for a discussion of "paternalism" in this type of [European] regime. In footnote 67, Kang and Buchner cite:

<sup>&</sup>lt;sup>179</sup> It is clear beyond the peradventure of a doubt that the ownership and possession of private property necessarily includes its lawful use - it would be of little or no value unless the owner can deal with and use it as he desires, so long as its use is lawful." *Cleaver v. Bd. of Adjustment, 200 A.2d 408, 411 (Pa. 1964).* 

<sup>&</sup>lt;sup>180</sup> Barrad, supra note 29, at 1055 (footnotes omitted); see also The Oxford Dictionary of Quotations 279 (5th ed. 1999) (quoting Thomas Drummond, "property has its duties as well as its rights.").

intuitively believe that we already have these rights and protections; but, as this note will show, the peril to which our genetic information is exposed is great.

#### [\*653]

#### d. Special Problems Related to Genetic Property

There are, of course, potential problems associated with personal control of genetic information. For example, family members who need the information may face difficulties obtaining it. <sup>181</sup> Public policy may limit these rights, but use, control, and the right to exclude should form the core of genetic liberty and property rights in genetic information. <sup>182</sup>

Currently, insurers have at least three ways to gain access to an individual's genetic information: (1) direct questions on the insurance application (for example, "Have you ever had a genetic test, and if so, what was the result?"); (2) applicant medical records (in many cases, insurers require that patients give them permission to contact their doctors and obtain copies of their medical records); or (3) insurance company databases, such as the Medical Information Bureau ("MIB"). <sup>183</sup> Legislation in a few states prohibits or limits these methods of access to genetic information, but only in patchwork fashion. <sup>184</sup>

#### B. Hypothetical Test Cases Under the Property and Privacy Regimes

This note uses three hypothetical cases to illustrate the dangers of the misuse of information and to test the possible solutions to the current problem. These cases are: (1) the denial of insurance coverage for a preexisting condition (for example, the genetic predisposition to Huntington's disease) after collection of a blood sample; (2) termination of insurance coverage because the insurance company [\*654] took a blood sample, for either a therapeutic or nontherapeutic reason, and thereby became privy to damaging genetic information; and (3) denial or termination of insurance coverage because a criminal suspect underwent mandatory DNA collection when arrested, and insurance companies then gained or were allowed access to the sample.

#### 1. Genetic Property: How the Regime Handles Test Cases

Genetic information in the hypothetical cases is satisfactorily protected by the laws of the three states utilizing property regimes and insufficiently protected by the laws of the states using privacy regimes.

The first scenario illustrates the dangers of the misuse of genetic information - the denial of insurance coverage for a pre-existing condition after collection of a blood sample. The Colorado, Georgia, and Louisiana laws make this illegal, using a property rationale to protect genetic information. <sup>185</sup>

<sup>&</sup>lt;sup>181</sup> Who Should Genetic Information Belong To?, Health & Med. Wk., Aug. 9, 2004 (suggesting a ""joint account model,' which classes genetic information as familial rather than personal, and makes it available for the treatment of other family members except where there are good reasons not to do so").

<sup>&</sup>lt;sup>182</sup> For example, persons might not be granted the right to sell their genetic information to the highest bidder or to disclose their information when knowing that it will unjustly harm others.

<sup>&</sup>lt;sup>183</sup> Nicoll, supra note 29, at 762-63 (arguing that the possibility of mandatory genetic testing may provide a fourth method for insurers to gain access to an individual's genetic information).

<sup>&</sup>lt;sup>184</sup> See supra Part II.A.2. See also The Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing Before the Subcomm. on Commerce, Trade, and Consumer Protection of the Comm. on Energy and Commerce, 107th Cong. 40 (2001) (statement of Karen H. Rothenberg, Professor of Law at the Univ. of Md. School of Law) (claiming that at least forty states have legislation regarding genetic information); Mezoff, supra note 82, at 323-24 (regarding case law protecting individuals from discrimination based on genetic information).

<sup>&</sup>lt;sup>185</sup> See supra notes 95-97 and accompanying text.

The second scenario involves the termination of insurance coverage because the insurance company took a blood sample and thereby became privy to damaging genetic information. The Colorado, Georgia, and Louisiana laws also make this behavior illegal. <sup>186</sup>

The third scenario involves denying or terminating insurance coverage because a criminal suspect underwent mandatory DNA collection when arrested, and then insurance companies gained or were allowed access to the sample. Again, the laws of all three states using property regimes make this conduct illegal. <sup>187</sup>

These three scenarios are revisited later in the note and analyzed through the lens of a privacy regime in order to demonstrate that the protection provided by such a regime is not as comprehensive as the protection provided by a property regime.

The previous parts of this note show that genetic information is best thought of as both a thing and a right, and is best protected as personal property. The tendency to think of property as tangible stands in the way of the proper understanding of these fundamental natural rights. Property rights offer the best method to protect genetic information. An alternative protection regime, which stands [\*655] in the way of protecting genetic information as personal property, is to protect this information utilizing "privacy" rights. The following sections discuss this alternative, concluding that, while adequate, privacy rights are an inferior way to protect our genetic information.

C. Using Privacy Rights to Protect Genetic Information

### 1. Why Property?

Imagine no possessions; I wonder if you can. 188

Before genetic information is protected as personal property, it is necessary to evaluate alternative protection regimes, such as privacy. The arguments against property regime protection and in favor of privacy regimes take a myriad of forms. Some argue that individuals should not have property rights in anything. <sup>189</sup> American courts, however, properly recognize a property right despite the intangible nature of genetic information. Despite this, the courts show reluctance in recognizing intangible property rights; some believe that privacy regimes best protect this information instead of recognizing and describing it as property. <sup>190</sup> The bias against intangible property is evidenced by the Supreme Court in the seminal case International News Service v. Associated Press, where the Court argued that granting rights in intangible property, such as the "news," would impose unacceptable costs upon others. <sup>191</sup> The Supreme Court's ruling in Feist Publications displayed hostility toward granting [\*656] copyright-

The rule for which the plaintiff contends would effect an important extension of property rights and a corresponding curtailment of the free use of knowledge and of ideas; and the facts of this case admonish us of the danger involved in recognizing such a property right in news, without imposing upon news-gatherers corresponding obligations.

<sup>&</sup>lt;sup>186</sup> Id.

<sup>&</sup>lt;sup>187</sup> Id.

<sup>&</sup>lt;sup>188</sup> John Lennon, Imagine, on Imagine (Capitol Records 1971).

<sup>&</sup>lt;sup>189</sup> For the individual the golden rule is that he will own nothing." Mohandas K. Ghandi, Ghandi On Non-Violence 68 §I-328 (Thomas Merton, ed.). "Property is robbery." Pierre Joseph Proudhon, What is Property?: An Enquiry into the Principle of Right and of Government 12 (Benjamin R. Tucker trans., Howard Fertig, Inc. 1966) (1841). Contra Merges et al., supra note 144, at 7 (Hegel said that "property is the first embodiment of freedom and so is in itself a substantive end.").

<sup>&</sup>lt;sup>190</sup> Suter, supra note 113, at 737 (arguing that privacy rights granting individuals remedies based on dignitary harm and breach of trust provide a better solution than the market-based solutions based on property rights).

<sup>&</sup>lt;sup>191</sup> As one Justice has stated:

based property rights in information contained in compilations of data. <sup>192</sup> One unfortunate result of the intangible property bias is that no one owns the data and anyone can "take" it and misuse it. <sup>193</sup>

Another argument against granting full property rights in genetic information involves health care professionals and relatives. These concerns, however, are handled best as property rights, limited by countervailing rights and duties. Health care professionals have duties and responsibilities including duties of confidentiality. <sup>194</sup> Do they have a corresponding duty to inform patients or the patients' relatives of the predisposition toward disease? Perhaps individuals do have this duty, and if so, the police power of the state can be used to limit property rights in genetic information. Relatives of individuals have interests in genetic information that will affect their own health care and life choices. Perhaps relatives should have limited rights to a related individual's genetic information. <sup>195</sup> Public policy may demand that an individual has a corresponding duty to warn a community, employer, or insurers of disease or predisposition if others are placed in any significant risk of harm. For example, exigencies may exist that demand the limited release of genetic information, such as outbreaks of communicable diseases. <sup>196</sup> Privacy [\*657] regimes filled a void left by a lack of vision regarding intangible personal property. It is property rights, however, that best protect genetic information.

#### 2. Genetic Privacy: A Potent but Ephemeral Solution

Specific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance. <sup>197</sup>

The ephemeral right to privacy only has true meaning as a property right. The right to privacy is not textually enshrined in either the Constitution or the Bill of Rights. American courts have understandable difficulty in

Nevertheless, it is well settled that that Constitutionally ordained right of property is and must be subject and subordinated to the Supreme Power of Government - generally known as the Police Power - to regulate or prohibit an owner's use of his property provided such regulation or prohibition is clearly or reasonably necessary to preserve or protect the health or safety or morals and general welfare of the people ....

However, neither the power of the Executive arm nor of the Legislative arm of our Government is unlimited.

Id. at 412 (citations omitted).

<sup>&</sup>lt;sup>192</sup> Feist Publ'ns v. Rural Tel. Serv., 499 U.S. 340, 345 (1991).

<sup>&</sup>lt;sup>193</sup> Such taking and gainful use of a product of another which, for reasons of public policy, the law has refused to endow with the attributes of property, does not become unlawful because the product happens to have been taken from a rival and is used in competition with him." *Int'l News Serv.*, 248 U.S. at 258 (Brandeis, J., dissenting).

There are exceptions to the duty of confidentiality. As Justice Scalia noted in <u>Ferguson v. City of Charleston, 532 U.S. 67, 91 (2001)</u> South Carolina "recognizes no physician-patient testimonial privilege and requires the physician's duty of confidentiality to yield to public policy ... and which requires medical conditions that indicate a violation of the law to be reported to authorities." <u>Id. at 102</u>, (Scalia, J., dissenting) (citations omitted). Justice Scalia further noted that, pursuant to <u>Whalen v. Roe, 429 U.S. 589 (1977)</u>, the "privacy interest does not forbid government to require hospitals to provide, for law enforcement purposes, names of patients receiving prescriptions of frequently abused drugs." Id.

<sup>&</sup>lt;sup>195</sup> Perhaps these needs are best addressed with a notion akin to "coterie." From the French, "coterie" references "an intimate and often exclusive group of persons with a unifying common interest or purpose." Merriam-Webster's Collegiate Dictionary, supra note 163, at 262.

<sup>&</sup>lt;sup>196</sup> See Nicoll, supra note 29, at 761 (citing John Balint, Issues of Privacy and Confidentiality in the New Genetics, <u>9 Alb. L.J.</u>

<u>Sci. & Tech. 27, 36 (1998)</u>). American courts have long recognized the importance of property rights and their limitations. See <u>Cleaver v. Bd. of Adjustment, 200 A.2d 408 (Pa. 1964)</u> (recognizing property rights and highlighting limitations to police power including the takings clause of the Fifth Amendment). In Cleaver, the Supreme Court of Pennsylvania noted:

<sup>&</sup>lt;sup>197</sup> Griswold v. Connecticut, 381 U.S. 479, 484 (1965).

ascertaining in just what part of the Constitution or the Bill of Rights privacy rights are enshrined. Rights related to the modern concept of privacy are of monumental importance, but this particular "right" cannot be found in the Constitution or the Bill of Rights. Privacy rights should be enshrined in law by our legislature, not cut out of whole cloth by law professors and activist judges. <sup>198</sup> The myriad of principals now protected by privacy rights are in peril as long as they are anchored to privacy's newly created, ill-defined, and ever-shifting principals instead of the bedrock of the time-tested rights and principles associated with property rights.

Privacy rights are often traced to a seminal law review article articulating "the right "to be let alone." <sup>199</sup> A recent commentator and supporter of "privacy" rights stated that "after attempting to rely on the "penumbras' of the First, Third, Fourth, Fifth, and Ninth Amendments to the Constitution, a majority of the Court found a less evanescent source for the right to privacy in the liberty component of **[\*658]** the Fourteenth Amendment's Due Process Clause." <sup>200</sup> Some would prefer a firmer foundation in law for "privacy" rights. Professor Laurence Tribe proposed a constitutional amendment effectively seeking to protect privacy rights in 1991.

In Griswold v. Connecticut, <sup>202</sup> the Court claimed, "We deal with a right of privacy older than the Bill of Rights." <sup>203</sup> This argument is a peculiar one: does the importance of a "right to privacy" transcend the documents put together by the framers, or is it implicit in the text of the Constitution? <sup>204</sup> Until a right to privacy is formally enshrined in the Constitution, and perhaps thereafter, the best way to protect genetic information is through property rights.

The Colorado statute protecting genetic information as an individual's unique property does so "to protect individual privacy and to preserve individual autonomy." <sup>205</sup> Legendary legal scholar William Prosser was instrumental in inventing privacy rights in a landmark law review article in which he identified four privacy torts. <sup>206</sup> The

This Constitution's protections for the freedoms of speech, press, petition, and assembly, and its protections against unreasonable searches and seizures and the deprivation of life, liberty, or property without due process of law, shall be construed as fully applicable without regard to the technological method or medium through which information content is generated, stored, altered, transmitted, or controlled.

Id. at 39 (emphasis added). This language is particularly relevant to genetic information if it is considered as a technological medium. Read as such, the proposed amendment would effectively extend constitutional "privacy" rights to genetic information.

<sup>&</sup>lt;sup>198</sup> See, e.g., Robert H. Bork, Neutral Principles and Some First Amendment Problems, 47 Ind. L.J. 1, 6-11 (1971).

<sup>&</sup>lt;sup>199</sup> Samuel D. Warren & Louis D. Brandeis, The Right to Privacy, 4 Harv. L. Rev. 193, 195 (1890). "It is the unwarranted invasion of individual privacy which is reprehended, and to be, so far as possible, prevented." Id. at 215.

<sup>&</sup>lt;sup>200</sup> Susan Frelich Appleton, Standards for Constitutional Review of Privacy-Invading Welfare Reforms: Distinguishing the Abortion-Funding Cases and Redeeming the Undue-Burden Test, <u>49 Vand. L. Rev. 1, 13-14 (1996)</u> (footnote omitted). Appleton notes, "Roe prompted criticism about the Court's resurrection of "substantive due process,' a phrase the Justices more forthrightly embraced a term later ...." Id. at 14 n.69 (footnotes omitted).

<sup>&</sup>lt;sup>201</sup> Laurence H. Tribe, Harv. L. Sch., The Constitution in Cyberspace: Law and Liberty Beyond the Electronic Frontier (Mar. 26, 1991), in 51 The Humanist, Sept.-Oct. 1991, at 15-21, 39. This speech was given prior to the adoption of the Twenty-Seventh Amendment dealing with congressional pay raises in 1992, and as such it would now be the Twenty-Eighth Amendment. Tribe's proposed amendment would read as follows:

<sup>&</sup>lt;sup>202</sup> 381 U.S. 479 (1965).

<sup>203</sup> Id. at 486.

<sup>&</sup>lt;sup>204</sup> See <u>Zablocki v. Redhail, 434 U.S. 374, 384 (1978)</u> (claiming the Supreme Court's "recent decisions" recognized a "fundamental "right of privacy' implicit in the Fourteenth Amendment's Due Process Clause.").

<sup>&</sup>lt;sup>205</sup> Colo. Rev. Stat. Ann. §10-3-1104.7(1)(c) (West 1999 & Supp. 2004).

conceptualization of publicity rights as a property right, **[\*659]** however, leads to a greater possible scope of protection than characterization as a privacy right. <sup>207</sup>

Expansion of a privacy right in genetic identity or persona is a way to protect an individual's genetic information. <sup>208</sup> However, it sidesteps the reality that to prohibit or control another's use of his identity for commercial gain, or to otherwise harm the individual, is exercising an individual's property right. The consequences to insurability are just one example of measurable harm flowing from the misappropriation or misuse of genetic information.

The "umbrella of privacy" is too ephemeral a concept to protect property as important as genetic information. <sup>209</sup> Genetic property [\*660] rights do not flow from emanations and penumbras of individual autonomy, but from the reality that they are ours in the most fundamental sense. That which is ours is best protected by property rights.

Privacy is sometimes a necessary, but certainly not a sufficient safeguard for protecting that which "belongs" to an individual. Modern technology takes what was once invisible, our genetic information, and makes it into something examinable - in every detail - turning a once opaque house into glass. Arguably, there is no reasonable expectation of privacy for one living in a glass house, yet all the associated property rights remain.

3. Genetic Privacy: How the Regime Handles Test Cases

william L. Prosser, Privacy, 48 Cal. L. Rev. 383 (1960). Prosser argues for a privacy protection regime based on what seems to be property rights in an individual's commercial image or persona. Prosser identifies at least four different privacy rights: "(1) Intrusion upon ... seclusion or solitude, or into his private affairs. (2) Public disclosure of embarrassing private facts ... . (3) Publicity which places the [individual] in a false light in the public eye. (4) Appropriation, for [another person's] advantage, of the [individual's] name or likeness." Id. at 389.

Privacy statutes began to appear in the 1970s:

Beginning in the 1970's, a number of states enacted "publicity" statutes, which continue to evolve today.

Thus, a critical distinction to make among jurisdictions is the extent to which the right of publicity is recognized separately from the right of privacy. Perhaps the most substantial difference between "publicity" regimes oriented toward privacy and those oriented toward property is that, as a property right, a celebrity's interest is assignable and descendable. However, some jurisdictions place limits on the duration of publicity rights following a celebrity's death, and still others do not recognize the descendability of publicity rights at all.

Merges et al., supra note 144, at 790.

<sup>207</sup> A privacy conception of publicity rights also leads to rights of a different scope than a property rationale does." Id. at 789-90. Judge Alex Kozinski, of the Ninth Circuit Court of Appeals, recognized this scope and expressed concern about its implications:

The panel majority erects a property right of remarkable and dangerous breadth: Under the majority's opinion, it's now a tort for advertisers to remind the public of a celebrity. Not to use a celebrity's name, voice, signature, or likeness; not to imply the celebrity endorses a product; but simply to evoke the celebrity's image in the public's mind.

White v. Samsung Elecs. Am., Inc., 989 F.2d 1512, 1514 (9th Cir. 1993) (Kozinski, J., dissenting) (disagreeing with the majority's decision to deny a petition for rehearing en banc). Kozinski's dissent raises the legitimate specter of an overly-broad property right. A broad property right in genetic information could certainly lead to abuses just as disturbing as those that arise from the under-protection of genetic information. Of course, this note does not propose an absolute and unlimited property right in genetic information and, as such, many of Kozinski's concerns are inapplicable.

<sup>208</sup> See e.g., Janet A. Kobrin, Confidentiality of Genetic Information, <u>30 UCLA L. Rev. 1283 (1983)</u> (entrusting patient genetic information to the physician duty of confidentiality).

<sup>209</sup> In Griswold v. Connecticut, Justice Douglas found a right to privacy in "penumbras, formed by emanations" from different parts of the *Bill of Rights. 381 U.S. 479, 484 (1965)*. Despite the brilliant critique of this view by those such as Judge Bork, see Bork, supra note 198, there is a principled argument for this position. See Appleton, supra note 200, at 13-15. However, the difficulties inherent in this cobbled-together nature of this right are solved by placing the right properly in a property right. Contra Genetic Bill of Rights, supra note 15, at 223-24 (listing privacy, not property, as a protectible interest).

This notion of privacy is not drawn from the blue. It emanates from the totality of the constitutional scheme under which we live. <sup>210</sup>

The test cases from Part II. A show that a privacy regime is barely adequate to protect genetic information. Only the brute force of positive law allows the individuals in those scenarios to vindicate their rights. As such, privacy is not the ideal regime to protect genetic information.

The first scenario illustrates the dangers of the misuse of information and tests the possible solutions to the problems associated with control of genetic information - the denial of insurance coverage for a preexisting condition after collection of a blood sample. Some states, including California, make this illegal using privacy laws.

The second hypothetical involves the termination of insurance coverage because the insurance company took a blood sample and thereby became privy to damaging genetic information. The privacy regime laws also make this behavior illegal. <sup>212</sup>

[\*661] The third test case involves the denial or termination of insurance coverage because a criminal suspect underwent mandatory DNA collection when arrested, after which insurance companies gained or were allowed access to the sample. Again, the laws of both states using privacy regimes, California and Michigan, make this conduct illegal. <sup>213</sup> If the information gleaned is evidence, a judge can decide whether that information is placed in a database or stored in some other fashion. Insurance and employment discrimination based on this information are likely to be prohibited under state law, but that does the individual no good if he is exposed to other potential peril, such as prejudice and subtler forms of discrimination.

Thus, privacy regimes can handle the hypothetical cases adequately, so long as privacy is given the legal standing and currency it commands. Why, then, does this note favor property over privacy? Privacy rights totter upon thin, shifting, and unstable conceptual "tectonic plates," placing whatever legal tenets happen to stand upon its framework on an unpredictable and dangerous legal "fault line." Property rights provide a sound and less ephemeral foundation; they are the bedrock best upon which to erect a framework for protection of genetic information.

If these claims are accepted, it is a small matter to adopt property regimes protecting genetic information, like those in Colorado, Georgia, and Louisiana. The states that utilize privacy regimes could easily adopt property language in their legislation, with a minimal degree of difficulty or displacement.

#### Conclusion

Every man has a "property" in his own "person." 214

<sup>&</sup>lt;sup>210</sup> Poe v. Ullman, 367 U.S. 497, 521 (1961) (footnotes omitted).

<sup>&</sup>lt;sup>211</sup> See, e.g., <u>Cal. Gov't Code §12940(a)</u> (West 2005) (prohibiting employment discrimination on the basis of a medical condition, including the requirement of tests); <u>Cal. Health & Safety Code §124975(k)</u> (West 1996) (requiring that any screening programs for heredity disorders comply with the Hereditary Disorders Act §27).

<sup>&</sup>lt;sup>212</sup> <u>Cal. Ins. Code §§742.405, 742.407, 10123, 10123.3(a), 10123.35, 10123.9</u>, <u>10140(b)</u>-(d), 10140.1, 10140.5, 10143, 10146-10149.1, 10198.9, 10233.1, 10705(j), and 10901.2(c)-(d) (West Supp. 2005).

<sup>&</sup>lt;sup>213</sup> See, e.g., id.; *Mich. Comp. Laws* §§333.17020, 333.17520, and 333.21072(a) (2001). The Michigan Legislature has since repealed §333.21072(a). See *Mich. Comp. Laws* §333.21072(a) (2001 & Supp. 2005).

<sup>&</sup>lt;sup>214</sup> Locke, supra note 158, at 20.

People have property rights in their personal genetic information. <sup>215</sup> They should be protected by state and federal law as an incorporeal thing (tangi non possunt) against misappropriation and misuse, including discrimination in employment or insurance contexts. In light of the relatively recent dawning of a fuller [\*662] conceptualization of property rights in the intangible, it is understandable, if regrettable, that privacy rights were cobbled together to shield rights best protected as property rights. Even if Professor Tribe's proposed constitutional amendment, explicitly establishing rights to privacy, is passed, it would merely carve out a square peg resting uncomfortably in the round hole completely filled by property rights. <sup>216</sup>

It is beyond the scope of this note to fully explore property rights in the human body, but more work is needed on this front. <sup>217</sup> Future work is also needed to fully explore property rights models in genetic information and genetic material and whether these rights are found in the natural law. <sup>218</sup>

The movie Gattaca <sup>219</sup> poignantly demonstrates the dangers of disclosure of genetic information. In the movie, the protagonist, Vincent, is subjected to a lifetime of genetic discrimination - the method by which the movie's fictional world is divided between "valid" individuals, who comprise a genetically engineered elite, and those who are regarded as "invalid" because of their birth in the absence of genetic intervention. <sup>220</sup> He becomes a "stolen ladder" as he adopts the identity of a "valid" to achieve his dream of space flight - a dream denied by society to anyone not genetically engineered as a member of the elite. <sup>221</sup> Despite his best efforts to eliminate any possibility of detection which might result from the discovery of his own genetic information, in the end Vincent is imperiled because of a single eyelash found at his place of work. He is finally exposed through his failure of a urine test. <sup>222</sup> It is only because of the mercy of the technician who discovers his failed test - a father with an "invalid" child - that Vincent is allowed to travel in space and fulfill [\*663] his dream. <sup>223</sup> The best way to protect against genetic discrimination and recognize this aspect of genetic liberty is to recognize that an individual's genetic information is that individual's personal property.

#### Appendix: A Brief Genetic Information Primer

To better understand genetic information, it is helpful to understand some of the science behind it. From the largest to the smallest concept, genetic information can be thought of as: genome, cell, DNA, chromosome, genes, bases, and proteins. The "genome" is composed of all the DNA in an organism. <sup>224</sup> Most human cells contain a complete

<sup>220</sup> Id.

<sup>221</sup> ld.

<sup>222</sup> Id.

<sup>&</sup>lt;sup>215</sup> Although genes do not completely define any one person, they are inextricably bound to personhood. Cf. O'Callaghan, supra note 8.

<sup>&</sup>lt;sup>216</sup> See supra note 201 and accompanying text.

<sup>&</sup>lt;sup>217</sup> Professor R. H. Helmholz suggests that rights models regarding genetic information and materials would profit from research and thought regarding the work of Heinz Huebner, Kerstin Gronau, and Pierre Tercier, particularly Heinz Huebner's essay, Das Personlichkeitsrecht im Spannungsfeld zwischen Informationsauftrag und Menschenwurde, 116 Archiv des offentlichen Rechts 297 (1989) (F.R.G.).

<sup>&</sup>lt;sup>218</sup> This author prefers the term "natural rights" to avoid the conflation of license with liberty found in modern "human rights" talk and the common lack of recognition of every right's connection with corresponding duties. This author also avoids the term "natural law" because of the unfair and unfortunate modern interpretation it has acquired as relevant only in a religious context.

<sup>&</sup>lt;sup>219</sup> Gattaca, supra note 49.

<sup>&</sup>lt;sup>223</sup> Vincent "fails" a urine test, exposing him as an imposter, but he is allowed to board the spaceship and fulfill his lifelong dreams because the technician has an invalid child that idolizes Vincent. Vincent represents a chance at fulfillment for all, whatever their genetic constitution. Id.

<sup>&</sup>lt;sup>224</sup> See David Shier et al., Hole's Human Anatomy & Physiology 115 (10th ed. 2004) [hereinafter Shier].

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set of that organism's DNA. <sup>225</sup> DNA contains the "exact instructions required to create a particular organism with its own unique traits." <sup>226</sup> The DNA sequence is understood as the arrangement of four complex molecules called bases, represented by two sets of paired letters: A-T and G-C. <sup>227</sup> The bases that form our DNA are arranged in a "double helix" <sup>228</sup> - in a way that looks like a twisted ladder. The order of the base pairs that make up an organism's DNA stays the same, absent mutation, throughout the life of the organism. <sup>229</sup> Human DNA is "arranged into" twenty-four chromosomes with approximately 50 million to 250 million base pairs per chromosome. <sup>230</sup> Each chromosome is composed of numerous genes. <sup>231</sup> Genes are the "basic physical and functional units of heredity." <sup>232</sup> The genome is composed of approximately 30,000 [\*664] genes. <sup>233</sup> Genes comprise approximately two percent of the human genome; "the remainder consists of noncoding regions, whose functions may include providing chromosomal structural integrity and regulating" protein production. <sup>234</sup> Proteins are "large, complex molecules" made up of amino acids that "perform most life functions and ... make up the majority of life structures." <sup>235</sup> As revolutionary as genomic studies are, and will be, proteomics - the study of the structure and function of proteins - has the potential to provide even more answers than genomic studies, yet also, simultaneously, raise even more disturbing questions. <sup>236</sup>

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<sup>230</sup> Id.

<sup>231</sup> ld.

<sup>232</sup> Id.

<sup>233</sup> Id.

<sup>234</sup> Id.

<sup>235</sup> Id.

<sup>236</sup> Id. The following quote is illustrative:

Although genes get a lot of attention, it's [sic] the proteins that perform most life functions and even make up the majority of cellular structures....

... Unlike the relatively unchanging genome, the dynamic proteome changes from minute to minute in response to tens of thousands of intra-and extracellular environmental signals. A protein's chemistry and behavior are specified by the gene sequence and by the number and identities of other proteins made in the same cell at the same time and with which it associates and reacts. Studies to explore protein structure and activities, known as proteomics, will be the focus of much research for decades to come and will help elucidate the molecular basis of health and disease.

<sup>&</sup>lt;sup>225</sup> See Science Behind the Human Genome Project, supra note 47 ("Except for mature red blood cells, all human cells contain a complete genome.").

<sup>&</sup>lt;sup>226</sup> Id.

The bases of nucleic acids in human DNA are adenine (A), thymine (T), guanine (G), and cytosine (C). See Shier, supra note 224, at 116.

<sup>&</sup>lt;sup>228</sup> For an entertaining account of Watson's "discovery" of the double helix form, see James D. Watson, The Double Helix 194-97 (Paperback Fiction ed., Scribner 1998) (1968).

<sup>&</sup>lt;sup>229</sup> See Science Behind the Human Genome Project, supra note 47.