

# KEEPING PACE WITH PROGRESS: A PROPOSAL FOR FLORIDA'S GENETIC TESTING STATUTE

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*Our laws and institutions must keep pace with the progress  
of the human mind.*

—Thomas Jefferson<sup>1</sup>

## I. INTRODUCTION

In 2008 Donna Campiglia learned that there was a genetic test available to identify what sports her then two-year-old son might later be gifted in.<sup>2</sup> Ms. Campiglia was thrilled with the opportunity to find out her son's athletic inclinations before he was old enough to manifest them.<sup>3</sup> With a simple cheek swab and \$149, her son could be on his way to a college scholarship or a career as a professional athlete.<sup>4</sup>

Although some, like Ms. Campiglia, are optimistic about such tests, critics argue that this and other non-medical genetic tests<sup>5</sup>

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1. Genetics & Pub. Policy Ctr., *Overview*, <http://www.dnapolicy.org/about.overview.html> (accessed Jan. 19, 2013).

2. Juliet Macur, *Born to Run? Little Ones Get Test for Sports Gene*, N.Y. Times A1 (Nov. 30, 2008) (reporting that there is a genetic test available that may be able to determine a child's propensity for certain sports).

3. *Id.* The article explains that the test determines a person's predisposition to speed and power sports, endurance sports, or sports that require a combination of abilities. *Id.*

4. *Id.* The test is marketed to parents who want to predetermine their child's abilities before they manifest and therefore is recommended for infants to eight-year-olds. *Id.*

5. See e.g. Monifa Thomas, *Is Baldness in Your DNA? Company Says Men with One Genetic Variant Have 60 Percent Chance of Going Bald by Age 40*, Chi. Sun-Times 18 (Apr. 1, 2008) (describing a genetic test that can reveal genetic variations associated with baldness, thus enabling individuals to take preventative measures against hair loss); Marilyn Marchione, *Gene Test Claims to Show What Diet Works Best*, Huffington Post, [http://www.huffingtonpost.com/2010/03/08/gene-test-claims-to-show\\_n\\_490603.html](http://www.huffingtonpost.com/2010/03/08/gene-test-claims-to-show_n_490603.html) (Mar. 4, 2010,

are ploys to make money, or as one doctor put it, “an opportunity to sell new versions of snake oil.”<sup>6</sup> Whether these tests are effective, the for-profit motive of non-medical genetic testing is readily apparent. What is less recognized, however, is that people who undergo testing for medical purposes may subject themselves to an even worse form of economic exploitation—use of their genetic information by doctors and researchers seeking to capture a part of the huge profits to be made in genetic research and treatment.<sup>7</sup> The researcher often accrues these profits without any remuneration—and sometimes, even knowledge—passing to the person who provided their information.<sup>8</sup> There are currently no viable legal mechanisms to prevent this practice, but there are big incentives to continue it.<sup>9</sup> Before this problem escalates, legal steps need to be taken that will both correct the current issues relating to genetic property rights and prepare society to address other problems that may arise in the future.

This Article examines the rapidly advancing field of genetic testing and its implications, specifically focusing on, and attempting to remedy, existing Florida legislation that purports, but in practicality fails, to protect all stakeholders involved in study.<sup>10</sup> This current legislation appears to grant property rights in genetic information to those who contribute it,<sup>11</sup> but in actuality gives researchers a proprietary stake in genetic information far

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5:22 p.m. EDT) (detailing how DNA testing can be used to create customized diets that aid in weight loss by determining how individuals’ bodies react to certain foods).

6. Macur, *supra* n. 2 (quoting Dr. Theodore Friedmann, “Director of the University of California-San Diego Medical Center’s interdepartmental gene therapy program”).

7. See Harriet A. Washington, Huffington Post: The Blog, *Gene Patenting Produces Profits, Not Cures*, [http://www.huffingtonpost.com/harriet-a-washington/gene-patenting-produces-p\\_b\\_645862.html](http://www.huffingtonpost.com/harriet-a-washington/gene-patenting-produces-p_b_645862.html) (July 14, 2010, 1:07 p.m. EDT) (explaining that by 1991, hospitals had earned more than \$218 million in patent royalties; by 2003, licensing arrangements had earned university researchers and academic institutions more than \$1.3 billion; and by 2006, “university technology transfer offices had generated at least \$45 billion, largely from licensing fees”).

8. See *infra* pt. II(C)(1) (using real life situations to illustrate how genetic information providers often have no knowledge that their genetic information is being used for commercial purposes).

9. See May Mowzoon, *Access Versus Incentive: Balancing Policies in Genetic Patents*, 35 *Ariz. St. L.J.* 1077, 1077 (2003) (noting that patent rights allow inventors the “exclusive right to exclude others from making, using, or selling claimed technology”); Washington, *supra* n. 7 (explaining the enormous profit potential in patenting genetic information).

10. See *infra* pt. III (discussing Florida Statutes Section 760.40).

11. The statute provides that “the results of [a person’s] DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested.” Fla. Stat. § 760.40(2)(a) (2011).

greater than the stake retained by contributors<sup>12</sup>—a result that is detrimental to genetic information providers and society as a whole.<sup>13</sup> By giving teeth to the existing legislation, the goal of reversing this impact and bringing about a balance that considers all parties involved is obtainable. Part I discusses a recent history of the darker side of genetic information use that eventually led to the enactment of legislation against the misuse of genetic information and discusses why these protections are not enough. Part II breaks down the current state-level protections of genetic information, specifically addressing Florida’s genetic information-protection statute and determining how it is applied. Part III proposes an amendment to Florida’s genetic information-protection statute, derived from and inspired by Florida’s right-of-publicity statute and the common law principle of license coupled with an interest. Finally, Part IV concludes that the next step in ensuring future progress in genetic study is to eliminate the threat of economic exploitation and loss of control in one’s own genetic information.

## II. GENETIC TESTING: BLESSING OR CURSE?

The modern study of genetics, which has existed for about 150 years,<sup>14</sup> has led to our current understanding of heredity and to some of our most promising medical advancements to date.<sup>15</sup> This Part, however, discusses the less altruistic side of genetics

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12. In this Article, people who provided genetic information used in a genetic study are referred to as “contributors” and “providers.”

13. See *infra* pt. II(C)(2) (explaining this result and the problems associated with it).

14. See Understanding Evolution, *Discrete Genes Are Inherited: Gregor Mendel*, [http://www.evolution.berkeley.edu/evolibrary/article/\\_0\\_0/history\\_13](http://www.evolution.berkeley.edu/evolibrary/article/_0_0/history_13) (accessed Jan. 19, 2013) (noting some of the first discoveries in genetics expressed in Charles Darwin’s 1859 publication, *Origin of Species*, and Gregor Mendel’s 1850s experiments on pea plants that noted how traits are passed from one generation to the next).

15. See U.S. Dep’t of Energy Genome Program’s Biological & Emt’l Research Info. Sys., *Potential Benefits of Human Genome Project Research*, [http://www.ornl.gov/sci/techresources/Human\\_Genome/project/benefits.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/project/benefits.shtml) (last modified Oct. 9, 2009). After the completion of the Human Genome Project (an initiative formally introduced in 1990 primarily to identify and sequence all the genes in human DNA), a host of possibilities for improvement in many fields have developed. *Id.* Genetic research is expected to lead to improved disease diagnosis, earlier detection of predispositions to disease, gene therapy to treat diseases, and drugs customized to treat particular patients. *Id.* Additionally, genome research is expected to be used in “molecular medicine; energy sources and environmental applications; risk assessment; bioarchaeology, anthropology, evolution, and human migration; DNA forensics; and agriculture, livestock breeding, and bioprocessing.” *Id.*

use in recent history and discusses the development of state and federal regulations that attempt to mitigate the uglier side of genetic study. This Part then examines some relatively recent illustrative cases that suggest a need for stronger, property-based protections of genetic information.

### A. Misuse of Genetic Information: A Brief History

Social Darwinism was a late nineteenth-century philosophy, under which Charles Darwin's theory of natural selection and survival of the fittest was applied to society.<sup>16</sup> Followers of the theory believed that like plants and animals whose subsequent generations could be improved by artificial selection, the human race could similarly be improved.<sup>17</sup> This theory led to a sort of science known as eugenics,<sup>18</sup> under which the human race was to be made ideal by eradicating "undesirable" hereditary traits, including mental illness, "feeble-mind," epilepsy, and criminal behavior.<sup>19</sup> Notoriously, Nazi Germany used eugenics as the basis of its inhumane practices of human experimentation and genocide.<sup>20</sup> This base way of thinking not only pervaded Nazi Germany but also took root in the United States, even garnering the Supreme Court's approval in its 1927 *Buck v. Bell*<sup>21</sup> decision. In *Buck*, the Court considered the forced sterilization of a young girl.<sup>22</sup> Justice Oliver Wendell Holmes, writing for the Court, ordered the sterilization of the supposedly mentally challenged Carrie Buck, justi-

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16. Daniel Kevles, *PBS, In the Name of Darwin*, <http://www.pbs.org/wgbh/evolution/darwin/nameof/> (accessed Jan. 19, 2013).

17. *Id.* Artificial selection is "[a] process in which humans consciously select for or against particular features in organisms," which "causes evolutionary change in the organism." Understanding Evolution, *Artificial Selection*, [http://evolution.berkeley.edu/evolibrary/glossary/glossary\\_popup.php?word=artificial+selection](http://evolution.berkeley.edu/evolibrary/glossary/glossary_popup.php?word=artificial+selection) (accessed Jan. 19, 2013).

18. Kevles, *supra* n. 16. Francis Galton coined the term "eugenics" in 1883 to, in his words, rid society of its "undesirables" while multiplying its "desirables." *Id.*

19. Katherine Castles, *Quiet Eugenics: Sterilization in North Carolina's Institutions for the Mentally Retarded, 1945-1965*, 68 *J. S. Hist.* 849, 849-850 (2002).

20. See generally Henry P. David, Jochen Fleischhacker & Charlotte Höhn, *Abortion and Eugenics in Nazi Germany*, 14 *Population & Dev. Rev.* 81, 81 (Mar. 1988) (discussing the evidence and evolution of abortion and eugenics in Nazi Germany).

21. 274 U.S. 200, 205 (1927).

22. *Id.* Buck was just one of a reported sixty thousand or more people who were legally sterilized under government-funded programs. Tiesha Rashon Peal, *The Continuing Sterilization of Undesirables in America*, 6 *Rutgers Race & L. Rev.* 225, 229 (2004).

fyng the decision through the assertion that “[t]hree generations of imbeciles are enough.”<sup>23</sup>

Although forced sterilization has long been abandoned,<sup>24</sup> this practice was not the last time in our nation’s history that genetics has been used for less than noble purposes; another unfortunate occurrence is the use of genetic information to execute racial discrimination.<sup>25</sup> Some genetic traits and conditions are present only in certain racial or ethnic groups.<sup>26</sup> These traits and conditions can lead to racial or ethnic discrimination under the guise that negative treatment or disadvantage is based on the genetic condition. One such discrimination case took place in the 1970s, when technology was developed to screen and identify sickle-cell anemia carriers.<sup>27</sup> Sickle-cell anemia is a disease of the red blood cells primarily afflicting African Americans, which can disrupt healthy blood flow and result in a variety of serious complications.<sup>28</sup> States began mandating genetic testing of all African Americans

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23. *Buck*, 274 U.S. at 207. The three generations referred to here were Buck’s mother, Buck herself, and Buck’s illegitimate daughter. Paul Lombardo, *Eugenics Archive, Image Archive on the American Eugenics Movement, Eugenic Sterilization Laws*, <http://www.eugenicsarchive.org/html/eugenics/essay8text.html> (accessed Jan. 19, 2013). Evidence has shown that Buck’s sterilization was actually based on her “promiscuity” that produced her illegitimate child. *Id.* As it turns out, however, Buck was not “promiscuous” but was “raped by a relative.” *Id.* Additionally, school records indicate that Buck’s daughter was not actually “feeble minded.” *Id.* Despite these facts, *Buck* stood as precedent justifying more than eight thousand sterilizations in Virginia. *Id.*

24. *Skinner v. Oklahoma* was the next Supreme Court case to address forced sterilization, and in that case, the Court struck down Oklahoma’s sterilization law. 316 U.S. 535, 545 (1942). Sterilization continued until the mid-1970s, however, and the *Buck* precedent has never been expressly overruled. Lombardo, *supra* n. 23.

25. See U.S. Equal Empl. Opportunity Comm’n, *Facts about Race/Color Discrimination*, <http://www.eeoc.gov/facts/fs-race.html> (last modified Sept. 8, 2008) (showing how genetic characteristics and conditions can be used to execute racial discrimination through the example of “no-beard” employment policies put in place to discriminate against African American men, the group of people most likely to suffer from “pseudofolliculitis barbae (severe shaving bumps)”).

26. U.S. Equal Empl. Opportunity Comm’n, *The Genetic Information Nondiscrimination Act of 2008, Sec. 2 Findings*, <http://www.eeoc.gov/laws/statutes/gina.cfm> (accessed Jan. 19, 2013).

27. *Id.* The test is done using a blood sample that is checked for hemoglobin S—the defective form of hemoglobin that causes the condition. Mayo Clinic, *Sickle Cell Anemia: Tests and Diagnosis*, <http://www.mayoclinic.com/health/sickle-cell-anemia/DS00324/DSECTION=tests-and-diagnosis> (Mar. 26, 2011).

28. Nat’l Ctr. for Biotechnology Info., U.S. Nat’l Library of Med., *Sickle Cell Anemia*, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001554/> (last reviewed Feb. 7, 2012) (noting that such complications might include anemia, blindness, neurologic issues, organ failure, and premature death).

to identify carriers of the disease,<sup>29</sup> despite the fact that carriers do not experience symptoms of true sickle-cell anemia.<sup>30</sup> This practice, coupled with inadequate confidentiality protections for test results, led to many African Americans falling victim to discrimination by employers and insurers who claimed that denial of employment or insurance was due to the applicants' disease risk, although it was usually due to race.<sup>31</sup> To remedy this issue, Congress passed the 1972 National Sickle Cell Anemia Control Act.<sup>32</sup> Additionally, Title VII of the Civil Rights Act of 1964 has since been interpreted to prohibit discrimination based on conditions, like sickle-cell anemia, that primarily affect a single race.<sup>33</sup>

Despite these attempts at alleviating misuse of genetic information, several more instances involving discrimination have arisen. Employment discrimination was at issue in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*,<sup>34</sup> where prospective employees were given employment offers made expressly conditional on "medical approval," "medical examination," or "health evaluation."<sup>35</sup> Although the potential employees consented to a general medical examination and voluntarily provided blood or urine samples, they did not consent to certain procedures, including genetic testing.<sup>36</sup> Additionally, no one informed the employees

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29. *Id.* Someone who carries the sickle-cell trait has "one gene for sickle hemoglobin and one gene for normal hemoglobin" and can never "develop [sickle-cell] disease." Ill. Dep't of Pub. Health, *Sickle Cell Disease and Sickle Cell Carrier Status*, <http://www.idph.state.il.us/HealthWellness/SickleCell.pdf> (accessed Jan. 19, 2013).

30. U.S. Equal Empl. Opportunity Comm'n, *supra* n. 26.

31. See Lori Andrews, *Body Science*, 83 ABA J. 44, 47-48 (Apr. 1997) (noting that "a number of companies discriminated against black employees and job applicants who carried sickle-cell anemia even though that status had no bearing on an employee's . . . ability to work since the only significance of carrying the trait was a 1-in-4 chance of passing the disease on to a child if the other parent also was a carrier"); Deborah Gridley, *Genetic Testing under the ADA: A Case for Protection from Employment Discrimination*, 89 Geo. L.J. 973, 975 (2001) (stating that both employers and states mandated such testing).

32. Pub. L. No. 92-294, 86 Stat. 136 (1972). The effect of this law is to "withhold . . . Federal funding from [s]tates unless [sickle-cell] testing is voluntary." U.S. Equal Empl. Opportunity Comm'n, *supra* n. 26.

33. U.S. Equal Empl. Opportunity Comm'n, *supra* n. 25 (stating that this prohibition applies with the caveat that the practice may be permissible if it "is job related and consistent with business necessity").

34. 135 F.3d 1260 (9th Cir. 1998).

35. *Id.* at 1264-1265.

36. *Id.* at 1265. Other tests that were not consented to, but were required, were for syphilis and pregnancy. *Id.*

of the screening,<sup>37</sup> and no one created safeguards for this information to preserve the privacy of those tested.<sup>38</sup> Although the court found for the plaintiffs in this case, the genetic discrimination issue was still looming, as shown in similar cases that followed.<sup>39</sup>

One case against Burlington Northern Santa Fe Corporation (BNSF) also involved an employer's misuse of genetic information.<sup>40</sup> Employees who complained of carpal tunnel syndrome (CTS)<sup>41</sup> symptoms were required to provide blood samples to their employer, who tested the samples for the genetic trait thought to cause the condition.<sup>42</sup> The company instituted the practice because it wanted to prove that CTS was not a work-related condition, so as to avoid workers' compensation claims.<sup>43</sup> Employees who refused to submit to the blood sample were subject to potential disciplinary action or termination.<sup>44</sup> The parties in this case

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37. *Id.*; see also U.S. Nat'l Lib. of Med., *Abstract: Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, <http://www.ncbi.nlm.nih.gov/pubmed/11648435> (accessed Jan. 19, 2013) (summarizing the *Norman-Bloodsaw* holding that "neither consent to a general medical examination nor consent to providing blood or urine samples abolishes the privacy right not to be tested for intimate, personal matters involving one's health").

38. *Norman-Bloodsaw*, 135 F.3d 1260 at 1265.

39. *Id.* at 1275 (reversing summary judgment in favor of the defendant due to the existence of "material and disputed issues of fact . . . with respect to whether reasonable persons in plaintiffs' position would have had reason to know that the tests were being performed"). For further discussion of the implications of the *Norman-Bloodsaw* decision, see Cristina E. Echevarria, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory: 135 F.3d 1260 (9th Cir. 1998)*, 29 Golden Gate U. L. Rev. 71, 78–79 (1999).

40. Stephen Fink, *EEOC v. BNSF: The Risk and Rewards of Genetic Exceptionalism*, 42 Washburn L.J. 525 (2003).

41. Carpal tunnel syndrome is a disorder that afflicts the median nerve in the forearm, hand, and wrist, and causes burning, itching, numbness, and difficulty grasping. Nat'l Inst. of Neurological Disorders & Stroke, *Carpal Tunnel Syndrome Fact Sheet*, [http://www.ninds.nih.gov/disorders/carpal\\_tunnel/detail\\_carpal\\_tunnel.htm](http://www.ninds.nih.gov/disorders/carpal_tunnel/detail_carpal_tunnel.htm) (last updated Sept. 18, 2012).

42. Fink, *supra* n. 40, at 527.

43. *Id.* Workers' compensation claims can be extremely costly to employers as illustrated by Florida's worker's compensation statistics, showing total benefits paid on claims in the past ten years reaching as high as \$2,620,003,944. Fla. Dep't of Fin. Servs., *WC Claims Database Statistics Results*, <http://www.myfloridacfo.com/wc/databases.html>; *select* Statistical Reports Based on Claims Data, *select* Injury Years from 01/01/2002 Through 12/31/2012, *select* ALL under County of Accident, *select* ALL for Disability Type, *select* ALL under Cause of Accident, *select* ALL for Nature of Accident, *select* ALL under Body Location, *select* ALL under Industry Type, *select* YEAR and ASCENDING under Sort Order, *select* Submit Query (updated Oct. 4, 2012, 12:11 a.m.).

44. U.S. Equal Empl. Opportunity Comm'n, *EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing under Americans with Disabilities Act*, <http://www.eeoc.gov/eeoc/newsroom/release/archive/2-9-01-c.html> (last modified Feb. 12, 2001).

reached a settlement, but again, the results did not put to rest the practice or the fear of genetic misuse.<sup>45</sup>

A study in 1996 found that several institutions, including “insurance companies, [healthcare] providers, adoption agencies, the military, and schools” engaged in genetic discrimination against individuals, although these individuals showed no signs of manifesting a certain condition.<sup>46</sup> Further, several surveys reveal Americans’ apprehension and unwillingness to undergo genetic testing. One 2001–2003 study showed that forty percent of the 86,859 adults surveyed believed that genetic testing “was not a good idea” because they feared being dropped from their insurance plans.<sup>47</sup> Another study from the Genetics and Public Policy Center at Johns Hopkins University<sup>48</sup> indicated that fear of genetic misuse was on the rise; eighty-five percent of those surveyed in 2002 did not want an employer to have access to their genetic information, and sixty-eight percent wanted their genetic information kept private from health insurers.<sup>49</sup> In 2004, those percentages rose to ninety-two and eighty, respectively.<sup>50</sup>

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45. U.S. Equal Empl. Opportunity Comm’n, *EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act*, <http://www.eeoc.gov/eeoc/newsroom/release/archive/5-8-02.html> (May 8, 2002).

46. H.R. Subcomm. on Health, Empl., Lab. & Pens. of the Comm. on Educ. & Lab., *Protecting Workers from Genetic Discrimination*, H.R. 493, 110th Cong. 11 (Jan. 30, 2007).

47. *Id.*; see generally Coalition for Genetic Fairness, *Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People* (July 2004) (available at <http://www.nationalpartnership.org/site/DocServer/FacesofGeneticDiscrimination.pdf?docID=971>) (describing the impacts of genetic discrimination and compiling several real-life instances of insurance and employment discrimination).

48. The Public Policy Center was created in 2002 to aid in understanding and responding to the challenges and opportunities presented by genetic study, through conducting “legal research and policy analysis, perform[ing] policy-relevant social science research, craft[ing] robust policy options and recommendations, conven[ing] and consult[ing] key stakeholders to identify common ground and develop consensus, and influenc[ing] national genetics programs and policy.” Genetics & Pub. Policy Ctr., *supra* n. 1.

49. H.R. Subcomm. on Health, Empl., Lab., & Pens. of the Comm. on Educ. & Lab., *supra* n. 46, at 11.

50. *Id.* In addition to these studies, this hearing transcript mentions three additional studies reflecting similar findings. *Id.*



## B. GINA: A Band-Aid for a Bullet Wound

In the wake of cases and studies like those described, and a myriad of anecdotal cases,<sup>51</sup> the support necessary to pass genetic antidiscrimination legislation gained momentum and eventually passed after a thirteen-year struggle.<sup>52</sup> The culmination of these efforts was the unanimous passage of the Genetic Information Nondiscrimination Act of 2008 (GINA).<sup>53</sup>

While a definite step in the right direction for providing the necessary protections of genetic information, GINA only extends to discriminatory misuse of genetic information by employers and insurance providers.<sup>54</sup> This leaves individuals' genetic information unguarded against discrimination by other institutions and completely susceptible to many other problems beyond discrimination.<sup>55</sup>

One such important issue left unaddressed by GINA is the potential to lose control over the use of one's own genetic information.<sup>56</sup> This issue relates in significant part to the debate over

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51. Representative Louise Slaughter's offered the following anecdotal testimony:

[Y]ou may not know about the North Carolina woman who was fired after a genetic test had revealed her risk for a lung disorder, even though she had begun the treatments that would keep her healthy. Or the social worker whom, despite outstanding performance reviews, was fired because of her employer's fears about her family history of Huntington's disease.

*Id.* at 10–11.

52. See Representative Louise M. Slaughter, *Rep. Slaughter, Author of Genetic Information Nondiscrimination Act, Applauds Bill's Passage in House of Representatives*, [http://www.louise.house.gov/index.php?option=com\\_content&view=article&id=964:may-1-2008-rep-slaughter-applauds-gina-bills-passage-in-house-of-representatives&catid%20=68:2008-press-releases&Itemid=111](http://www.louise.house.gov/index.php?option=com_content&view=article&id=964:may-1-2008-rep-slaughter-applauds-gina-bills-passage-in-house-of-representatives&catid%20=68:2008-press-releases&Itemid=111) (May 1, 2008) (describing the background of, and events leading up to, GINA's eventual passage).

53. 42 U.S.C. § 2000ff (2008).

54. *Id.*; see also Lib. of Cong., *Bill Summary & Status 110th Congress (2007–2008) H.R. 493 CRS Summary*, <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@D&summ2=m&> (May 21, 2008) (summarizing GINA's protections against insurance and employment discrimination).

55. See Laurie A. Vasichek, *Genetic Discrimination in the Workplace: Lessons from the Past and Concerns for the Future*, 3 St. Louis U. J. Health L. & Policy 13, 36–39 (2009) (explaining GINA's deficiencies including a lack of protection for persons who have a condition that is somewhere between nascent and fully manifest, and situations beyond insurance and employment); see e.g. pt. IV(C) (predicting the paparazzi's potential misuse of a celebrity's DNA).

56. See e.g. Mowzoon, *supra* n. 9, at 1094 (quoting John Moore, a man who had his genetic information used for commercial profit without his consent, as stating, "What the doctors had done, was to claim that my humanity, my genetic essence, was their invention and their property").

whether each person's genetic information should be considered his or her property.<sup>57</sup> A few states—Alaska, Colorado, Florida, Georgia, and Louisiana—have taken the affirmative stance on this issue and legislatively attached property rights to genetic information.<sup>58</sup> Such rights appear to offer protection against the uncompensated use, patenting, and sale of certain genetic material without the genetic information provider's consent.<sup>59</sup> But these state statutes may not actually confer this protection because of shortcomings in the text of the statutes themselves or their interpretation by state courts.<sup>60</sup>

### C. Why Property Rights in Genetic Information Are Worth Caring About

Who has ultimate control of genetic information not only impacts the genetic information contributor and the scientists studying it, but it also affects society as a whole. When the interests of researchers and genetic information contributors are in conflict, advancements that benefit society are less likely because the cooperation of both researchers and information contributors is vital to progress in genetic study.<sup>61</sup> As laws currently stand,

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57. See generally Donna M. Gitter, *Ownership of Human Tissue: A Proposal for Federal Recognition of Human Research Participants' Property Rights in Their Biological Material*, 61 Wash. & Lee L. Rev. 257 (2004) (proposing a Congressional enactment of a model recognizing property interests in body tissue); Natalie Ram, *Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research*, 23 Harv. J.L. & Tech. 119 (2009) (suggesting that genetic information should be protected as "informational property"); Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 Ave Maria L. Rev. 611 (2006) (proposing that the best solution for protecting genetic information is to protect it as property); but see Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 Geo. Wash. L. Rev. 737 (2004) (arguing against treating genetic information as property).

58. See Nat'l Conf. of St. Legis., *Genetic Privacy Laws*, <http://www.ncsl.org/default.aspx?tabid=14287> (updated Jan. 2008) (illustrating that Alaska, Colorado, Florida, Georgia, and Louisiana consider genetic information to be property).

59. This is because property rights come with the right to exclude another person from the use of one's own property, and thus a genetic information provider who has a property right in their genetic information would be able to exclude such unconsented uses. See *Kaiser Aetna v. United States*, 444 U.S. 164, 176 (1979) (asserting that the right to exclude others is "one of the most essential sticks in the bundle of rights that are commonly characterized as property").

60. See *infra* pt. II(C)(2) (describing existing state statutes dealing with protection of genetic information).

61. To achieve economic benefit and scientific breakthroughs, researchers need genetic information to study. To glean any benefit from a contributor's genetic information, such

researchers have almost complete control, leaving genetic information providers, their families, and society open for economic exploitation.<sup>62</sup> As the following cases involving such economic exploitation demonstrate, something beyond existing law is necessary to balance the rights of genetic information contributors and researchers, so as to maximize the progress that benefits all people.

### 1. Illustrative Cases

One famous case, *Moore v. Regents of the University of California*,<sup>63</sup> illustrates a situation in which a researcher was granted economic control over genetic information, even though the researcher took and used the information without the information contributor's consent.<sup>64</sup> In *Moore*, John Moore was diagnosed with hairy cell leukemia and sought treatment at the University of California, Los Angeles (UCLA) Medical Center.<sup>65</sup> His attending physician, Dr. Golde, confirmed his diagnosis after several tests and recommended that Moore's spleen be removed to slow the disease's progress.<sup>66</sup> Unbeknownst to Moore, Dr. Golde had determined prior to the spleen removal that Moore's genetic material could be useful for research and commercial purposes.<sup>67</sup> After Moore's spleen was removed, Dr. Golde prompted him to return to the UCLA Medical Center, from his home in Seattle,

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as a cure for a genetic disease, genetic information contributors need researchers to analyze and interpret the genetic information.

62. See Gina Kolata, *Who Owns Your Genes?* N.Y. Times A17 (May 15, 2000) (quoting "Dr. Robert Cook-Deegan, an investigator at the Kennedy Institute of Ethics at Georgetown University," as stating in reference to genetic patents, "We have a system where the research participants are treated as pure altruists, but everyone else is treated as a pure capitalist").

63. 793 P.2d 479 (Cal. 1990).

64. *Id.* at 480.

65. *Id.* Hairy cell leukemia is "a rare, slow-growing cancer of the blood in which your bone marrow makes too many B cells (lymphocytes), a type of white blood cell that fights infection." Mayo Clinic, *Hairy Cell Leukemia, Definition*, <http://www.mayoclinic.com/health/hairy-cell-leukemia/DS00673> (Mar. 21, 2012). As the leukemia cells increase, the number of "healthy white blood cells, red blood cells, and platelets" decreases. *Id.* There is no cure for the condition, but treatment can lead to remission. *Id.*

66. *Moore*, 793 P.2d at 481.

67. *Id.*; see also Washington, *supra* n. 7 (explaining how Dr. Golde made a deal with Sandoz (a pharmaceuticals company) for three billion dollars "to produce and refine nine valuable cancer-fighting pharmaceuticals produced by Moore's spleen").

several more times.<sup>68</sup> Although Moore was under the impression that these return visits were medically necessary, they were actually conducted for Dr. Golde's research purposes.<sup>69</sup> Dr. Golde and his research team eventually patented a cell line created from Moore's genetic material and entered into agreements for commercial development that had an estimated profit potential of over three billion dollars.<sup>70</sup> Moore filed suit against the researcher and his affiliates, arguing, among other things, that he had a property right in his excised genetic material and that Dr. Golde had illegally converted this property.<sup>71</sup> The Court, however, found that there cannot be property rights in genetic material, and Moore recovered nothing on this claim.<sup>72</sup>

Another example of an individual's loss of economic control of his or her genetic information is the story of Henrietta Lacks.<sup>73</sup> At age thirty-one, Henrietta Lacks, a poor tobacco farmer, died of cervical cancer.<sup>74</sup> Prior to her death, doctors extracted cells from

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68. *Moore*, 793 P.2d at 481. Moore made twelve follow-up visits, and during the last two visits, Dr. Golde presented Moore with two "previously unseen consent forms that purported to waive" Moore's rights to any commercial products made from his tissue. Jennifer Lavoie, *Ownership of Human Tissue: Life after Moore v. Regents of the University of California*, 75 Va. L. Rev. 1363, 1365–1366 (1989). Moore reluctantly signed the first "but refused to sign the second." *Id.* Despite this fact, Dr. Golde filed initial patent applications for the cell line developed from Moore's cells, even before he presented the waiver forms to Moore. *Id.*

69. *Moore*, 793 P.2d at 481.

70. *Id.* at 516. The patent was actually sold "for several million dollars in cash and stock." Nat'l Health Fed'n, *Does Legal Ownership of Genes, Stem Cells Go Beyond the Pale?* <http://www.thenhf.com/article.php?id=345> (May 18, 2006).

71. *Moore*, 793 P.2d at 482. Moore's causes of action included "(1) conversion; (2) lack of informed consent; (3) breach of fiduciary duty; (4) fraud and deceit; (5) unjust enrichment; (6) quasi-contract; (7) bad faith breach of the implied covenant of good faith and fair dealing; (8) intentional infliction of emotional distress; (9) negligent misrepresentation; (10) intentional interference with prospective advantageous economic relationships; (11) slander of title; (12) accounting; and (13) declaratory relief." *Id.* at 482 n. 4 (internal quotation marks omitted).

72. *Id.* at 489. For Moore, the impact of the events that befell him went beyond economic loss, as evidenced by his statement regarding his feelings on the matter:

How does it feel to be patented? There was a sense of betrayal. I mean, they owned a part of me that I could never recover. I certainly have no objection to scientific research . . . but it was like a rape. In a sense, you've been violated, for dollars. My genetic essence is held captive.

Washington, *supra* n. 7.

73. CBS News, *Sunday Morning, The Immortal Henrietta Lacks*, <http://www.cbsnews.com/stories/2010/03/15/sunday/main6300824.shtml> (Mar. 15, 2010, 1:20 p.m.).

74. *Id.* For more information describing the life and legacy of Henrietta Lacks, see Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (Broadway 2011).

her tumor for use in a number of important and influential studies and products.<sup>75</sup> This fact was unknown to Ms. Lacks and her family until twenty-five years after the extraction of her cells.<sup>76</sup> Her family did not receive any financial compensation, despite the fact that Ms. Lacks' cells were the first cells ever commercialized and today are available for sale online from anywhere between two hundred and ten thousand dollars per vial.<sup>77</sup> Additionally, Ms. Lacks' surviving family was disappointed by the failure to recognize Ms. Lacks for her important contribution to medicine; as her eldest son put it, "I think it's wrong, out of all that money they made off my mother, she's down there in Virginia in an unmarked grave."<sup>78</sup>

One case where the genetic information rights at stake were more than monetary is *Greenberg v. Miami Children's Hospital Research Institute, Inc.*<sup>79</sup> In this case, placing all rights to genetic information in the hands of researchers not only resulted in detriment to the individual donors but also potentially harmed society as a whole.<sup>80</sup> In *Greenberg*, the plaintiffs formed a group to help gather familial information and genetic samples from families that suffered from Canavan disease, a genetic condition primarily suffered by Ashkenazi Jewish people.<sup>81</sup> The plaintiffs sought the assistance of a particular researcher to help discover

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75. CBS News, *supra* n. 73; see also Rebecca Skloot, *Henrietta's Dance*, Johns Hopkins Mag. (Apr. 2000) (explaining how before Ms. Lacks' first cancer treatment began, a resident, George Gey, removed a sample of Ms. Lacks' tumor, learning that the cells could live outside the body and multiply quickly—an advancement that could perhaps lead to a cure for cancer—all while neither Ms. Lacks nor her family had any idea of the use for over a quarter century).

76. CBS News, *supra* n. 73.

77. *Id.*; see e.g. BIOTANG Inc., *Human, HeLa Cell Lysate, 500ug*, <http://www.biotangusa.com/bt/human-hela-cell-lysate-500ug.html> (accessed Jan. 19, 2013) (selling copies of Ms. Lacks' cells for \$198 per vial); Novus Biologicals, *HeLa Whole Cell Lysate (NB820-59462) (1 mg)*, <http://www.novusbio.com/HeLa-Whole-Cell-Lysate-NB820-59462.html?rr=true> (accessed Jan. 19, 2013) (selling 1.0 mg worth of Ms. Lacks copied cells for \$215).

78. CBS News, *supra* n. 73.

79. 264 F. Supp. 2d 1064 (S.D. Fla. 2003).

80. *Id.*

81. *Id.* at 1066–1067. Canavan disease is a “neurological disorder[ ] in which the brain deteriorates” because the disease “interferes with the body’s normal production of myelin[,] . . . a protective coating around each nerve in the brain and spinal cord.” Canavan Research Found., *Canavan Disease, What Is It?* <http://www.canavan.org/canavan-disease/canavan-disease.html> (accessed Jan. 19, 2013). Children afflicted with Canavan disease live only to about a maximum of ten years of age and in that short time span will “become blind, paralyzed, [and] prone to seizures.” *Id.*

the disease's genetic cause, hoping that this discovery would eventually lead to a cure.<sup>82</sup> When the researcher agreed, the plaintiffs donated genetic material, familial information, and financial support, which eventually did lead to the discovery of the gene that causes Canavan disease.<sup>83</sup> Without the plaintiffs' knowledge or permission, however, the researcher and affiliated hospital patented the gene to limit its use and obtain economic profit.<sup>84</sup> This action was taken despite the fact that the plaintiffs made the researcher aware at the outset that they wanted all discoveries and research derived from their donated genetic information shared in the public domain to maximize progress in Canavan disease research.<sup>85</sup> The plaintiffs sued the researcher and the hospital, alleging several causes of action and seeking an injunction on the patent and a return of the resulting profits.<sup>86</sup> One cause of action was a conversion claim that the genetic information donated was property used for purposes, such as obtaining economic benefit, that were not authorized by the plaintiffs.<sup>87</sup> The court, however, found that there was no cause of action because the information had willingly been donated without a contemporaneous expectation of receiving something in return.<sup>88</sup>

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82. *Greenberg*, 264 F. Supp. 2d at 1066.

83. *Id.* at 1067. Mutations in the aspartoacylase (ASPA) gene cause Canavan disease. Genetics Home Ref., ASPA, <http://ghr.nlm.nih.gov/gene/ASPA> (last reviewed Jan. 2008).

84. *Greenberg*, 264 F. Supp. 2d at 1067.

85. *Id.* One of the plaintiffs, Judith Tsipis, stated in reference to the isolated Canavan gene that "[h]ad they told us they wanted to patent it, we probably would have found another researcher who had the same goals as we did. Finding the gene is not an impossible task." Kolata, *supra* n. 62. Another plaintiff, Daniel M. Greenberg, echoed the sentiments, stating, "I am disappointed and disheartened and disgusted." *Id.*

86. *Greenberg*, 264 F. Supp. 2d at 1068. The potential damage to society as a whole is the fact that the defendant-researcher was not enjoined from limiting use and access to discoveries made as a result of using the plaintiffs' donated genetic material. *Id.* at 1067. The plaintiffs wanted this information shared freely to help maximize the potential of finding a cure for Canavan disease. *Id.*

87. *Id.* at 1074. Other causes of action included "(1) lack of informed consent; (2) breach of fiduciary duty; (3) unjust enrichment; (4) fraudulent concealment"; and (5) misappropriation. *Id.* at 1068.

88. *Id.* at 1076. Although not recovering in court on their conversion claim, the parties reached an agreement in 2003, which included agreement that (1) the plaintiffs would not "further challenge [the hospital's] ownership and licensing of the Canavan gene patent"; (2) the hospital could "continue to license and collect royalty fees for clinical testing for the Canavan gene mutation"; and (3) there could be "license free use of the Canavan gene in research to cure Canavan disease, including in gene therapy research, genetic testing in pure research, and in mice used to research Canavan disease." Canavan Found., *Canavan in the News, Joint Press Release*, [http://www.canavanfoundation.org/news/09-03\\_miami.php](http://www.canavanfoundation.org/news/09-03_miami.php) (Sept. 29, 2003).

## 2. Defining the Problems under Current Law

Economically exploitative situations, like those in the cases just described, perpetuate fear and mistrust regarding genetic study. By allowing researchers this unchecked ability to profit from the genetic information of others, not only do researchers have no legal reason to cease economically driven misuse, but individuals that might otherwise undergo genetic testing are dissuaded from doing so.<sup>89</sup> Individuals who choose not to undergo genetic tests for fear of genetic information misuse may forego learning of their own important health information and preventable conditions.<sup>90</sup> Without a willing population to test, genetic research and the advancements promised by it may come to a standstill, and the significant time and capital invested in the Human Genome Project and its progeny will be for naught.<sup>91</sup> Even if progress is not entirely halted, researchers' legal ability to control use of genetic information through patents creates a strong possibility of monopolization of, and high costs for, advancements derived from the patents.<sup>92</sup>

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89. See H.R. Subcomm. on Health, Empl., Lab. & Pens. of the Comm. on Educ. & Lab., *supra* n. 46, at 8–9 (showing testimony of New York Representative, Louise Slaughter, indicating that several surveys demonstrate the public's apprehension to undergo genetic testing for fear of its misuse); see also Mary Taylor Danforth, *Cells, Sales, and Royalties: The Patient's Right to a Portion of the Profits*, 6 Yale L. & Policy Rev. 179, 190 (1988) (arguing that "[r]esearch 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").

90. See Mayo Clinic, *Genetic Testing, Definition*, <http://www.mayoclinic.com/health/genetic-testing/MY00370> (Jan. 7, 2011) (explaining that "genetic testing can provide important information for diagnosing, treating[,] and preventing illness").

91. See H.R. Subcomm. on Health, Empl., Lab. & Pens. of the Comm. on Educ. & Lab., *supra* n. 46, at 8 (showing testimony of Representative Louise Slaughter, indicating that research might be hindered because people are unwilling to undergo genetic testing out of fear of misuse of their results).

92. Such a result is not unlikely, as a similar outcome has already been demonstrated in the pharmaceuticals industry. See Melissa K. Davis, *Monopolistic Tendencies of Brand-Name Drug Companies in the Pharmaceutical Industry*, 15 J.L. & Com. 357, 357 (1995) (noting that "[f]or several decades, large pharmaceutical companies have been free to charge whatever they wished for brand-name prescription drugs because the patents that such pharmaceutical companies hold on the brand-name drugs have prevented competition in the market"); Washington, *supra* n. 7 (comparing the potential results of genetic patents to how the sixty-billion-dollar pharmaceutical industry became the most profitable industry in the world).

To quiet these fears, the majority of states have legislatively granted some protections for genetic information.<sup>93</sup> These protections mostly require varying degrees of consent,<sup>94</sup> and some even offer “specific penalties for genetic privacy violations.”<sup>95</sup> These protections, however, do not do enough to address the major catalyst contributing to researchers’ unrestrained economic control over genetic information—the fact that there is no legally defined path to benefit economically from one’s own genetic information.<sup>96</sup> To remedy this issue, genetic information contributors should be granted property rights in their own genetic information, thereby creating the legal path necessary for contributors to garner an economic stake in the genetic research process. A few states—Alaska, Colorado, Florida, Georgia, and Louisiana—appear at first glance to statutorily provide this solution.<sup>97</sup>

Alaska Statutes Section 18.13.010 offers genetic information contributors the broadest protections against economic exploitation; the genetic sample and the results of a genetic test are deemed to be the genetic information contributor’s property,<sup>98</sup> and violation of the statute results in steep civil penalties.<sup>99</sup> Conversely, Colorado’s,<sup>100</sup> Georgia’s,<sup>101</sup> and Louisiana’s<sup>102</sup> statutes

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93. Nat’l Conf. of St. Legis., *supra* n. 58. Eighteen states, however, have no such legislation: Alabama, Connecticut, Indiana, Iowa, Kansas, Kentucky, Maine, Mississippi, Montana, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, Tennessee, West Virginia, Wisconsin, and Wyoming. *Id.*

94. Four states require “personal access to genetic information,” twelve states require consent to perform a genetic test, seven states require consent to access genetic information, eight states require consent to retain genetic information, and twenty-seven states require consent to disclose genetic information. *Id.*

95. Nineteen states provide specific penalties. *Id.*

96. See Eric B. Chen, *Who Owns the Property Rights to Your Genetic Material?* 13 U. Balt. Intell. Prop. L.J. 1, 9–11 (2004) (explaining how a patient’s legal remedies under current law are limited and proposing a profit-sharing model as a solution to this problem).

97. Nat’l Conf. of St. Legis., *supra* n. 58 (noting the types of genetic information protections offered in each of the fifty states).

98. Alaska Stat. Ann. § 18.13.010 (WL current through 2012 2nd Reg. Sess.).

99. *Id.* Alaska Statutes Section 18.13.020 provides:

A person may bring a civil action against a person who . . . [is] in violation of this chapter. In addition to the actual damages suffered by the person, a person violating this chapter shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000.

100. Colo. Rev. Stat. Ann. § 10-3-1104.6 (WL current through 2010 2nd Reg. Sess.).

101. Ga. Code Ann. § 33-54-1 (WL current through 2010 Reg. Sess.).

102. La. Rev. Stat. Ann. § 22:1023 (WL current through 2009 Reg. Sess.).



offer minimal property protections. Each of these statutes indicates that only the results of a genetic test are property, and they only apply in the context of providing information to health insurers.<sup>103</sup> Florida Statutes Section 760.40 appears to offer protections somewhere between Alaska's broad level and Colorado's, Georgia's, and Louisiana's minimal level, but the exact protections are harder to pinpoint.<sup>104</sup> It is therefore important to clarify whether Florida's genetic information-protection statute actually creates this legal path to property rights in one's own genetic information.

### *III. FLORIDA'S GENETIC INFORMATION-PROTECTION STATUTE LEAVES ROOM FOR INTERPRETATION*

As it currently stands, Florida's genetic information-protection statute provides:

(1) As used in this section, the term "DNA analysis" means the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person's body. The term includes DNA typing and genetic testing.

(2)(a) Except for purposes of criminal prosecution, except for purposes of determining paternity as provided in s. 409.256 or s. 742.12(1), and except for purposes of acquiring specimens as provided in s. 943.325, DNA analysis may be performed only with the informed consent of the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of

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103. See Colo. Rev. Stat. Ann. § 10-3-1104.6 (detailing the intent of the statute "to prevent genetic information from being used to deny access to [healthcare] insurance or [M]edicare supplement insurance coverage"); Ga. Code Ann. § 33-54-1 (describing the intent of the statute "to prevent accident and sickness insurance companies, health maintenance organizations, managed care organizations, and other payors from using information derived from genetic testing to deny access to accident and sickness insurance"); La. Rev. Stat. Ann. § 22:1023 (stating that "[a]n insured's or enrollee's genetic information is the property of the insured or enrollee," and not extending this protection to those who are not an "insured" or an "enrollee").

104. Fla. Stat. § 760.40. Unlike Colorado, Georgia, and Louisiana, Florida Statutes Section 760.40 applies in more than the insurance context, since it is drafted as a civil rights statute. *Id.* Also, the Florida statute provides a criminal penalty for violation, but like the Colorado, Georgia, and Louisiana statutes, it considers only the results of genetic tests (rather than the genetic sample itself) to be property. *Id.*

the person tested, are confidential, and may not be disclosed without the consent of the person tested. Such information held by a public entity is exempt from the provisions of s. 119.07(1) and s. 24(a), Art. I of the State Constitution.

(b) A person who violates paragraph (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083.

(3) A person who performs DNA analysis or receives records, results, or findings of DNA analysis must provide the person tested with notice that the analysis was performed or that the information was received. The notice must state that, upon the request of the person tested, the information will be made available to his or her physician. The notice must also state whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. If the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.<sup>105</sup>

Turning first to subsection (1), certain important questions about the scope of the “DNA analysis” definition arise. A clear delineation of this scope is crucial in determining Florida’s current protections of genetic information because subsection (2) of the statute defines rights of genetic information contributors in regard to their “DNA analysis.”<sup>106</sup> As *Moore* and the *Henrietta Lacks* situation illustrate, procedures meant for a medical purpose can lead to the discovery of certain genes or genetic material that prove to be useful or unique for genetic study purposes.<sup>107</sup> Bearing this in mind, questions arise as to whether the term “DNA analysis” under Florida Statutes Section 760.40 encompasses testing that uncovers these unintended, but potentially valuable, discoveries.<sup>108</sup> If the Statute does not, Florida’s potential genetic information contributors may be susceptible to the same loss of economic control that befell John Moore and

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105. *Id.*

106. *Id.*

107. *See supra* pt. II(C)(1) (discussing *Moore* and the story of *Henrietta Lacks*).

108. Fla. Stat. § 760.40.

Henrietta Lacks.<sup>109</sup> A further related question about the scope of “DNA analysis” under Florida Statutes Section 760.40 is whether further tests on the extracted genetic material (rather than tests on the actual genetic information contributor) are covered under its definition. Again, as demonstrated in *Moore* and the case of Henrietta Lacks, excised genetic material can be used, replicated, and manipulated to create patentable products.<sup>110</sup> If further testing of extracted material is not considered “DNA analysis” for the purposes of Florida Statutes Section 760.40, Florida’s potential genetic information contributors have no statutory recourse against doctors or researchers who use their genetic information for purposes beyond those for which the contributor intended.

Subsection (2)(a) gives context for why defining the scope of “DNA analysis” is important, but in doing so elicits questions of its own.<sup>111</sup> One important issue of subsection (2)(a) is determining what performing DNA analysis “only with the informed consent of the person to be tested” entails.<sup>112</sup> In *Greenberg*, the court found that the researcher’s concealment of his intent to patent and commercialize donated genetic material did not violate the duty of informed consent.<sup>113</sup> The *Greenberg* court did recognize in a footnote, however, an American Medical Association (AMA) promulgation that requires disclosure of potential commercial use of biological material before a profit can be realized from it.<sup>114</sup> The court dismissed the plaintiffs’ claim that this regulation extended the duty of informed consent to cover economic interests, reason-

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109. See *supra* pt. II(C)(1) (explaining how neither John Moore nor Henrietta Lacks were allowed a share in the profit made from their genetic information).

110. See Michael M. J. Lin, Student Author, *Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act*, 22 Am. J.L. & Med. 109, 112 n. 21 (1996) (noting that cell lines like those created in the case of John Moore and Henrietta Lacks are “capable of perpetual replication”).

111. See *id.* at 112 (describing the lack of “relevant [caselaw]” in the biotechnology field).

112. *Id.*

113. 264 F. Supp. 2d at 1070 (“declining to extend the duty of informed consent to cover economic interests” because it would “chill medical research” by “mandat[ing] that researchers constantly evaluate whether a discloseable event has occurred”).

114. *Id.* at 1070 n. 2. This promulgation states, “Potential commercial applications must be disclosed to the patient before a profit is realized on products developed from biological materials” and “[h]uman tissue and its products may not be used for commercial purposes without the informed consent of the patient who provided the original cellular material.” Am. Med. Ass’n, *AMA Code of Medical Ethics, Opinion 2.08—Commercial Use of Human Tissue*, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion208.page> (accessed Jan. 19, 2013).

ing that it was not binding on the parties because it was promulgated in 1994 and the primary sequence of events at issue in the case took place between 1987 and 1994.<sup>115</sup> Perhaps current or future cases regarding informed consent under Florida Statutes Section 760.40 would be subject to this AMA provision, but whether courts will construe it this way or make it binding remains to be seen.

Another significant point to consider in this subsection is the purported grant of property rights in the “results of . . . DNA analysis.”<sup>116</sup> The distinction between “results,” or the genetic information gleaned from the testing, and physical bodily material, is an important feature of Florida’s Statute because it defines the reach of the property protection.<sup>117</sup> This leads to the next, and arguably, most significant issue presented—determining which rights attach to this property grant. Caselaw dealing with Florida Statutes Section 760.40 offers little elucidation. In *Doe v. Suntrust Bank*,<sup>118</sup> the court offered its interpretation of the Statute:

Viewed as a whole, it appears to us that the primary purpose of the statute is to protect individuals who undergo DNA analysis by requiring informed consent before the analysis is performed, by providing confidentiality for the results, including exempting the results from disclosure as a public record, by providing control over how the results are disclosed, and by requiring notification that the analysis was performed and how it was used.<sup>119</sup>

Additionally, the court noted the legislative intent of the Statute, stating that it is to “provide confidentiality for the results of genetic testing.”<sup>120</sup> Although both the court and the legislature emphasize confidentiality, neither gives emphasis to the section of

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115. *Greenberg*, 264 F. Supp. 2d at 1070–1071.

116. Fla. Stat. § 760.40(2)(a) (stating “the results of such DNA analysis . . . are the exclusive property of the person tested”).

117. This means that had *Moore* been decided in Florida, rather than California, the plaintiff may have been able to succeed on his conversion claim. Whereas the court in *Moore* found that there is no property right in excised genetic material, 793 P.2d at 489, a case arising under the jurisdiction of Florida Statutes Section 760.40 may have resulted in the plaintiff succeeding on his conversion claim regarding the “results” of the “DNA analysis” conducted.

118. 32 So. 3d 133 (Fla. 2d Dist. App. 2010).

119. *Id.* at 138.

120. *Id.* at 138 n. 7.

the Statute that states that “the results of such DNA analysis . . . are the exclusive property of the person tested.”<sup>121</sup> It appears then, that Florida Statutes Section 760.40 may simply be a precursor to GINA’s protections of genetic information confidentiality.<sup>122</sup>

Assuming this hypothesis is correct, the question still remains: why would a statute—one of only five in the nation that purports to include property protections—include this “property” language if its only intent was to protect confidentially through informed consent and notice requirements. In *State v. Thomas*,<sup>123</sup> the court examined the Statute’s “exclusive property of the person tested” language in a criminal context.<sup>124</sup> In this case, a homicide suspect’s DNA was taken from a discarded water bottle, without his permission, and police then used the DNA to link the suspect to blood found at the scene of the homicide.<sup>125</sup> Although the court found that the suppression of evidence was not warranted under the “inevitable discovery” exception,<sup>126</sup> the court also asserted that Florida Statutes Section 760.40 “must be strictly construed” as granting rights to the defendant and that the actions of the sheriff’s deputies who took and used the water bottle were “likely improper.”<sup>127</sup> While this case does not specifically acknowledge property rights under Florida Statutes Section 760.40, it does seem to suggest that even in criminal circumstances (as opposed to genetic testing circumstances where the tested party arguably

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121. Fla. Stat. § 760.40(2)(a).

122. This hypothesis remains untested, however, as there have been no Florida cases on point dealing with Florida Statutes Section 760.40 since the passage of GINA. Although *Suntrust Bank* was a 2010 case, and thus arose after the passage of GINA, it dealt with the ability to compel DNA testing for paternity determinations of two potential beneficiaries under a trust. 32 So. 3d at 135. Therefore, although helpful in clarifying the statutory intent, *Suntrust Bank* is not useful in determining property versus confidentiality rights of genetic information contributors in the context of this Article.

123. Or. Denying Mot. to Suppress DNA Samples, *State v. Thomas*, 2007 WL 7086406 (Fla. 4th Cir. July 30, 2007) (No. 16-2006-CF-11212-AXXX).

124. *Id.* at 3.

125. *Id.* at 2.

126. See *Nix v. Williams*, 467 U.S. 431, 447–448 (1984) (establishing the inevitable discovery rule, which allows evidence obtained through illegal or unconstitutional police procedure to be admitted into evidence if it would have ultimately been discovered by legal means).

127. Or. Denying Mot. to Suppress DNA Samples, *State v. Thomas*, 2007 WL 7086406 at 3.

ought to have even more rights than a criminal suspect), there is something more to the statute than just GINA-type protections.

Turning next to subsection (2)(b), dealing with penalties for violation of the Statute, there are several issues to address. First, the Statute offers only a criminal penalty as punishment for its violation; a person whose rights have been violated cannot receive an injunction or monetary relief based solely on violation of the Statute.<sup>128</sup> Alaska's counterpart statute explicitly allows for a civil action against a violator, and on top of any actual damages recovered from such a suit, the Statute requires the violator to pay the damaged party "\$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000."<sup>129</sup> While Florida genetic information providers are not precluded from bringing civil claims such as conversion, these claims have not yet proven to provide the relief sought.<sup>130</sup> Additionally, since there is no civil cause of action in the Statute for genetic information contributors, the penalty does little for them, except perhaps deter violators who are fearful of the criminal sanctions it provides.<sup>131</sup>

This leads to the next issue: whether the threatened criminal sanction actually deters potential violators. A misdemeanor of the first degree is punishable "by a definite term of imprisonment not exceeding [one] year"<sup>132</sup> and/or a fine of up to one thousand dollars.<sup>133</sup> While arguably the threat of imprisonment deters would-be violators, the imposition of a fine is equally, if not more, likely the penalty that would be imposed against researchers. If a fine of one thousand dollars or less, or even a stint in jail for under a year, are the only functional deterrents against violating Florida

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128. Fla. Stat. § 760.40(2)(b) (mandating a criminal penalty but no civil remedy).

129. Alaska Stat. § 18.13.020.

130. See e.g. *Greenberg*, 264 F. Supp. 2d at 1075 (stating that Florida Statutes Section 760.40 "is inapplicable under a common law theory of conversion . . . even assuming, *arguendo*, that the statute [760.40] does create a property right in genetic material donated for medical research purposes, it is unclear whether this confers a property right for conversion, a common law cause of action").

131. This assumes that the sanctions are constructed in a way that allows them to have a deterrent effect. See Paul H. Robinson & John M. Darley, *The Role of Deterrence in the Formulation of Criminal Law Rules: At Its Worst When Doing Its Best*, 91 Geo. L.J. 949, 953 (2003) (describing that for a criminal law to deter violators, "three prerequisites must be satisfied: The potential offender must know of the rule; he [or she] must perceive the cost of violation as greater than the perceived benefit; and he [or she] must be able and willing to bring such knowledge to bear on his conduct decision at the time of the offense").

132. Fla. Stat. § 775.082(4)(a).

133. *Id.* at § 775.083(1)(d).

Statutes Section 760.40, researchers who stand to make thousands, or even millions, of dollars from genetic information research are not likely to abandon such potentially lucrative opportunities.<sup>134</sup> Even assuming that the first-degree misdemeanor penalties are sufficient, enforcement may still be an issue, as evidenced by the fact that there are no published cases where a violator has been punished under Florida Statutes Section 760.40.<sup>135</sup>

A third issue raised by subsection 2(b) is determining if and how the penalty prescribed by the Statute compensates genetic information contributors for their loss of property rights. While researchers have a legal path to recoup money lost in paying the Statute's penalty,<sup>136</sup> a fine of a thousand dollars or less does not begin to compensate genetic information contributors for losing control of their genetic information. This is especially true because the fine is a criminal penalty, meaning the money paid by a violator would go to the state, not the genetic information contributor who was actually harmed.<sup>137</sup> This also negates the idea that property protections are the Statute's main intent; if genetic information contributors truly had property rights in their genetic information, a one-thousand-dollar criminal penalty would be an unsuitable property protection.<sup>138</sup>

The final subsection of Florida Statutes Section 760.40 deals with notice requirements to those who have been tested.<sup>139</sup> This subsection offers no more clarity regarding genetic information contributors' property rights in their genetic information because it deals with use of genetic information by specific institutions,

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134. See Robinson & Darley, *supra* n. 131, at 953 (explaining that deterrence is not effective if the potential offender perceives the benefit of the offense to be greater than the cost of the violation).

135. Although the genetic-testing area is still in its developing years and cases in this area are not common, the fact remains that violators in cases invoking this statute have not been punished as evidenced by the outcomes in *Greenberg*, 264 F. Supp. 2d at 1075, and *Thomas*, 2007 WL 7086406 at 4.

136. See Washington, *supra* n. 7 (describing the tremendous profit potential of gene patenting).

137. See Randy E. Barnett, *Restitution: A New Paradigm of Criminal Justice*, 87 Ethics 279, 285 (1977) (arguing that a victim of a crime "stands to gain little if at all by the conviction and punishment of the person who caused his [or her] loss").

138. See 18 Am. Jur. 2d *Conversion* § 116 (2004) (explaining that the proper damages for conversion of property is to compensate the owner "for the actual loss sustained").

139. See Fla. Stat. § 760.40(3) (detailing the notice that must be provided to persons whose DNA was analyzed).

including insurance and employment—the areas to which GINA’s protections extend.<sup>140</sup> Since this final subsection is similar to GINA, it is even more reasonable to assume that full property protections were not intended by the Statute, but rather Florida Statutes Section 760.40 was simply a measure with GINA-like intent, put into place before GINA was made law.<sup>141</sup>

Unfortunately for Florida’s genetic information providers, Florida Statutes Section 760.40’s notice protections are convoluted at best and certainly provide no more protection than GINA. Further, the Statute does not appear to penalize discriminatory use of genetic information in employment and insurance decisions, but only mandates that the results on which the decision was based are medically accurate.<sup>142</sup> Given this analysis, it can be determined that Florida Statutes Section 760.40 does not provide the protections necessary to defend genetic information contributors from confidentiality problems, much less protect them from economic exploitation.

#### IV. CLARIFYING THE PROPERTY INTEREST— THE PROPOSED APPROACH

Just as the practice of eugenics has been outlawed and legislation has reduced genetic information discrimination, the still unaddressed issue of economic exploitation of genetic information must be remedied. As it stands now, Florida Statutes Section 760.40 contains many of the necessary components to achieve this outcome, but these components are ambiguous and do not carry the force necessary to balance economic control between researchers and genetic information providers. Adding additional protections to the current statutory framework that address current issues and create new benefits for the future will be the next

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140. Lib. of Cong., *supra* n. 54 (describing that GINA’s protections apply in the context of insurance and employment).

141. Florida Statutes Section 760.40 was created in 1992. Fla. Stat. § 760.40 (1992). GINA was not enacted until 2008. 42 U.S.C. § 2000ff.

142. Florida Statutes Section 760.40 provides:

The notice must also state whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. If the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.



step needed to ensure the progress of genetic study and adequate rights to all individuals involved in the process.

#### A. Looking to Other Laws for Guidance

To understand how a statute that grants full property rights in genetic information should function, and to expound on why such a statute is warranted, it is helpful to examine laws that cover analogous situations. Specifically, this Part compares researchers' profits from the use of genetic information without the genetic information provider's consent with scenarios that invoke (1) Florida's right-of-publicity statute and (2) the common law principle of license coupled with an interest.

A right of publicity is a specific type of property law<sup>143</sup> that in Florida protects against the commercial use of "the name, portrait, photograph, or other likeness of any natural person without . . . express written or oral consent."<sup>144</sup> One Florida case, *John Daly Enterprises, LLC v. Hippo Golf Co.*,<sup>145</sup> illustrates the function of this Statute. In that case, John Daly, a professional golfer, entered into contracts with the defendant to act as its principal spokesman and to license to the defendant his name, likeness, and marks for the sale of golf equipment.<sup>146</sup> After these contracts ended, the defendant company continued to use Daly's name and likeness on its website.<sup>147</sup> Among other claims, Daly alleged unauthorized use of his name and likeness, in violation of Florida Statutes Section 540.08.<sup>148</sup> The court found that since the purpose of using Daly's name and likeness was to promote directly the defendant's products, the defendant violated Florida Statutes Section 540.08, and Daly was entitled to damages as prescribed by the Statute.<sup>149</sup>

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143. 63C Am. Jur. 2d *Property* § 6 (2009).

144. Fla. Stat. § 540.08.

145. 646 F. Supp. 2d 1347 (S.D. Fla. 2009).

146. *Id.* at 1348. John Daly turned professional in 1987, earning the title of Rookie of the Year in 1990 and becoming the "fourth American since World War II to win two majors before his 30th birthday." Official Site of John Daly, *Bio*, <http://www.johndaly.com/bio/> (accessed Jan. 19, 2013). Daly now resides in Clearwater, Florida and is best known for his "driving distance off the tee, his most recent wardrobe[,] and his no-frills philosophy of 'grip it and rip it.'" *Id.*

147. *John Daly Enter.*, 646 F. Supp. 2d at 1348.

148. *Id.* at 1351.

149. *Id.*

Similarly, in *Weinstein Design Group, Inc. v. Fielder*,<sup>150</sup> Weinstein Design provided interior decorating services for former professional baseball player, Cecil Fielder.<sup>151</sup> In an effort to promote its design services, Weinstein Design used Fielder's name in an article in *Florida Design* magazine without Fielder's permission.<sup>152</sup> At a jury trial, Fielder was awarded three hundred thousand dollars in compensatory damages and fifteen thousand dollars in punitive damages under Florida Statutes Section 540.08.<sup>153</sup>

Much like a person's name, picture, or likeness, a person's genetic information is a reflection of himself or herself.<sup>154</sup> If a name, for instance, can be so intertwined with one's identity as to render the need for property protections of it, how can one's genetic information—the information that literally defines a person's identity—not deserve similar protections?

The Supreme Court of California, in *Moore v. Regents of the University of California*, attempted to answer this question and to distinguish genetic information from an individual's name or likeness.<sup>155</sup> Before *Moore* reached California's highest court, the California Court of Appeal found in Moore's favor on his conversion claim, basing its opinion in part on a line of cases involving unwanted publicity.<sup>156</sup> It stated, "If the courts have found a sufficient proprietary interest in one's persona, how could one not have a right in one's own genetic material, something far more profoundly the essence of one's human uniqueness than a name or

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150. 884 So. 2d 990 (Fla. 4th Dist. App. 2004).

151. *Id.* at 993. Cecil Fielder became a professional baseball player in 1985, earning a reputation for his batting skills, including the accomplishment of hitting "more home runs than any other player in the game from 1990 to 1995." The Baseball Page, *Cecil Fielder*, <http://www.thebaseballpage.com/players/fieldce01/bio> (accessed Jan. 19, 2013). Most recently, "Fielder became the manager of the Atlantic City Surf of the Canadian-American Association of Professional Baseball in 2008." *Id.*

152. *Weinstein Design Group*, 884 So. 2d at 996. Florida Design Magazine "is dedicated to those who appreciate fine interior design, furnishings, architecture[,] and a luxurious lifestyle." Florida Design Magazine, *About Florida Design Magazine*, [http://www.floridadesign.com/about\\_us.php](http://www.floridadesign.com/about_us.php) (accessed Jan. 19, 2013).

153. *Weinstein Design Group*, 884 So. 2d at 993.

154. See Susan M. Denbo, *What Your Genes Know Affects Them: Should Patient Confidentiality Prevent Disclosure of Genetic Test Results to a Patient's Biological Relatives?* 43 Am. Bus. L.J. 561, 562 (2006) (stating that "genetic information reveals unique, involuntary, and presently immutable attributes of our genetic endowment").

155. 793 P.2d at 489–490.

156. *Id.*

a face?”<sup>157</sup> The Supreme Court of California later dismissed this analogy as one that “seriously misconceives the nature of the genetic materials and research involved in this case.”<sup>158</sup> The Court reasoned that the proteins taken from Moore’s body, lymphokines, “have the same molecular structure in every human being,” perform the same functions in every immune system, and stem from the same genetic material in every human.<sup>159</sup>

In dismissing the analogy, however, the Supreme Court of California seemed to ignore a fact presented in its own opinion in footnote two stating: “While the genetic code for lymphokines does not vary from individual to individual, it can nevertheless be quite difficult to locate the gene responsible for a particular lymphokine.”<sup>160</sup> The Court went on to note, however, that Moore’s body “overproduced certain lymphokines, thus making the corresponding genetic material easier to identify.”<sup>161</sup> So while all human bodies produce lymphokines, there was something unique about Moore that distinguished him from others and made his genetic material extremely valuable.<sup>162</sup>

Analogously, a famous person has a unique persona that makes his or her name or likeness valuable.<sup>163</sup> The difference is that the right of publicity entitles famous public figures to share in the profits that are made from their likenesses,<sup>164</sup> while genetic information contributors, who have a profit made from the “essence of [their] human uniqueness,”<sup>165</sup> are apparently not similarly entitled.

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157. *Id.* at 490. For a more in-depth exploration and proposed expanded application of the lower court’s assertion in *Moore*, see Jonathan Kahn, *Biotechnology and the Legal Constitution of the Self: Managing Identity in Science, the Market, and Society*, 51 *Hastings L.J.* 909 (2000).

158. *Moore*, 793 P.2d at 490.

159. *Id.* Lymphokines are a type of blood protein that is produced by T cells and play a role in the immune system. J.E. Ferrell, *Who Owns John Moore’s Spleen?* Chi. Trib. A1 (Feb. 18, 1990).

160. *Moore*, 793 P.2d at 482 n. 2.

161. *Id.*; see also Washington, *supra* n. 7 (explaining how Dr. Golde made a deal with Sandoz, a pharmaceuticals company, “to produce and refine nine valuable cancer-fighting pharmaceuticals produced by Moore’s spleen”).

162. The defendants in the case conducted a study that concluded that the uniqueness of Moore’s cells was caused by a virus, HTLV-II. *Moore*, 793 P.2d at 491 n. 30.

163. See generally Penny Manship, *Oh What a Tangled Web: The Entanglement of “Fan Web Sites” and the Right of Publicity*, UCLA Online Inst’n for Cyberspace L. & Policy (July 2, 1999) (available at <http://legacy.gseis.ucla.edu/iclp/manship1.htm>).

164. *Id.*

165. *Moore*, 793 P.2d at 490 (referring to genetic information).

Arguably, celebrities like John Daly and Cecil Fielder are more deserving of royalties than Moore, as they had to put in effort to achieve their fame (i.e., practice and dedication), whereas genetic information contributors, like Moore, did nothing consciously to make their genetic information valuable.<sup>166</sup> This argument breaks down, however, when one considers the prominence of socialites, royalty, or celebrities' children, who essentially expend no effort to achieve their fame.<sup>167</sup> Despite a lack of labor, the protections of publicity rights would apply to these types of celebrities in the same manner as they apply to those celebrities like John Daly and Cecil Fielder.<sup>168</sup> Beyond this, the labor theory fails to recognize the role of factors beyond one's own effort that contribute to fame, including the media,<sup>169</sup> society's values at the time of fame,<sup>170</sup> and, most importantly, genetically inherited talent.<sup>171</sup> Although each of these other factors is beyond the control of celebrities and contributes to their fame equally, if not greater than, their own efforts, celebrities are still afforded the right of publicity protections.<sup>172</sup>

License coupled with an interest, a common law concept under which a person is given authorization to enter real property

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166. See Manship, *supra* n. 163 (stating that one public policy reason behind the right of publicity is "the labor theory" and a "right to 'reap what one sows'").

167. See Michael Decker, *Goodbye, Norma Jean: Marilyn Monroe and the Right of Publicity's Transformation at Death*, 27 *Cardozo Arts & Ent. L.J.* 243, 259 (2009) (arguing that the labor theory's failure to explain a right of publicity becomes "even more striking when applied to the celebrities' legatees, who have an even more tenuous relationship to fame creation").

168. See Manship, *supra* n. 163 (noting that although part of the policy behind a right of publicity statute is that the celebrity is entitled to "the fruits of his [or her] labors," celebrity status achieved through luck does not change the applicability of the right of publicity).

169. See Decker, *supra* n. 167, at 259 (arguing that "news and entertainment . . . play a large role in the phenomenon of fame").

170. *Id.* at 258 (stating that fame is "something that is conferred by others"; that "[a] person's talents alone cannot make [him or] her famous, as fame is not a merit-based phenomenon"; and that once fame is acquired, it "perpetuates and feeds on itself").

171. See e.g. Jordan Lite, *Can Genes Predict Athletic Performance?* *Scientific American*, <http://www.scientificamerican.com/article.cfm?id=genes-sports-talent> (Dec. 1, 2008) (stating that "[m]ost research suggests that genetics contribute significantly to sports performance"); ScienceDaily, *More Evidence That Intelligence Is Largely Inherited: Researchers Find That Genes Determine Brain's Processing Speed*, <http://www.sciencedaily.com/releases/2009/03/090317142841.htm> (Mar. 18 2009) (stating that there is strong evidence that genes determine intelligence).

172. See Manship, *supra* n. 163 (describing the balancing act between fan websites and celebrities' right to publicity).

for the purpose of removing something from the land, is also instructive in creating a law that accords property rights in genetic information.<sup>173</sup> *Richbourg v. Rose*<sup>174</sup> illustrates the function of the license-coupled-with-an-interest concept. In that case, dealing with a contract for the sale of trees to be severed from land, the court stated that one who has permission to enter the land and remove the trees has “a license . . . to enter upon the [seller’s] land for the purpose of making such severance.”<sup>175</sup> This concept, which allows one party to enter the land of another for the purpose of reaping valuable goods from it, is much like a researcher using a genetic information contributor’s body to access and “harvest” valuable information. Like landowners who are compensated for their provision of access to valuable resources, genetic information providers should be similarly compensated for their provision of access to valuable genetic information.<sup>176</sup>

This notion of license coupled with an interest also helps address the argument that genetic information providers should not be compensated due to the fact that they performed no innovative or creative work.<sup>177</sup> Society takes no issue when landowners who discover oil (or any other valuable resource) on their property receive compensation for licensing the rights to it.<sup>178</sup> Some of these landowners have done nothing more than have the luck to own land that contains the valuable resources.<sup>179</sup> Simi-

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173. 53 C.J.S. *Licenses* § 133 (2005).

174. 44 So. 69 (Fla. 1907).

175. *Id.* at 69.

176. This proposal is meant to provide only compensation for genetic information; it is not meant to lead to sale of bodily material or organs. Further, the proposal safeguards against such an occurrence. For further discussion of this issue, see *infra* Part IV(B)(1).

177. See *supra* pt. IV(A) (discussing the argument that labor theory underlies right of publicity but could not support allowing genetic information contributors an economic share in their genetic information).

178. Oil discovery is sometimes even celebrated and considered legendary, rather than touted as unjust enrichment of the landowner. See Tom Henry, *Experts Explore Possibilities of Drilling for Oil in NW Ohio Again*, Toledo Blade, <http://toledoblade.com/local/2011/04/25/Experts-explore-possibilities-of-drilling-for-oil-in-NW-Ohio-again.html#cfocus> (Apr. 25, 2011) (explaining the supposedly true story of how the most productive oil well in Michigan was discovered in 1957 at “Rattlesnake Gulch” when a fortune teller had a vision that her friend who owned the land would discover oil there).

179. See *Oil Strike near Edge of St. Louis*, St. Joseph News-Press 5 (July 9, 1953) (describing how oil was discovered “purely by accident,” and the owner of the farm where the discovery was made was, in his words, “swamped by persons wanting me to sign leases”).

larly, certain people's bodies contain unique and valuable genetic information that they had no part in creating.<sup>180</sup> Again, the difference is that genetic information providers have no legally recognized path to achieve compensation for their "good" fortune, while those who discover oil on their land do. Genetic information contributors' deservingness of compensation for their "valuable material" becomes even more compelling considering that unique genetic information often comes coupled with an ailment.<sup>181</sup> Take for instance Henrietta Lacks, whose cancer cells proved invaluable to science.<sup>182</sup> It is hard to deny that this woman of limited means, dying of cancer, is as deserving of compensation for her valuable genetic information as a landowner who happens to discover oil on his or her property.

Given that genetic information providers' entitlement to protection is on par with that of celebrities who enjoy the property protections of publicity rights and landowners who enjoy the ability to license their valuable property, genetic information providers similarly ought to enjoy a legal avenue that respects a property interest in their own genetic information.

### B. Why Change Is a Good Thing: The Proposed Statute

Drawing from the principles behind right of publicity and license coupled with an interest, the following lays out a proposed amendment to Florida Statutes Section 760.40 and describes how it clarifies and balances the rights and desires of genetic information providers, researchers, and society. The proposed statute would read:<sup>183</sup>

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180. See *supra* pt. II(C)(1) (noting that John Moore's cells were potentially worth three billion dollars and Henrietta Lacks' cells are available online for between two hundred and ten thousand dollars per vial).

181. In each dealing with valuable genetic information that this Article examines, the genetic information contributors have been afflicted with some serious condition or disease. Specifically these conditions included: Canavan disease in *Greenberg*, 264 F. Supp. 2d at 1067; hairy cell leukemia in *Moore*, 793 P.2d at 480; and cervical cancer in Henrietta Lacks' story, CBS News, *supra* n. 73.

182. See *supra* pt. II(C)(1) (telling the story of Henrietta Lacks).

183. The underlined language is the proposed additions to the statute, and the language that is struck through indicates removal of the old language. To view the proposed statute apart from the text of this Article, see *infra* Appendix.

(1) As used in this section, the term “DNA analysis” means the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person’s body. The term includes DNA typing and genetic testing, and encompasses initial as well as any subsequent examination and analysis, conducted for any purpose, on extracted genetic material, or previously documented DNA analysis results.

(2)(a) Except for purposes of criminal prosecution, except for purposes of determining paternity as provided in s. 409.256 or s. 742.12(1), and except for purposes of acquiring specimens as provided in s. 943.325, DNA analysis may be performed only with the informed consent of, and full disclosure to, the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested. Such information held by a public entity is exempt from the provisions of s. 119.07(1) and s. 24(1), Art. I of the State Constitution. Where informed consent after full disclosure is lacking, the analysis may not be performed and/or use of the DNA analysis for profit or economic gain (“commercial use”) is precluded.

(b) As used in this section, the term “full disclosure” includes revelation of all material facts, specifically including risks and benefits of undergoing DNA analysis and potential commercial use of the DNA analysis.

(c) Where informed consent is obtained for commercial use of a DNA analysis, the person tested maintains the right to license the use. The terms of such license must be agreed to by the licensor and licensee prior to commencement of the DNA analysis, and upon commencement of the DNA analysis, the license becomes irrevocable.

(d)(3) The person tested, has the exclusive right to dictate A person who performs the DNA analysis or receives records, results, or findings of the DNA analysis unless a licensing agreement pursuant to subsection (c) provides otherwise. must provide the person tested with notice that the analysis

~~was performed or that the information was received. The notice must state that, upon the request of the person tested, the information will be made available to his or her physician. The notice must also state whether the information was used. The person tested also maintains the exclusive right to determine how the DNA analysis is used unless a licensing agreement pursuant to subsection (c) provides otherwise. The unconsented sale or purchase of a DNA analysis, or the use of a DNA analysis in any decision, to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity, is a prima facie violation of this section. If the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.~~

~~(3)(b) A person who violates paragraphs (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083. Upon violation of a provision in subsection (2) the person upon whom the DNA analysis was performed may enjoin the unauthorized use and recover damages for any injury it caused. In addition to the actual damages suffered by the person, a violator of this section shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, for the greater of \$100,000 or ten percent of the monetary profit or gain.~~

*1. Property Rights Are Accorded to the Results of Genetic Tests Only—Not to Genetic Material*

The proposed statute follows the original statutory construction of according property rights to the results of “DNA analysis,” rather than genetic material, but also expands the current statute to explain the extent of “DNA analysis.”<sup>184</sup> By clarifying that it covers all testing and results, including that which uncovers unin-

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184. See *supra* pt. III (discussing the question of the “DNA analysis” definition’s scope).



tended but potentially valuable results, individuals are less prone to economic exploitation.<sup>185</sup> Additionally, the proposed definition of “DNA analysis” allows for individuals to share in profit (via license coupled with an interest) but negates the argument that compensation for genetic testing is akin to selling organs and making the human body a commodity.<sup>186</sup> There is no risk of the predicted slippery slope that once genetic material can be sold, human organs will be the next item to go on the market, because only an analysis of the contributor’s DNA can garner profit for the contributor.<sup>187</sup>

## *2. License Coupled with an Interest and Up-Front Contracting*

By incorporating the spirit of the AMA promulgation regarding informed consent into subsection (2)(a) and (b), the proposed statute now dictates the standards that the medical community has deemed as best practice.<sup>188</sup> After informed consent has been obtained, subsection (2)(c) offers a legally defined path—license coupled with an interest<sup>189</sup>—for contributors to share in profit made from their genetic information. Such an arrangement gives force to the property right granted by the current statute and provides several benefits to genetic information contributors, the researchers, and in turn, the rest of society.

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185. According protection in this way helps prevent situations like those experienced by Henrietta Lacks and John Moore, neither of whom was undergoing genetic testing, but rather each was receiving medical treatment when the genetic information was ascertained and commercialized without their knowledge. For a more in-depth description of these situations, see *supra* Part II(C)(1).

186. See Gitter, *supra* n. 57, at 299 (noting that some commentators warn against according property rights in genetic tissue, as it “would both commercialize and commodify the human body”).

187. *But see* Charles A. Erin & John Harris, *An Ethical Market in Human Organs*, 29 J. Med. Ethics 137, 137–138 (2003) (arguing that the sale of human organs, through a regulated organ market, is preferred to the current ban on organ sales).

188. This means that in regard to informed consent, the statute is not imposing a duty on doctors that is any greater than what doctors have voluntarily imposed upon themselves. See Am. Med. Ass’n, *supra* n. 114 (noting the AMA promulgation that requires disclosure “to the patient before a profit is realized on products developed from biological materials”).

189. Contracting with a researcher for a licensed interest would not be requisite to undergo genetic testing. Rather, a person wishing to undergo genetic testing for his or her own personal knowledge could simply give consent as prescribed by the statute. Additionally, those wishing to donate their genetic information rather than contract for a proprietary interest in it could sign consent agreements to that effect.

First, as explained by *Richbourg*, a license coupled with an interest, once acted on, is generally irrevocable.<sup>190</sup> This prevents the potential problem that the court in *Greenberg* pointed out: the “dead-hand control that research subjects could hold” by subsequently revoking or limiting the researcher’s use of the genetic information.<sup>191</sup> The proposed statute gives researchers free reign to use the genetic information as allowed by the contract, uninhibited by fear of this “dead-hand control.” The information contributors also have a stake in the process because they can outline allowable usage of their genetic information up front. In conjunction with the expanded informed-consent requirement, this solution encourages full and open discussion between researchers and genetic information contributors<sup>192</sup> about potential genetic information use, testing procedure risks, and profit division, putting the parties on a more level bargaining field.<sup>193</sup> This license-coupled-with-an-interest mechanism also protects information providers by allowing them to retain the right to revoke the license before commencing testing.<sup>194</sup> This would help prevent patients from becoming locked into arrangements they no longer feel comfortable with.

To illustrate the license-coupled-with-an-interest section of the proposed statute, consider if *Greenberg* had arisen under the proposed Florida Statutes Section 760.40. The plaintiffs and the researcher involved could have contracted up front to establish the terms of the agreement, and with such a contract in place, the researchers would have effectively been enjoined from monopoliz-

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190. 44 So. at 69 (holding that “if the license is not revoked before the trees are severed, the title to the trees will vest in the [buyer], and the license after such severance will become coupled with an interest and irrevocable, and the [buyer] will have a right to enter and remove the trees thus severed”).

191. 264 F. Supp. 2d at 1071.

192. Open discussion also brings a clear understanding that could reduce the transaction costs of litigation. See Gillian Birkby, *A Case for the Law?* <http://www.mayerbrown.com/litigation/article.asp?id=779&nid=258> (June 2002) (stating that “[i]f . . . contractual ground rules are set out clearly at the outset, it is far less likely that there will be disputes subsequently if things go wrong”).

193. This is particularly true when compared to a situation where there is no such remedy, and the doctor may withhold his expert knowledge from a genetic information provider so as to give him or her a better bargaining position that could lead to manipulation of the genetic information provider.

194. See *Richbourg*, 44 So. at 69 (holding in regard to a license coupled with an interest in trees that “if before the trees are severed the [seller] should revoke such license, no title will pass to the [buyer], and no rights will vest”).

ing and limiting the scientific community's access to the patented information at issue.<sup>195</sup> Further, instead of the court being left to decipher the current ambiguous Florida Statutes Section 760.40,<sup>196</sup> there would be clear guidance from the terms of the parties' agreement, and if those terms (or other default provisions of the statute) were violated, the plaintiffs would have a remedy in breach of contract and a statutorily defined remedy under proposed subsection (3).<sup>197</sup>

Beyond hypothetical applications of the proposed statute, a real-life example mirroring this proposal has proven extremely successful. PXE International is a group for PXE (or pseudoxanthoma elasticum) sufferers and their families<sup>198</sup> who, like the plaintiffs in *Greenberg*, sought the help of researchers to aid in their study of the disease.<sup>199</sup> The group negotiated up front to exchange biological materials and financial support for a share in the researcher's patent rights, including economic gains and ability to control licensing rights.<sup>200</sup> PXE International did not contract for the property rights strictly for monetary gain, but did so also to ensure that one group of researchers could not inhibit other researchers' access to discoveries made regarding the disease.<sup>201</sup> This altruism dispels the idea that the proposed statute would discourage all philanthropic genetic information contribution. Under this mutually beneficial arrangement, great strides in

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195. See generally The Economist, *Genes and Patents: More Harm than Good?* <http://www.economist.com/node/15905837> (Apr. 15, 2010) (describing a study conducted by Duke University, upon the request of the American Government, that found "patent exclusivity is not necessary to spur innovation in genetic testing . . . [because] testing, unlike pricey drug development, has low barriers to entry and is relatively cheap, so a monopoly is not required to lure investors").

196. The court in *Greenberg* admitted that Florida Statutes Section 760.40 is "at best unclear" and then failed to accord the plaintiffs the property rights that Florida Statutes Section 760.40 appears to create. 264 F. Supp. 2d at 1069.

197. See *infra* pt. IV(B)(4) (explaining the penalty for violation of the amended statute).

198. This disorder is genetically inherited and "causes select elastic tissue in the body to become mineralized . . . , [which] can result in changes in the skin, eyes, cardiovascular system[,] and gastrointestinal system." PXE Int'l, *About PXE, What Is PXE?* <http://www.pxe.org/what-pxe> (last modified Apr. 26, 2011).

199. See Gitter, *supra* n. 57, at 315–319 (recounting the contractual arrangements of PXE International and researchers).

200. *Id.* at 317–318.

201. *Id.* at 318; see also Sharon F. Terry & Charles D. Boyd, *Researching the Biology of PXE: Partnering in the Process*, 106 Am. J. Med. Genetics 3, 177–184 (2001) (explaining the success of the PXE collaboration and describing how similar partnerships with lay advocacy groups and researchers can be beneficial in discovering medical advancements).

PXE research continue with no challenge from either party to their 2001 agreement.<sup>202</sup>

### 3. *Bringing Notice Requirements into the GINA Age*

The proposed statute's property-right grant is given further force by removing the outdated language of current subsection (3), which does not even appear to comply with the protections of GINA.<sup>203</sup> Proposed subsection (2)(d) ensures that genetic information providers can exercise their property rights in a way that puts their genetic information in the hands of only those specifically designated. Additionally, this proposed subsection brings the current statute into compliance with GINA and supplements the Statute in areas that GINA's protections do not extend.<sup>204</sup>

### 4. *Penalties for Violation Mirror that of Alaska Statutes Section 18.13.020 and Florida's Right of Publicity*

In addition to an action for breach of contract when genetic information is used contrary to what researchers and genetic information providers agree, violators of the proposed Florida Statutes Section 760.40 face a specific statutory penalty.<sup>205</sup> Modeled after the penalty sections of Alaska's genetic information-protection statute<sup>206</sup> and Florida's right of publicity statute,<sup>207</sup> the proposed subsection (3) gives a true remedy to aggrieved genetic

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202. *Id.*

203. For further explanation of how current Florida Statutes Section 760.40 appears not to comply with GINA, see *supra* Part III.

204. See H.R. Subcomm. on Health, Empl., Lab., & Pens. of the Comm. on Educ. & Lab., *supra* n. 46, at 11 (explaining that insurance companies and employers are not the only institutions that use genetic information for discriminatory purposes, as adoption agencies, the military, and schools have also been found to do so).

205. *Supra* pt. IV(B)(4) (discussing the penalties under the proposed statute).

206. See Alaska Stat. § 18.13.020 (mandating in regard to Alaska's genetic information-protection statutes that "[a] person may bring a civil action against a person who . . . [is] in violation of this chapter. In addition to the actual damages suffered by the person, a person violating this chapter shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000").

207. See Fla. Stat. § 540.08 (requiring that "the person whose name, portrait, photograph, or other likeness is [used in violation of the statute] . . . may bring an action to enjoin such unauthorized publication, printing, display or other public use, and to recover damages for any loss or injury sustained by reason thereof, including an amount which would have been a reasonable royalty, and punitive or exemplary damages").

information providers.<sup>208</sup> Under the existing statute, even common law civil remedies have not been granted, whereas plaintiffs under the proposed statute have a statutorily defined path to seek compensation when their property rights are violated.<sup>209</sup> Additionally, the new penalty section poses a serious economic threat to those that misuse genetic information and thus acts as the deterrent against misuse of genetic information that the current statute fails to provide.<sup>210</sup> The proposed statute's deterrent penalty and a viable method for compensation help to level the balance of power in the genetic study process between researcher and genetic information provider.

### C. Looking to the Future: Potential Problems Addressed by the Proposed Statute

Beyond addressing current issues, proposed Florida Statutes Section 760.40 is designed to address certain unsettling implications that, under current law, could arise in the future. For instance, consider a situation where genetic information contributors do not consent to the use of their genetic information for any purpose beyond analysis conducted as part of regular health screening. If researchers used this genetic information for commercial or any other purposes, and this alleged misuse was brought to court for violation of current Florida Statutes Section 760.40, the plaintiff genetic information contributors would likely not prevail. This outcome arises because of the precedent set in *Greenberg*, where out of desire to avoid “chill[ing] medical research,” doctors were given effective economic carte blanche in the genetic information they study.<sup>211</sup> If granting freedom in medical research is the court's primary concern, a court would likely

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208. Under the current statute, the penalty for violation is criminal, and there is no civil remedy available. See Fla. Stat. § 760.40(2)(b) (stating that “[a] person who violates paragraph (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083”). The proposed statute, however, offers a civil remedy for plaintiffs. See *supra* pt. IV(B) and accompanying text (proposing a civil remedy for the breach of a genetic information-use agreement).

209. See *supra* pt. III (discussing how there has been no relief granted to plaintiffs under the existing statute).

210. See *supra* pt. III (explaining the problems with the penalty section of current Florida Statutes Section 760.40).

211. 264 F. Supp. 2d at 1070.

use the *Greenberg* precedent in this hypothetical issue to reach a decision in favor of the researcher.<sup>212</sup>

To perpetuate such a precedent, however, invites the chilling of medical research that the *Greenberg* court feared, as patients who seek to avoid misuse of their genetic information will avoid genetic testing.<sup>213</sup> In turn, there would be fewer individuals learning of important health information and fewer sources from which potential breakthroughs could be made, harming the individuals being tested, researchers, and society.<sup>214</sup>

Viewing this same situation under the proposed amendment to Florida Statutes Section 760.40, however, these unwanted consequences would be avoided because there would be appropriate checks in researcher control. First, since the scope of agreement to undergo genetic testing only encompassed testing for health-screening purposes, the researcher would have violated the pre-arranged contract with the provider by using his or her genetic information in an unauthorized manner.<sup>215</sup> Additionally, the researcher would be in violation of the Statute itself for using the information for commercial purposes without obtaining informed consent for this use.<sup>216</sup> These violations subject the researcher to threat of serious penalty, both deterring future misuse and compensating aggrieved genetic information contributors.<sup>217</sup> With these protections for the genetic information provider in place, researcher power is placed in balance and genetic information providers are more willing to participate in genetic study, thus

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212. See 12A Fla. Jur. 2d *Courts and Judges* § 162 (WL current through Oct. 2012) (noting that Florida courts adhere to the doctrine of stare decisis, and when the decision is “resolving a deeply divisive societal controversy, the presumption in favor of stare decisis is at its zenith”).

213. See *supra* pt. II(C)(2) (discussing potential genetic information contributors’ aversion to genetic testing when they perceive that the information will be misused).

214. See H.R. Subcomm. on Health, Empl., Lab. & Pens. of the Comm. on Educ. & Lab., *supra* n. 46, at 11 (indicating that research might be hindered because people are unwilling to undergo genetic testing out of fear of misuse of their results).

215. This is because the proposed statute requires explicit up-front agreement as to how the genetic information may be used. For further discussion, see *supra* Part IV(B)(2).

216. The proposed statute states: “Where informed consent after full disclosure [including disclosure of potential commercial use of the DNA analysis] is lacking, the analysis may not be performed and/or use of the DNA analysis for profit or economic gain (‘commercial use’) is precluded.” For the rest of the proposed statutory language, see *supra* Part IV(B).

217. See *supra* pt. IV(B)(4) (describing the penalty section of the proposed statute).

bringing favorable results to the parties involved and society at large.

Another situation that could produce undesirable results under the current statute is the potential for DNA to be stolen and used for purposes other than medical research.<sup>218</sup> Celebrities, athletes, and government officials are in the public eye and are therefore particularly susceptible to having their genetic information taken<sup>219</sup> from (or even by) researchers who may sell to fans or tabloids.<sup>220</sup> Even non-famous people could be at risk, due to blackmailers, stalkers, or those who would use it for discriminatory purposes not covered by GINA.<sup>221</sup> Since genetic information reveals many scientifically verifiable facts about a person, the implications for the victims of this type of situation may be vast.<sup>222</sup> With current Florida Statutes Section 760.40 offering no safeguards against such a situation, use of genetic information for unauthorized purposes is likely.<sup>223</sup> The proposed amendment to

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218. See Jeannie Baumann, *Bioethics: Genetic Discrimination Risks Persist*, NIH Director Tells Bioethics Commission, 10 Med. Research L. & Policy Rpt. 152 (Mar. 2, 2011) (describing the threat to someone running for public office of “surreptitious collection of genetic information” from a “cigarette or . . . a glass of wine left at the table after an individual has left a restaurant”).

219. Genetic information stolen from “entertainers, politicians, athletes, and other public figures” might be used to gather and sell information about these people’s “relatedness to other celebrities . . . ; ancestral place of origin; cognitive ability; behavioral genetic profile (e.g., genetic contribution to sexual orientation, propensity to addiction, and degree of risk-seeking behavior); and predisposition to various illnesses.” Mark A. Rothstein, *Genetic Stalking and Voyeurism: A New Challenge to Privacy*, 57 U. Kan. L. Rev. 539, 539 (2009).

220. Reportedly, tabloids will pay in the hundreds of thousands, and sometimes millions, of dollars for photographs of certain celebrities. See e.g. Starpulse.com, *Tabloids Would Pay \$500,000 for Photos of Paris Hilton in Jail*, [http://www.starpulse.com/news/index.php/2007/06/06/tabloids\\_would\\_pay\\_500\\_000\\_for\\_photos\\_of](http://www.starpulse.com/news/index.php/2007/06/06/tabloids_would_pay_500_000_for_photos_of) (June 6, 2007, 12:39 p.m. EDT) (referring to Paris Hilton’s time in jail after her June 2007 arrest).

221. *Supra* n. 208.

222. See George Annas, *Privacy Rules for DNA Databanks: Protecting Coded “Future Diaries”*, 270 J. Am. Med. Ass’n 2346, 2347–2348 (1993) (comparing an individual’s genetic information to his or her “future diary,” which could be used to predict a person’s “projected life history”); Denbo, *supra* n. 154, at 562 (describing how genetic information reveals unique and unchangeable information about the person from whom it originates).

223. See Rothstein, *supra* n. 219, at 541 (explaining the ease with which covert DNA testing can be undertaken by noting that one web-based laboratory will test, without the consent of the person whose DNA is being tested, several items including: “chewed chewing gum (\$240—Wrigley Juicy Fruit is claimed to work best); cigarette butts (\$240—six should be sent); hard candy (\$300—well-sucked lollipops are preferred); used condoms (\$300); semen stains on clothing (\$300); used tampons or feminine pads (\$240); sweaty hats or ball caps (\$300); ‘hocked loogies’ (\$300—best if uninfected); plucked hair (\$240—three to ten strands); Q-tips with ear wax (\$300—up to three swabs); snotty Kleenex (\$300—best if full of mucus); and fecal matter (\$360—must be frozen immediately).”

Florida Statutes Section 760.40, however, makes researchers liable for violations of the contract between them and the genetic information contributor. Any use of the genetic information contrary to what was agreed, such as sale on the public market, would, again, result in breach of contract and the risk of serious penalty.

Although researchers themselves could possibly attempt to capitalize on their possession of famous genetic information, it would more likely be the case that an outsider would attempt to take and use this information.<sup>224</sup> In this situation, the proposed statute establishes that such a taking would violate the genetic information contributor's right to dictate who is in receipt of his or her "DNA analysis." Additionally, the presumed violation of the Statute for the unconsented sale or purchase of "DNA analysis" provides an extra level of incentive for would-be celebrity-DNA profiteers to avoid taking such action.<sup>225</sup> In turn, this protection preserves confidentiality for genetic information contributors, furthering the original intent of Florida Statute's Section 760.40 "to provide confidentiality for the results of genetic testing," and also makes potential contributors more comfortable that their genetic information will be safe after testing.<sup>226</sup>

Although predicting all the issues that may arise regarding genetic testing is impossible, the proposed statute neutralizes these two potential negative situations. With the knowledge that genetic information contributors are statutorily guarded against exploitation in an array of genetic testing scenarios, they are more likely to undergo genetic testing, benefitting them, researchers, and society.

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224. *See id.* at 541–543 (discussing the possibility of celebrity stalkers and tabloids seeking out a celebrity's genetic information for commercial use).

225. "Prima facie evidence is evidence which, if unexplained or uncontradicted, is sufficient to sustain a judgment in favor of the issue which it supports, but which may be contradicted by other evidence." *Black's Law Dictionary* 621 (Henry Campbell Black ed., 5th ed., West 1979). Therefore, under the proposed amendment, a profiteer would have to be able to explain a valid purpose for the unconsented sale or purchase of a DNA analysis, or show that such action was not taken at all, to avoid a significant monetary judgment in favor of the plaintiff.

226. *Suntrust*, 32 So. 3d at 138 n. 7 (citing to the legislative intent).



## V. CONCLUSION

Still just developing, genetic research is likely to yield many important medical advancements.<sup>227</sup> As has been proven, with this tremendous potential comes the risk of misuse that threatens to hinder the promised progress.<sup>228</sup> Throughout genetic study's history, legal corrective action for these threats to advancement have been taken: outlawing eugenics; instituting laws to combat racial discrimination executed through the use of genetics; and most recently, enacting GINA to help eliminate employment and insurance discrimination. There is still work to be done, however, as the threat of economic exploitation and losing control over one's own genetic information still goes unchecked. The next step, which the individual states have the opportunity to undertake, is to eliminate this risk. Several states have already enacted laws specific to genetic testing, with some even purporting to extend a property right in genetic information. Florida is among these states, but unfortunately, this property protection has been ambiguous and currently lacks force in its effect.

Following Florida's established framework and infusing it with concepts derived from the right-of-publicity and license-coupled-with-an-interest laws, the solution needed to achieve the best results for individuals and society as a whole can be obtained. The proposed statute creates a bona fide property interest in one's own genetic information and lays out a legal path by which researchers and genetic information contributors can bargain for it on a level playing field in terms of use, risk, monetary compensation, and any other concerns that the parties may have. Additionally, under the proposed statute, if someone violated these contractually agreed to relationships, genetic information contributors would have a viable method of recourse to compensate for the violation of their rights. This, in turn, would increase

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227. Australian Gov't, Australian L. Reform Comm'n, *The Regulation of Human Genetic Research, The Importance of Human Genetic Research*, [http://www.alrc.gov.au/publications/13-regulation-human-genetic-research/importance-human-genetic-research#\\_ftnref11](http://www.alrc.gov.au/publications/13-regulation-human-genetic-research/importance-human-genetic-research#_ftnref11) (accessed Jan. 19, 2013) (stating that "it is likely that human genetic research will become an increasingly important component of medical research generally").

228. See Patrick L. Brockett, Richard MacMinn & Maureen Carter, *Genetic Testing, Insurance Economies, and Societal Responsibility*, 3 N. Am. Actuarial J. 1, 1 (1999) (quoting Francis Collins, Director of the Human Genome Project, as stating, "Genetic testing has the potential to revolutionize medicine. But revolutions can have casualties.").

researchers' incentive to be protective of patient confidentiality and respectful of genetic information contributors' rights, which encourages more participation in genetic study—a result beneficial to researchers, the individuals being tested, and all of society. With the proposed amendment to Florida Statutes Section 760.40, Florida's researchers and genetic information contributors would be among the first who are truly in the position to make the most of the incredible future genetic study can bring.

## APPENDIX

### PROPOSED FLORIDA STATUTES SECTION 760.40

- (1) As used in this section, the term “DNA analysis” means the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person’s body. The term includes DNA typing and genetic testing, and encompasses initial as well as any subsequent examination and analysis, conducted for any purpose, on extracted genetic material, or previously documented DNA analysis results.
  
- (2) (a) Except for purposes of criminal prosecution, except for purposes of determining paternity as provided in s. 409.256 or s. 742.12(1), and except for purposes of acquiring specimens as provided in s. 943.325, DNA analysis may be performed only with the informed consent of, and full disclosure to, the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested. Such information held by a public entity is exempt from the provisions of s. 119.07(1) and s. 24(1), Art. I of the State Constitution. Where informed consent after full disclosure is lacking, the analysis may not be performed and/or use of the DNA analysis for profit or economic gain (“commercial use”) is precluded.  
  

(b) As used in this section, the term “full disclosure” includes revelation of all material facts, specifically including risks and benefits of undergoing DNA analysis and potential commercial use of the DNA analysis.

  

(c) Where informed consent is obtained for commercial use of a DNA analysis, the person tested maintains the

right to license the use. The terms of such license must be agreed to by the licensor and licensee prior to commencement of the DNA analysis, and upon commencement of the DNA analysis, the license becomes irrevocable.

~~(d) (3) The person tested, has the exclusive right to dictate A person who performs the DNA analysis or receives records, results, or findings of the DNA analysis. must provide the person tested with notice that the analysis was performed or that the information was received. The notice must state that, upon the request of the person tested, the information will be made available to his or her physician. The notice must also state whether the information was used The person tested also maintains the exclusive right to determine how the DNA analysis is used. The unconsented sale or purchase of a DNA analysis, or the use of a DNA analysis in any decision, to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity-, is a prima facie violation of this section. If the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.~~

- (3) ~~(b) A person who violates paragraphs (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083. Upon violation of a provision in subsection (2) the person upon whom the DNA analysis was performed may enjoin the unauthorized use and recover damages for any injury it caused. In addition to the actual damages suffered by the person, a violator of this section shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, for the greater of \$100,000 or ten percent of the monetary profit or gain.~~