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## Identification of the Unknown Soldier and the Fight for the Right to Anonymity: The Human Genome Project and Implications of a National DNA Database

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IDENTIFICATION OF THE UNKNOWN SOLDIER AND THE  
FIGHT FOR THE RIGHT TO ANONYMITY: THE HUMAN  
GENOME PROJECT AND IMPLICATIONS OF A NATIONAL  
DNA DATABASE

As more of our medical records are stored electronically the threats to all of our privacy increase...[O]ne way or another, we can all say to the American people, we will protect the privacy of medical records, and we will do it this year.

William Jefferson Clinton  
State of the Union Address, Jan. 19, 1999

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I. INTRODUCTION

When President Reagan honored the “Unknown Soldier” from the Vietnam War on Memorial Day in 1984, the remains were added to the Tomb of the Unknowns with other unknown soldiers from World Wars I, II, and the Korean War in one of the country’s most revered memorials.<sup>1</sup> With the development of a new type of

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<sup>1</sup>Steven Lee Meyers, *Unknown Vietnam Soldier Now Has a Name*, N.Y. TIMES, June 30, 1998, at A1.

genetic test approved for use in 1995, a sample of DNA was removed from the remains and matched with the DNA of the mother of First Lieutenant Michael Blassie, an Air Force pilot whose jet crashed in a South Vietnam village in 1972.<sup>2</sup> This discovery could mark the end of any further additions to the Tomb, as Pentagon officials have already questioned the utility of searching for another unknown, since advances in genetic identification could render “unknown” remains a thing of the past.<sup>3</sup>

Advances in technology, as well as the progress of the Human Genome Project, a now multi-faceted race to crack the human genetic code,<sup>4</sup> have increased the potential applications for the information that can be extracted from human DNA. With each new use for the information comes new potential for controversy. Dispute has arisen in the context of evidentiary use,<sup>5</sup> paternity testing, and identification, and moral and ethical debate has raged concerning various medical and diagnostic applications.<sup>6</sup> The legal issues raised include privacy, confidentiality, and property rights, to name a few.<sup>7</sup> The focus of this writing is the use of DNA for identification purposes and the issues that arise when genetic traits and/or predisposition to physical or mental conditions are linked to the individual specifically, along with the implications of a national DNA database as a system of identification.

It has become the general rule that it is not an unreasonable invasion of privacy to take DNA for the purpose of identifying criminal offenders through a DNA database.<sup>8</sup> This writing will examine the potential for nonconsensual inclusion of

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<sup>2</sup>*Id.*

<sup>3</sup>*Id.*

<sup>4</sup>What began solely as a federally-funded venture of the Department of Energy (DOE) and National Institute of Health (NIH) which was carried out by universities and government laboratories in the United States, as well as international facilities, is now competing against private projects which have since emerged and announced plans to complete the sequence of the human genome ahead of the government's time schedule. Michael D. Lemonick and Dick Thompson, *Racing to Map Our DNA*, TIME, Jan. 11, 1999, at 44.

<sup>5</sup>Thomas M. Fleming, J.D., Annotation, *Admissibility of DNA Identification Evidence*, 84 A.L.R. 4th 313 (1991).

<sup>6</sup>*See generally*, Charles H. Sanders, *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, 11 HARV. J.L. & TECH. 865 (1998) (book review).

<sup>7</sup>*Id.*

<sup>8</sup>*See, e.g.*, Shaffer v. Saffle, 148 F.3d 1180 (10th Cir. 1998), *cert. denied*, 119 S. Ct. 520 (1998); Schlicher v. Peters, 103 F.3d 940 (10th Cir. 1996); Boling v. Romer, 101 F.3d 1336 (10th Cir. 1996); Rise v. Oregon, 59 F.3d 1556 (9th Cir. 1995); Ewell v. Murray, 11 F.3d 482 (4th Cir. 1993); Jones v. Murray, 962 F.2d 302 (4th Cir. 1992); United States v. Goodridge, 945 F. Supp. 371 (D. Mass. 1996); Shelton v. Gudmanson, 934 F. Supp. 1048 (W.D. Wis. 1996); Kruger v. Erickson, 875 F. Supp. 583 (D. Minn. 1995), *aff'd*, 77 F.3d 1071 (8th Cir. 1996); Vanderlingen v. Kansas, 874 F. Supp. 1210 (D. Kan. 1995), *aff'd sub nom.* Schlicher v. Peters, 103 F.3d 940 (10th Cir. 1996); Sanders v. Coman, 864 F. Supp. 496 (E.D. N.C. 1994); Ryncarz v. Eikenberry, 824 F. Supp. 1493 (E.D. Wash. 1993); *In re.* Appeal in Maricopa County Juvenile Action Nos. JV-512600 and JV-512797, 930 P.2d 496 (Ariz. Ct. App. 1996); Cooper v. Gammon, 943 S.W.2d 699 (Mo. Ct. App. 1997); People v. King, 232 A.D.2d 111 (Sup. Ct. N.Y. 1997) *appeal denied*, 691 N.E.2d 646 (N.Y. 1997); State *ex rel.* Juvenile Dep't

nearly everyone into such a system, as well as the ramifications in the areas of employment and individual insurance coverage if access to genetic information is not controlled. Current legislative efforts will be explored in an attempt to advocate the best direction for future legislation of information that is too vitally useful to prohibit, yet too indiscriminately dangerous to leave vulnerable to all who may find it useful.

## II. BACKGROUND INFORMATION: DNA AND THE HUMAN GENOME PROJECT

The word "DNA" has recently moved from an almost exclusively scientific arena to the living rooms and workplaces of society-at-large, so it is helpful, if not essential, to have at least a basic understanding of what it is and how it can be used as a means of identification. All living things, from simple bacteria to human beings, contain deoxyribonucleic acid (DNA) within the nucleus of all their cells.<sup>9</sup> In humans, the DNA molecule looks like a twisted ladder—two strands made up of a sugar and phosphate chain held together by "rungs" which contain pairs of molecules called bases.<sup>10</sup> The particular order of these bases along the backbone is called the DNA sequence, and it is the specific genetic instruction for creating an organism with unique traits.<sup>11</sup>

Genes are a specific sequence of bases, and there are many genes within each DNA molecule which serve as the fundamental units of heredity.<sup>12</sup> The complete set of instructions for making an organism is called its genome;<sup>13</sup> in humans, DNA and other protein molecules are packed into chromosomes to make up the complete human genome. The human genome is estimated to contain at least 100,000 genes.<sup>14</sup> To put its complexity in perspective, consider the following comparison: the E.Coli bacterium genome is made up of 4.6 million bases.<sup>15</sup> The smallest human chromosome (the "Y" chromosome) has 50 million bases, the largest has 250 million, and the entire human genome consists of 3 *billion* bases.<sup>16</sup>

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of Multnomah County v. Orozco, 878 P.2d 432 (Or. Ct. App. 1994); Washington v. Olivas, 856 P.2d 1076 (Wash. 1993).

<sup>9</sup>U.S. DEP'T OF ENERGY, *Primer on Molecular Genetics*, DOE Human Genome 1991-2 Program Report 6 (June 1992) [hereinafter *Primer*].

<sup>10</sup>There are only four different bases: adenine, cytosine, guanine, and thymine, each of which pairs with only one of the others. *Id.* at 5.

<sup>11</sup>*Id.* at 6.

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

<sup>13</sup>*Id.* at 5.

<sup>14</sup>*Id.* at 7.

<sup>15</sup>*Primer*, *supra* note 9, at 7.

<sup>16</sup>*Id.*

The Human Genome Project<sup>17</sup> is dedicated to determining the complete human genetic code. This involves dividing chromosomes into smaller fragments and ordering them to correspond to their location on the genome.<sup>18</sup> Then, the base sequence of the fragments is determined. The aim is to find all the genes in the DNA sequence and to use this information to create advances in biology and medicine. In fact, the impact of the completion of the project is immense, promising to revolutionize medical practice.<sup>19</sup> For instance, it will be possible to diagnose inherited diseases. Genes associated with some diseases have already been identified.<sup>20</sup> I emphasize just how important the results of the Human Genome Project are because this paper will indicate potential legal dilemmas and dangers arising from the use of this data.<sup>21</sup> This is in no way meant to suggest that the scientific progress should be halted; rather, it is meant to stress the importance of controlling the dangers by identifying and addressing them. In spite of the new problems that will ride the wave of this breakthrough, the benefits outweigh the detriment.

The new plan devised by the Human Genome Project predicts completion of the full sequence by the end of 2003, two years ahead of the initial schedule.<sup>22</sup> One of the goals specifically outlined by the Human Genome Project is making the sequence "totally and freely accessible."<sup>23</sup> This presumably refers to the scientific community, since public funding of the project is on the basis of public availability to promote an environment of shared information for the purpose of stimulating research.<sup>24</sup> While commendable in the research context, this policy becomes a terrifying thought if extended to include the uninhibited publication of hereditary characteristics in conjunction with the individual who possesses them. The Human Genome Project acknowledges this concern as well by emphasizing the necessity for anonymity concerning studies of individuals whose ancestors come from a wide range of geographic areas in order to discover the most common variants possible in all human populations.<sup>25</sup> In addition, the NIH/DOE have expressed awareness of and concern for the social implications inherent in this advance in the understanding of

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<sup>17</sup>See Lemonick and Thompson, *supra* note 4. The NIH and DOE reportedly welcome the private enterprises, which have stated the intention to periodically release data in a collaboration with the public effort. See also, Francis S. Collins et al., *New Goals for the U.S. Human Genome Project: 1998-2003*, 282 *SCIENCE* 682, 685 (Oct. 23, 1998).

<sup>18</sup>*Primer*, *supra* note 9, at 10.

<sup>19</sup>*Id.* at 30.

<sup>20</sup>Cystic fibrosis, Duchenne muscular dystrophy; genetic susceptibilities have been implicated in diabetes, stroke, and several cancers. *Id.*

<sup>21</sup>The Human Genome Project acknowledges that the use of data from its studies could present challenges which should be addressed before a significant amount of data is accumulated. In an effort to assist in this end, the Project is funding conferences and research projects in consideration of potential issues and to promote public awareness. *Id.*

<sup>22</sup>Collins et al., *supra* note 17, at 682.

<sup>23</sup>*Id.* at 685.

<sup>24</sup>*Id.*

<sup>25</sup>*Id.* at 686.

human genetics and have created the Ethical, Legal, and Social Implications (ELSI) program<sup>26</sup> to guide both the conduct of the research and the development of public policy.<sup>27</sup>

The “ultimate repositories” of data from the Human Genome Project are DNA databases,<sup>28</sup> but there is another, more controversial compilation of DNA aimed not at anonymity, but rather at using DNA to identify criminal offenders.<sup>29</sup> The controversy is not whether we should use the DNA to catch criminals, but rather who else will have access to the information. This especially becomes a concern if lesser offenders (i.e. traffic violators) or innocent individuals are included in the database, with the potential for harm in that respect.<sup>30</sup> The FBI has opened a national DNA database at an undisclosed location in an effort to unify the databases now set up in all fifty states, making it possible to compare a DNA sample with samples from suspects and crime scenes from all others in the system.<sup>31</sup> Recall that DNA can be found wherever cells are found,<sup>32</sup> including in dead skin cells shed constantly by all of us, in blood and sweat.<sup>33</sup> Law enforcement officials hope to prevent recidivism and more serious crime by nipping the petty criminal in the bud.<sup>34</sup>

While the DNA database is new to the U.S., England and Wales established one in 1995 which now holds 360,000 entries and has so far matched 28,000 people to crime scenes at fifty-five dollars per analysis—a cost effective tool for police forces.<sup>35</sup> While the police force’s enthusiasm is understandable, a senior police officer created a media storm in Britain when he called for inclusion of the whole population in the DNA database.<sup>36</sup> Because the people currently in the database were not asked permission for the samples,<sup>37</sup> and the U.S. has followed a similar trend as far as felons are concerned, the logical question is one of limits: what is the minimal offense for which we will justify nonconsensual taking of DNA, and does there follow from this a natural progression which will justify even nonconsensual taking from everyone for the purpose of a criminal database?

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<sup>26</sup>*Id.* at 687.

<sup>27</sup>Collins et al., *supra* note 17, at 688. For more goals of ELSI research, see [www.nhgri.nih.gov/98plan/elsi/](http://www.nhgri.nih.gov/98plan/elsi/).

<sup>28</sup>*Id.* at 688.

<sup>29</sup>Nicholas Wade, *FBI to Open National DNA Data Base*, CLEVELAND PLAIN DEALER, Oct. 12, 1998, at 10-A.

<sup>30</sup>*Id.*

<sup>31</sup>*Id.*

<sup>32</sup>*Primer, supra* note 9, at 5.

<sup>33</sup>Wade, *supra* note 29.

<sup>34</sup>*Id.*

<sup>35</sup>*Id.*

<sup>36</sup>Alun Anderson, *Murderers Have Rights Too*, NEW SCIENTIST, *print edition*, May 23, 1998, at 18. Closer to home, in December, 1997, the police commissioner of New York city recommended that anyone arrested for a crime- not necessarily convicted- be required to submit a DNA sample. Jeffrey Kluger, *DNA Detectives*, TIME, Jan. 11, 1999, at 62.

<sup>37</sup>Anderson, *supra* note 36, at 18.

## III. THE “FELON” CASES: AN ANALYSIS OF CURRENT LAW

In order to predict the limits of nonconsensual taking of DNA, it is necessary to examine the parameters of current non-consensual taking and the reasoning behind existing decisions. Several federal courts as well as a number of states have upheld statutes authorizing the nonconsensual taking of blood from certain offenders for the purpose of establishing a DNA database to aid law enforcement officials in solving crimes.<sup>38</sup> While the Supreme Court has not yet ruled on the issue of the constitutionality of taking DNA for the specific purpose of establishing a database, several Supreme Court cases speak to the issue of taking physical specimens generally and serve as a foundation for the circuit courts’ decisions. Defendants most frequently assert Fourth Amendment rights.<sup>39</sup> The Supreme Court first held in *Schmerber v. California*<sup>40</sup> that at least with respect to free persons, the bodily intrusion which results from taking a blood sample is a search within the scope of the Fourth Amendment.<sup>41</sup> The Court later affirmed this holding in *Skinner v. Railway Labor Ex’rs’ Ass’n*<sup>42</sup>, which justified taking blood from railway employees for drug and alcohol testing.<sup>43</sup> These cases classified the test as a “minor intrusion”<sup>44</sup> which is relevant in establishing that a search and seizure is “reasonable” under the Fourth Amendment.

To satisfy the Fourth Amendment requirement of “reasonableness,” searches generally must be based on individualized suspicion.<sup>45</sup> *Brown v. Texas*<sup>46</sup> established an exception to the requirement for a warrant in the context of roadside checkpoints, where the minimal intrusion involved in the search and seizure of automobiles was balanced against the government’s interest in the search and seizure and the degree to which the search advanced that interest.<sup>47</sup> In a subsequent decision, the Court created an additional exception providing that an intrusion which is “slight” or “minimal” may be justified as reasonable even without individualized suspicion.<sup>48</sup> Two years later in 1992, the first challenge to a state statute authorizing mandatory blood samples for a DNA databank was decided against this backdrop in *Jones v. Murray*.<sup>49</sup>

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<sup>38</sup>See *supra* note 8.

<sup>39</sup>U.S. CONST. amend. IV.

<sup>40</sup>384 U.S. 757 (1966).

<sup>41</sup>*Id.* at 767.

<sup>42</sup>*Skinner v. Railway Labor Executives’ Ass’n.*, 489 U.S. 602, 616 (1989).

<sup>43</sup>*Id.* at 634.

<sup>44</sup>*Id.* at 625, *Schmerber* 384 U.S. 757 at 772.

<sup>45</sup>*Terry v. Ohio*, 392 U.S. 1, 20-21 (1968).

<sup>46</sup>443 U.S. 47 (1979).

<sup>47</sup>*Id.* at 50-51.

<sup>48</sup>*Michigan Dep’t of State Police v. Sitz*, 496 U.S. 444 (1990), *aff’d*, 506 N.W.2d 209 (Mich. 1993) (in the context of sobriety checkpoints and applying the *Brown* balancing test).

<sup>49</sup>962 F.2d 302 (4th Cir. 1992).

The Fourth Circuit upheld a Virginia statute which authorized the involuntary extraction of blood from inmates in custody prior to release for the purpose of establishing a DNA databank to aid in future law enforcement. In addition, Virginia's Department of Corrections regulations provided for punishment by loss of good conduct credits if an inmate refused.<sup>50</sup> The inmates claimed that the statute and punishment provision violated their Fourth Amendment rights against unreasonable search and seizure. The court responded by distinguishing the prison blood test from a criminal investigation, and indicated that it also served the separate purpose of ascertaining and recording the identification of a person who is lawfully confined to prison.<sup>51</sup> The court went further to say that no case establishes a requirement of probable cause or even a lesser requirement of individual suspicion for such purpose, because this has already supplied the basis for bringing the person into the criminal justice system.<sup>52</sup> In response to the objection that the blood sample may not be necessary as proof of the specific crime for which the inmate has been incarcerated, the court stated that the identity of a suspect arrested on probable cause becomes a matter of legitimate state interest. At this point the suspect cannot claim privacy in his identity, just as he cannot when fingerprints are used as a routine part of the booking procedure, even if they are not necessary as proof of the particular crime.<sup>53</sup> Judges have made both analogies and contrasts between DNA and fingerprints as identifying characteristics in the sense of the extent of the invasion of privacy involved.

The majority in *Jones* likens the governmental justification for taking DNA as a form of identification to the justifications advanced for taking fingerprints and photos.<sup>54</sup> In another case, the court goes further to say that "the information derived from the blood sample is substantially the same as that derived from fingerprinting."<sup>55</sup> These statements, while true with strict respect to the identification record, ignore the immense difference in the potential information that the two samples can provide. If a person's fingerprints become public knowledge, others will only be limited in the use of that information to discovering where the person has put their hands. By contrast, misuse of genetic information could ultimately result in publication of the person's predisposition to mental and physical conditions, which could be stigmatizing at least and potentially damaging to employment opportunity or accessibility to insurance coverage.

In another decision, the majority also makes a colorful analogy and a convincing argument that DNA samples are no more a "hidden attribute" than fingerprints, pointing out that just as the public ordinarily does not scrutinize others' hands with a magnifying glass, nor is a person's DNA public knowledge any more than if the person had a bloody nose.<sup>56</sup> This comparison is a good illustration of why the taking

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<sup>50</sup>*Id.*

<sup>51</sup>*Id.* at 306.

<sup>52</sup>*Id.*

<sup>53</sup>*Id.*

<sup>54</sup>*Jones*, 962 F.2d at 307.

<sup>55</sup>*Rise v. Oregon*, 59 F.3d 1556, 1559 (9th Cir. 1995).

<sup>56</sup>*State ex rel. In re Orozco*, 878 P.2d 432, 435 n.6 (Or. Ct. App. 1994).

of a blood sample is within constitutional limits as a means of identifying criminals, a concept with which there is little disagreement.<sup>57</sup> The potential for misuse with its resultant implications and the need for protective legislation have not completely escaped all judges. For example, the lengthy dissent in *Rise v. Oregon* cautions that DNA information is more than an “identifying marker,” and notes that uniquely private genetic facts should be subject to rigorous confidentiality requirements even broader than those which protect medical records.<sup>58</sup> Some of the state legislatures have also recognized the need for protecting how DNA sample information is used, and have incorporated limitations on use within the statutes.<sup>59</sup> Application and enforcement of such provisions remains to be seen.

The court in *Jones* also weighed the government’s interest in preserving a permanent identification record of convicted felons for resolving past and future crimes against the “minor intrusion” on the person.<sup>60</sup> The government interest was supported by statistics from a Department of Justice study of recidivism,<sup>61</sup> but the court stipulated that the effectiveness of the plan need not be high where the objective is significant and the privacy intrusion is limited.<sup>62</sup> The court relied on *Dunn v. White*, which allowed the mandatory blood testing of prisoners for H.I.V., to demonstrate that the inmate has a diminished expectation of privacy in his body.<sup>63</sup> The court in *Jones* ultimately found that the Fourth Amendment does not require an additional finding of individual suspicion before blood can be taken from incarcerated felons for the purpose of identifying them, thus defeating the prisoners’ challenge.<sup>64</sup> The Ninth and Tenth Circuits followed suit on the same reasoning.<sup>65</sup>

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<sup>57</sup>See Jeffrey Kluger, *DNA Detectives*, TIME, Jan. 11, 1999, at 62 (reporting results of an opinion poll which indicated that seventy-one percent of people polled think it is a good idea for the FBI to create a DNA database with information gathered from suspected criminals and crime scenes throughout the country).

<sup>58</sup>*Rise*, 59 F.3d at 1556 n.3 (Nelson, D.W., dissenting).

<sup>59</sup>See *Jones*, 962 F.2d at 304 (citing VA. CODE ANN. § 19.2-310.6, which establishes as a crime the unauthorized dissemination or use of information from the databank); and *Rise*, 59 F.3d at 1561 (citing OR. REV. STAT. §181.085(2) which prohibits analysis for genetic predisposition to mental or physical conditions, and also limits who has access to the information).

<sup>60</sup>*Jones*, 962 F.2d at 306.

<sup>61</sup>See *id.* Since the DNA database would be compiled from samples from persons already convicted, its usefulness would be primarily in identifying repeat offenders. The Department of Justice Study was used to show that a significant amount of crime is committed by prior offenders.

<sup>62</sup>*Id.* at 308.

<sup>63</sup>880 F.2d 1188, 1196-97 (10th Cir. 1989), *cert. denied*, 493 U.S. 1059 (1990).

<sup>64</sup>962 F.2d at 306-07.

<sup>65</sup>*Shaffer v. Saffle*, 148 F.3d 1180 (10th Cir. 1998); *Schlicher v. Peters*, 103 F.3d 940 (10th Cir. 1996); *Boling v. Romer*, 101 F.3d 1336 (10th Cir. 1996); *Rise v. Oregon*, 59 F.3d 1556 (9th Cir. 1995).

The challenges to the mandatory DNA sample statutes do not end with the Fourth Amendment. The Ex Post Facto clause<sup>66</sup> has also been implicated. An ex post facto law has been defined as one that “punishes as a crime an act previously committed, which was innocent when done, which makes more burdensome the punishment for a crime, after its commission...”<sup>67</sup> The *Jones* court held that Virginia’s enactment punishing an inmate’s refusal to submit DNA samples is not such a law, indicating that the United States Supreme Court expressly overruled the broader definition suggested in *Kring v. Missouri*.<sup>68</sup> The Virginia statute authorizing the databank was found to be a “reasonable regulation,” not penal in nature, and was therefore subject to reasonable amendments as necessary for good prison administration.<sup>69</sup> This paved the way for other corrections institutions to enforce state statutes that provide for enforcement of the mandatory DNA samples from criminal offenders by denying parole and removing good behavior credits. The trend in striking down constitutional challenges continues to hold.

In response to an inmate’s contention that the drawing of blood was contrary to his religious beliefs and would, according to those beliefs, condemn him to eternal damnation,<sup>70</sup> the court denied relief under the Free Exercise clause of the First Amendment.<sup>71</sup> If a statute is neutral and generally applicable, and is not applied differently to the inmate because of his religious beliefs, there is no violation, and such laws may be enforced even absent a compelling governmental interest.<sup>72</sup> Given this interpretation of the statute in *Shaffer*, and assuming that the similar statutes of other states are also generally applicable and applied even-handedly, those statutes will have the support of the Supreme Court against a claim that the right to freely exercise religion is violated as well.

In another innovative challenge, a Kansas statute survived a Fifth Amendment claim that such a law compelled self incrimination.<sup>73</sup> The court found that the DNA samples are not testimonial in nature, and that due process does not pose a barrier to the statute’s conditioning of parole on submission of samples, because there is no constitutional right to be released before the expiration of a valid sentence.<sup>74</sup> As a result, the statute may stand in absence of the implication of a liberty interest protected by due process.

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<sup>66</sup>U.S. CONST. art. I, § 10, cl. 1.

<sup>67</sup>*Beazell v. Ohio*, 269 U.S. 167, 169-70 (1925).

<sup>68</sup>107 U.S. 221, 228-9 (1883) (the definition included any law which “alters the situation of a party to his disadvantage”), *overruled by Collins v. Youngblood*, 497 U.S. 37, 41 (1990).

<sup>69</sup>*Jones*, 962 F.2d at 309. *See also Ewell v. Murray*, 11 F.3d 482, 486 (4th Cir. 1993) (holding that the statute does not add punishment for the original crime).

<sup>70</sup>*Shaffer v. Saffle*, 148 F.3d 1180 (10th Cir. 1998).

<sup>71</sup>U.S. CONST. amend. I.

<sup>72</sup>*Employment Div., Dep’t of Human Resources v. Smith*, 494 U.S. 872, 882-5 (1990).

<sup>73</sup>*Boling v. Romer*, 101 F.3d 1336 (10th Cir. 1996).

<sup>74</sup>*Id.* at 1340-41; *accord Ewell*, 11 F.3d at 488 (statute does not violate due process because the Department of Corrections’ operating procedure provides “due process and more” by specifying procedures for recourse for inmates).

The preceding discussion has effectively demonstrated that nonconsensual taking of samples for DNA databases as a tool for the accurate identification and prosecution of adult felons can withstand the demands of the First, Fourth, and Fifth Amendments, the Ex Post Facto clause, and due process. These verdicts, taken as a whole, provide a general rule: DNA may be taken from adult convicted felons without consent and without any additional requirements of individualized suspicion or probable cause, and may be cataloged in a database and used for identification purposes in future criminal investigations. It is easy to see the appeal of a system that can identify criminals more quickly and efficiently. It is also worth noting that this method of identification serves the public interest by accurately prosecuting crimes and potentially exculpating an accused innocent.<sup>75</sup> The following sections will develop the rule regarding mandatory DNA sampling of more controversial groups and also regarding applications beyond criminal investigation.

With statutes very similar to those which pertain to adult felons, states have mandated drawing blood from juveniles for use in a DNA database as well.<sup>76</sup> The Oregon statute authorizes the procedure only if the juvenile commits an act which, if done by an adult, would constitute one of the enumerated felonies, including mostly sex offenses and murder.<sup>77</sup> In *Maricopa* as well, the court held that the state may take DNA from a juvenile pursuant to the Arizona statute based on a delinquent act and may use it for identification purposes beyond the age of majority.<sup>78</sup> The court's holding is significant because on its face, it could be interpreted to contradict another Arizona statute which prohibits using the disposition of a child in juvenile court in any other court.<sup>79</sup> While the court recognized the role of the juvenile system in the protection, treatment and guidance of children, it still held that the use of DNA test results beyond the age of majority does not violate the Arizona statute because the statute relates to adjudication and punishment, whereas the DNA test is not punitive.<sup>80</sup> This holding could be viewed as indicative of the movement of mandatory DNA testing into general society, in light of the traditional protectionist role of the state over children. This could, however, be a hasty conclusion if one recognizes that, as applied to juveniles, the practice serves the same law enforcement objectives and is premised on the fact that the individual committed a crime and is in the lawful custody of the state.

These cases indicate that the previously stated rule for the nonconsensual taking of DNA may be expanded to encompass juvenile felony offenders as well as convicted adult felons. Based on the holdings which emphasize that the same intrusion on privacy involved in nonconsensual DNA sampling of criminal offenders

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<sup>75</sup>*Rise*, 59 F.3d at 1561.

<sup>76</sup>*See, e.g., In re Appeal in Maricopa County Juvenile Action Nos. JV-512600 and JV-512797*, 930 P.2d 496 (Ariz. Ct. App. 1996) [hereinafter *Maricopa*], and *State ex rel. Juvenile Dep't of Multnomah County v. Orozco*, 878 P.2d 432 (Or. Ct. App. 1994).

<sup>77</sup>*Orozco*, 878 P.2d at 434.

<sup>78</sup>930 P.2d at 500-01.

<sup>79</sup>ARIZ. REV. STAT. § 8-207(C) (1998).

<sup>80</sup>*Maricopa*, 930 P.2d at 501.

would not be acceptable as applied to free persons,<sup>81</sup> it seems unlikely that DNA as a system of national identification would be extended to all citizens. This proposition is not as sound as one might assume, considering both international precedent and, even closer to “innocents” at home, precedent from the United States Armed Forces.

#### IV. NON-CRIMINALS AND THE RIGHT TO REFUSE

##### A. *Mayfield v. Dalton*<sup>82</sup>

Due mainly to concerns about the lack of safeguards against the use of DNA samples for purposes other than identification, two Marines challenged the constitutionality of a Department of Defense program to collect and store blood and tissue samples from all members of the armed forces on active duty for future DNA analysis.<sup>83</sup> Ultimately, the Ninth Circuit held the challenge to the DNA collection program moot, because the two Marines were “honorably separated from active duty” after the district court decision.<sup>84</sup> This meant that they were no longer required to give blood or tissue samples for the Department of Defense repository. Furthermore, the court refused to consider the challenges to “regulations that might apply to them in the future” because those issues were not “ripe” controversies.<sup>85</sup> The court indicated changes that the military made to the DNA repository scheme in support of its holding that the issue of misuse was not ripe for adjudication.

The court stated that the changes made “appear to respond to some of the plaintiffs-appellants’ main concerns,” and included the full text of the April 1996 Memorandum from the Assistant Secretary of Defense for Health Affairs (“Memorandum”) within the opinion.<sup>86</sup> Essentially, then, the court endorsed the military’s voluntary schematic changes while simultaneously avoiding a legal analysis and decision on the merits by dismissing the case.<sup>87</sup> The military Memorandum specifically addresses the concerns that the samples could be used to deny employment or insurance on the basis of the genetic information that the samples can provide.<sup>88</sup> As a result, the length of time for which the samples are retained was decreased from seventy-five to fifty years, and individual specimen samples will be destroyed upon the request of the donor after completion of the service obligation.<sup>89</sup> Permissible uses of the specimens are itemized in the Memorandum. In addition to more benign uses such as identification of human remains, internal quality assurance to validate the process, and purposes consented to by the donor or next-of-kin, the Memorandum also provides for a more controversial

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<sup>81</sup>*Jones*, 962 F.2d at 306 (citing *Davis v. Mississippi*, 394 U.S. 721, 727 (1969)).

<sup>82</sup>*Mayfield v. Dalton*, 109 F.3d 1423 (1997).

<sup>83</sup>*Id.*

<sup>84</sup>*Id.* at 1425.

<sup>85</sup>*Id.*

<sup>86</sup>*Id.* at 1425-26.

<sup>87</sup>*Id.* at 1426.

<sup>88</sup>*Mayfield*, 109 F.3d at 1426.

<sup>89</sup>*Id.*

use of the samples—investigation or prosecution of any crime which is punishable by one year or more of confinement.<sup>90</sup> This compels a discussion of the proper legal standard for the nonconsensual search and seizure of the DNA of non-criminals, and, if it is ever permissible, how the information may be used.

The district court held that taking blood and tissue samples for the military repository constitutes a search within the scope of the Fourth Amendment,<sup>91</sup> but did not apply the “special needs” test.<sup>92</sup> Under the “special needs” exception to the warrant and probable cause requirements in a noncriminal search, a warrant may not be required “when special needs, beyond the normal need for law enforcement, make the warrant and probable cause requirements impracticable.”<sup>93</sup> *Skinner* is the only case where a special need sufficient to support searches of government employees was recognized by the Supreme Court.<sup>94</sup> The special need which justified the involuntary blood and urine drug analysis was public protection and safety, because the employees were railway operators.<sup>95</sup> The Court emphasized that the exception was justified due to the safety concern, and that the government’s objective was not prosecution.<sup>96</sup> The initial rule from *Skinner* instructs that DNA may be taken from non-criminals without a warrant and without consent, provided the government’s objective is the protection of the public’s health and safety and does not relate to criminal prosecution.

This emphasis was ignored by the district court in *Mayfield*, which distinguished the case from *Skinner* by noting that disciplinary and criminal consequences were possible.<sup>97</sup> Notice that while *Skinner* emphasized a *non*-prosecutorial objective to justify the nonconsensual search of government employees, *Mayfield* relied on the *possibility* of penalty to distinguish the military repository as a lesser invasion of privacy that was, therefore, outweighed by the government’s greater interest in the identification of remains.<sup>98</sup> This is somewhat confusing, because the district court distinguished the case from *Skinner*, suggesting that the “special needs” balancing test was not applicable, yet went on to balance the lesser invasion of privacy in favor of the government’s interest. Despite the contradiction, *Skinner* supplies the proper standard for searches and seizures whenever the government breaches constitutional

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<sup>90</sup>*Id.*

<sup>91</sup>U.S. CONST. amend. 4.

<sup>92</sup>*Mayfield v. Dalton*, 901 F. Supp. 300, 303 (D. Haw. 1995), *vacated*, 109 F.3d 1423 (9th Cir. 1997).

<sup>93</sup>*New Jersey v. T.L.O.*, 469 U.S. 325, 351 (1985).

<sup>94</sup>*Skinner v. Railway Labor Ex’rs’ Ass’n*, 489 U.S. 602 (1989).

<sup>95</sup>*Id.* at 620-21. Other special needs have justified exceptions to the warrant and probable cause requirements, but none are implicated in *Mayfield*. See *Griffin v. Wisconsin*, 483 U.S. 868 (1987) (government’s need to run an effective probation program); *O’Connor v. Ortega*, 480 U.S. 709 (1987) (the need for effective operation of a government office); *Bell v. Wolfish*, 441 U.S. 520 (1979) (the need to operate a federal prison safely).

<sup>96</sup>*Skinner*, 489 U.S. at 621 n.5.

<sup>97</sup>*Mayfield*, 901 F. Supp. at 303.

<sup>98</sup>*Id.*

requirements and does not rely on established exceptions to the requirement of a warrant: the government may take DNA without probable cause or individualized suspicion only if the primary objective relates to the protection of public health and safety, and is outside normal law enforcement needs.

In the case of the military repository, the government's special need does not actually exceed the normal needs of law enforcement as required under the "special needs" test because the information can potentially be used in the course of criminal prosecution.<sup>99</sup> In other words, if the court in *Mayfield* had applied the test correctly, it would have found that taking DNA samples for the purposes outlined by the Department of Defense constitutes an unconstitutional search and seizure. If this position is accepted, it leads to the conclusion that the repository is not amenable to the "special needs" exception, because the potential for use of the DNA is not beyond the needs of normal law enforcement.<sup>100</sup>

The preceding analysis reiterates the real, underlying fear where the taking and storing of DNA samples is involved. It is apparently an accepted practice as it pertains to the identification of convicted felons, and it appears acceptable as used in identifying the remains of military personnel; even the two marines in *Mayfield* did not contest that. Apprehension enters once it appears possible that the genetic information is not sufficiently safeguarded against misuse, or that Fourth Amendment requirements may be circumvented by justifying a warrantless, nonconsensual search and seizure as not motivated by law enforcement needs, but then using the fruits of that warrantless search later in a criminal prosecution. International trend does little to allay these fears.

#### B. A National DNA Database in Iceland

On December 16, 1998, Iceland passed a bill which will allow a single, private biotechnology company called deCODE to build a database of the genetic code of the entire population.<sup>101</sup> The corporation will also hold a twelve year monopoly on data marketing rights.<sup>102</sup> The plan to collect blood and obtain DNA samples is expected to begin in six months,<sup>103</sup> through agreements with hospitals, clinics, and individual physicians to submit patients' medical records.<sup>104</sup> The purpose of the project is to speed up the search for specific disease-linked genes for the development of improved diagnostic tools, and to improve the country's health care system.<sup>105</sup> Iceland is an ideal nation for the study because of its incredibly

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<sup>99</sup>Robert Craig Scherer, *Mandatory Genetic Dogtags and the Fourth Amendment: The Need for a New Post-Skinner Test*, 85 GEO. L.J. 2007, 2014 (1997) (suggesting that *Mayfield* did not properly apply the "special needs" test, and proposing an amended test).

<sup>100</sup>*Id.*

<sup>101</sup>Martin Enserink, *Iceland Oks Private Health Databank*, SCIENCE, Jan. 1, 1999 at 13.

<sup>102</sup>John Schwartz, *Iceland to Sell the Genetic Code of Whole Country*, CLEVELAND PLAIN DEALER, Jan. 12, 1999 at 7-A.

<sup>103</sup>*Id.*

<sup>104</sup>Enserink, *supra* note 101.

<sup>105</sup>*Id.*

homogeneous population of approximately 270,000 residents, which translates into a comparatively simple gene pool.<sup>106</sup>

Critics, though in the minority, include the nation's leading scientists and scholars who have been vocal and relentless. On one hand is concern over deCODE's influence over the Icelandic legislature in the drafting of the bill.<sup>107</sup> On the other is the privacy issue. Patients will not be asked for their consent before the addition of the information into the database.<sup>108</sup> Opponents admonish that there is a potential for stigmatization and job discrimination when details about mental illness or other health problems are made public.<sup>109</sup> Due to the project's reliance on the medical field, there is also the potential for patients to withhold such personal information about their medical history from their doctors.<sup>110</sup> Critics argue for official safeguards for privacy, and have considered possibilities for recourse, including a movement to overturn the law.<sup>111</sup> Aside from that, a significant number of doctors have pledged not to send information to the database without the specific request of their patients, in an effort to "drag their feet" and thwart the effort to utilize physicians to accumulate the genetic data of their patients.<sup>112</sup> While one physician working for deCODE insists that people are being unduly paranoid, David Banisar of the Electronic Privacy Information Center in Washington urges that "turning the population into electronic guinea pigs" should serve as a warning to Americans.<sup>113</sup>

According to a Time magazine opinion poll, most Americans are indeed uncomfortable with the same practices that concern critics in Iceland.<sup>114</sup> Seventy-one percent of those polled said they disapproved of private companies getting patents on genes.<sup>115</sup> Even though the United States could hardly be said to have a small, homogeneous population like that of Iceland, private companies are working, in fact racing, against the federal Human Genome Project in an effort to have patent rights to genetic information.<sup>116</sup> Although the legal standard regarding government

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<sup>106</sup>Schwartz, *supra* note 102.

<sup>107</sup>Enserink, *supra* note 101.

<sup>108</sup>*Id.*

<sup>109</sup>Schwartz, *supra* note 102.

<sup>110</sup>*Id.*

<sup>111</sup>Enserink, *supra* note 101.

<sup>112</sup>*Id.*

<sup>113</sup>Schwartz, *supra* note 102.

<sup>114</sup>Dick Thompson, *Gene Maverick*, TIME, January 11, 1999 at 54.

<sup>115</sup>*Id.*

<sup>116</sup>Michael D. Lemonick and Dick Thompson, *supra* note 4, at 46-7. The article discusses the Human Genome Project and the profit motive, and reports that pharmaceutical companies stand to make billions of dollars by turning research into new treatments for diseases. Those that find and patent the information first stand to make the most; hence the "race." Private projects (conducted, for example, by Celera Genomics Corp., Incyte Pharmaceuticals in California and Genset in France) are finding ways to beat out the federally-funded project.

searches and seizures of non-criminals' DNA samples has been clarified and may assuage fears of a government-mandated database, there are grounds to believe that private genetic discrimination is more than unfounded paranoia.

## V. GENETIC PREDISPOSITION AND DISCRIMINATION

### A. Employers and Genetic Discrimination

Genetic discrimination has been defined as the "denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests."<sup>117</sup> Employers take an interest in the use of genetic information to predict physical and mental health conditions for several reasons, including the potential for increased medical insurance premiums, absenteeism, lowered productivity, and greater risk in the line of duty, which translates into more workers' compensation claims.<sup>118</sup> While these may be legitimate reasons with respect to safety and economic concerns of a business, there is a potential for unnecessary discrimination if results of genetic testing are not carefully interpreted. The individuals most at risk for this type of discrimination include the following: 1) asymptomatic individuals who carry a gene that increases the probability of developing some disease, 2) individuals called "carriers" who are heterozygotes for some recessive genetic condition, but who are and will remain asymptomatic, 3) individuals with one or more genetic polymorphisms that are not known to cause any medical condition, and 4) immediate relatives of individuals with known or presumed genetic conditions.<sup>119</sup>

Just how great is the risk that employers will actually rely extensively on genetic information in the course of hiring and making business decisions? Trend data on genetic screening and monitoring was produced in a 1989 survey by the United States Congress Office of Technology Assessment (OTA).<sup>120</sup> At that time, few companies were actually using genetic testing- only twenty health officers from the 330 Fortune 500 companies (6%), but twice the number of companies were using genomic information in 1989 than were in 1982.<sup>121</sup> Granted, these surveys are now ten years old, but there was also a survey designed to predict growth. While the

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After Celera announced its projected completion date, the federal project announced its own ahead-of-schedule plan.

<sup>117</sup>Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employers and Insurers*, 17 AM. J.L. & MED. 109, 110 (1991). Another definition is "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal" genome in the genetic constitution of that individual." George P. Smith and Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. CONTEMP. HEALTH L. & POL'Y 23, 26 (1994) (citing Marvin R. Natowicz, et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS 465, 466 (1992)). This definition, based on discrimination in reliance on genetic information used to assess future risk of disability, attempts to distinguish discrimination based upon present disability).

<sup>118</sup>Smith and Burns, *supra* note 117, at 27.

<sup>119</sup>*Id.* at 26.

<sup>120</sup>Gostin, *supra* note 115, at 117.

<sup>121</sup>*Id.*

OTA reported fewer companies anticipated using genetic testing in 1989 than in 1982, a 1989 survey of 400 firms by a life insurance company reported that fifteen percent planned to check the genetic status of prospective employees and their dependents by the year 2000 before making employment offers.<sup>122</sup> Employers who responded based their answers on scientific consensus, cost, and the value of the data for predicting disease.<sup>123</sup> It follows, then, that the progress of the Human Genome Project could serve only to increase the number of employers who will find genetic testing a viable basis for employment decisions as the predictive nature of the data is increased and the costs of the tests are driven down through technological advances.

Even at the early date of those surveys, a real impact on employees or potential employees was becoming evident, usually to the detriment of the employee in the form of transferal or dismissal from their position.<sup>124</sup> It is a common misconception that the presence of a genetic trait can be equated with actual disability, even without correlating any existing impairment with the actual ability to meet qualification standards. In reality, however, a person could be an unaffected carrier, asymptomatic, “at risk” only, or could have just a minor form of the impairment.<sup>125</sup> This type of misconception is relevant to the application of disability discrimination law, discussed in the next section.

Before turning the attention to current legislative protections, and whether genetic predisposition fits into any of the current frameworks, it makes sense to first determine whether it is feasible that employers will have access to genetic information by examining legal precedent. Historically, occupational physicians and their relationship with patients in that context was not categorized as a physician-patient relationship.<sup>126</sup> Accordingly, the physicians were considered clients of the employer, not the worker/patient, and therefore were not liable for medical malpractice by failing to disclose information to patients about their own condition.<sup>127</sup> This view has become more relaxed, however, and courts have distinguished between mere testing and care and treatment in passing judgment on disclosure requirements.<sup>128</sup> As a result, when an employee is treated by an

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<sup>122</sup>*Id.* at 116.

<sup>123</sup>*Id.*

<sup>124</sup>*Id.* at 117-18 (The 1982 OTA survey reported that seven of the eighteen companies that were taking action on the basis of genetic testing transferred or dismissed the “at risk” employee, although the 1989 data reported that only two of the Fortune 500 companies surveyed admitted to rejecting an applicant or transferring an employee due at least in part to genetic test results).

<sup>125</sup>Gostin, *supra* note 117, at 118. *See also* Smith and Burns, *supra* note 117, at 26 (describing individuals most at risk for genetic discrimination).

<sup>126</sup>Lori B. Andrews and Ami S. Gaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 88 (1991).

<sup>127</sup>*Id.* at 89.

<sup>128</sup>*Id.*, *citing* Greenstein v. Forrell, 143 Misc. 880, 257 N.Y.S. 673 (1932) (Where a physician actually treats a patient, a physician-patient relationship exists), and Keene v. Wiggins, 138 Cal. Rptr. 3, 7 (Cal. Ct. App. 1977) (no physician-patient relationship where physician merely examined worker).

occupational physician, the employee as a patient has a right to the pertinent medical information, but what information does the employer have a right to know?

Courts do recognize that employees' medical information can be important to an employer, and have held that physicians employed by the company primarily answer to the company and may disclose information about patients in which the company has an interest.<sup>129</sup> In addition, some doctors who are not employed by a company may be able to disclose patient information to their employer.<sup>130</sup> In one example, a Virginia statute provides that any workers' compensation health care provider attending any injured employee shall furnish the employer with a copy of the medical report at the employer's request.<sup>131</sup> This statute does not seem amenable to expansion to include genetic information, since it specifically addresses examinations into work-related injury. However, Connecticut specifically allows the disclosure of information collected about an employee to the employer by entities other than physicians, such as NIOSH, regarding occupational illness and susceptibility to illness.<sup>132</sup> In contrast to the enactments which treat the divulgence of medical information to employers permissively, the American Occupational Medical Association advises in its Code of Ethical Conduct that employers are entitled to counsel about medical fitness in relation to work, but not to diagnoses or details of a specific nature, even if the physician is paid by the company.<sup>133</sup> By the language, then, this principle would not be effective against genetic information which the employer could demonstrate had a relation to work. Remember, too, that even if the information could potentially affect some work aspect or performance, we are dealing with genetic predisposition only, which is not an absolute indicator of actual impairment. Keep this in mind as current federal disability legislation is examined as one possible safeguard against genetic discrimination.

*B. Genetic Predisposition in the Framework of the Americans with Disabilities Act (ADA)*<sup>134</sup>

The ADA of 1990 extends the protection from discrimination based upon disability afforded under the Rehabilitation Act of 1973 to private employers, public services, public accommodations, and telecommunications.<sup>135</sup> State disability

<sup>129</sup>Andrews and Gaeger, *supra* note 126, at 94-95, citing *Leonard v. Wilson*, 8 So.2d 12, 14 (Fla. 1942). The authors warn that this holding could lend to the interpretation that genetic testing in the workplace implies consent to release of all results to the employer.

<sup>130</sup>*Id.* at 95.

<sup>131</sup>*Id.*, at 96 citing VA. CODE ANN. § 65.1-88.1 (1987).

<sup>132</sup>*Id.*, citing CONN. GEN. STAT. § 31-383 (1987).

<sup>133</sup>*Id.* at 95. An absolute prohibition of genetic discrimination may not be the desired end. In some circumstances, discrimination may protect the safety of workers or the public. Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653, 663 (1998). Care must be taken, then, not to allow employers to claim this as a guise, when routine physical exams could detect early symptoms of disease, or an occupational exposure could be eliminated, rather than excluding those more susceptible to the resulting harm.

<sup>134</sup>Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended by the Civil Rights Act of 1991 at 42 U.S.C. § 12101).

<sup>135</sup>29 U.S.C. §§ 701-794 (1988).

statutes closely follow the federal civil rights format,<sup>136</sup> so the ADA will be the focus of this analysis of disability discrimination statutes as a form of redress for genetic discrimination. According to information received by the Congressional Bioethics Advisory Committee, the legislative history behind the ADA indicates that genetic discrimination was “not raised or discussed,” and so could not be addressed by the Conference Committees, leaving the issue of whether genetic discrimination fits within the scope of the ADA to the courts for determination.<sup>137</sup>

The first step in determining whether genetic discrimination is properly adapted to the statutory framework of the ADA is looking at how the statute defines “disability.” The ADA defines disability as “(A) a physical or mental impairment that substantially limits one or more of the major life activities... (B) a record of such impairment, or (C) being regarded as having such an impairment.”<sup>138</sup> The ADA also defines what constitutes an impairment as “any physiological disorder or condition, disfigurement or anatomical loss affecting any of the major bodily systems, or any mental or psychological disorder such as mental retardation, mental illness or dementia.”<sup>139</sup> The definition indicates that a person need not actually have a physical or mental impairment; rather, it is sufficient if the individual has a record of impairment or is perceived to have an impairment. The distinction was meant to include discrimination based on false belief as to an individual’s limitation in the scope of the ADA, in order to guard against discrimination based on prejudice and irrational fear.<sup>140</sup> It is in these situations that society’s reaction, rather than an actual disability, limits a person’s ability to enjoy equal access to rights and services.<sup>141</sup>

By definition, a person is considered disabled for purposes of coverage under the ADA only if the physical or mental impairment “substantially limits” one or more “major life activities.”<sup>142</sup> Courts have interpreted the statute to include working (employment) as a major life activity.<sup>143</sup> It follows, then, that by treating someone as if he or she were unable to work, for example by not hiring that person on the basis

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<sup>136</sup>Gostin, *supra* note 117, at 120.

<sup>137</sup>This information was relayed to the Congressional Bioethics Advisory Committee by Congressman Steny Hoyer, the Floor Manager in the House, who, while indicating the lack of attention to the issue, also indicated that genetic discrimination was “improper” and “very dangerous.”

<sup>138</sup>42 U.S.C.A. § 12102(2) (West Supp. 1990).

<sup>139</sup>*Id.*

<sup>140</sup>Gostin, *supra* note 117, at 122 (citing S. Rep. No. 116, 101st Cong., 1st Sess. 22, 23 (1989)). It is suggested that genetic traits for diseases should be covered under the ADA, whereas genetic determinants for eye and hair color, for example, which are designated as general personal characteristics, should not be covered. *Id.*

<sup>141</sup>Gostin, *supra* note 117, at 123. In the EEOC’s interpretive guidelines, it is also unlawful to discriminate on the basis of genetic information relating to illness or disease. Bryce A. Lenox, *Genetic Discrimination in Insurance and Employment: Spoiled Fruits of the Human Genome Project*, 23 U. DAYTON L.REV. 189, 205 (1997). However, these are not statutory enactment’s, and the courts are not required to defer to them.

<sup>142</sup>42 U.S.C.A. § 12102(2).

<sup>143</sup>*Cook v. Rhode Island*, 10 F.3d 17 (1st Cir. 1993).

of genetic predisposition when there is no actual disability, an employer could essentially be said to be regarding that person as having the disease itself.<sup>144</sup> Under this interpretation, the ADA could be a viable remedy for discrimination based on genetic predisposition. On the other hand, this is not the only possible interpretation. It can also be argued that by not hiring someone solely on the basis of genetic predisposition, the employer is not regarding that person as having a present impairment. Although discrimination against a person who has a record of an impairment is prohibited,<sup>145</sup> discrimination based on future potential to develop an impairment is not strictly within the text of the ADA. Therefore, genetic predisposition is not necessarily a prohibited characteristic, and the ADA is not an automatic safeguard against discrimination on that basis.

The next logical inquiry would be whether a person who is presently healthy but carries a gene for a certain disease can be classified as "disabled" within the meaning of the ADA. Obesity has been held to be a handicap even without current disability to the individual, with the admonition that an "employer cannot deny employment simply because the condition has been detected before it has actually begun to produce deleterious effects."<sup>146</sup> In a more recent, and even more analogous United States Supreme Court case, it was held that even in the asymptomatic stage, HIV infection is an impairment which substantially limits the major life activity of reproduction, strongly suggesting that HIV infection is a disability per se.<sup>147</sup> The Court reasoned that people infected with HIV are already experiencing major physiological effects, even before they manifest symptoms, and that knowledge of the impending consequences to themselves and to their sexual partners and future children has a substantial effect on those types of decisions.<sup>148</sup> The Court's reasoning could support the proposition that genetic predisposition is in itself a disability, but only if the disease to which an individual is predisposed is one which affects an established major life activity even in the asymptomatic period. This would seem feasible in regard to many major diseases, especially those that are hereditary or terminal, because just as HIV infection affects the decision to have children, so does predisposition to a disease that has similar effects on family planning. The downside is that this does not definitively provide recourse for all genetic discrimination under the ADA, especially where the potential disease can be distinguished from the category of impairments which affect a major life activity (such as reproduction) in the asymptomatic stage.

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<sup>144</sup>This analysis relies on the ADA definitions which prohibit discrimination against a person who is regarded as having an impairment which limits a major life activity, and the assumption that work is a major life activity, such that by refusing to hire a person on the basis of genetic predisposition, an employer is actually attempting to exclude that person based on the possibility that a disability will eventually develop. 42 U.S.C.A. § 12102(2). This would also be in accord with the legislative intent to distinguish genetic traits for diseases from those for personal characteristics. Gostin, *supra* note 115, at 144, n.70.

<sup>145</sup>42 U.S.C.A. § 12102(2).

<sup>146</sup>State Div. of Hum. Rts. v. Xerox Corp., 480 N.E.2d 695, 698 (1985).

<sup>147</sup>Bragdon v. Abbott, 118 S. Ct. 2196, 2207 (1998).

<sup>148</sup>*Id.* at 2206.

Many states have recognized the need for legislation to control genetic discrimination, and perhaps the shortcomings of available federal legislation, as evidenced by more than thirty states which have passed laws which prohibit the genetic testing of applicants for purposes of employment or insurance.<sup>149</sup> In addition, as of this writing, at least seventy more genetic discrimination bills are pending in twenty-four states and twelve are pending before Congress.<sup>150</sup> The content and efficacy of some of the various state statutes currently in effect will be examined later in this paper. As indicated earlier, the effects of the availability of genetic information on employment and insurance are the main focus of this note. The basic structure of federal disability discrimination law as it applies to employment appears to be insufficient as a means of specifically targeting genetic discrimination. Next, the insurance industry provides its own unique combination of law and public policy which creates different challenges for legislation aimed at the prohibition or control of genetic testing and discrimination.

### C. Insurers and Genetic Discrimination

The ADA does not restrict insurers or health care providers from carrying on with their normal activities consistent with basic principles of underwriting, classifying, and administering risks.<sup>151</sup> Along the same lines, employers may set up and comply with the terms of employee benefit plans based on sound actuarial data.<sup>152</sup> As a result, certain standard practices are acceptable, such as pre-existing condition clauses in health insurance contracts, limitations on coverage for certain procedures, or charging premiums proportionate to risk.<sup>153</sup> In regard to genetic predisposition, the ramifications of these practices could be limited coverage if the actuarial data shows a likelihood of future illness, or denial of coverage if genetic predisposition is viewed as a pre-existing condition.<sup>154</sup> One analogy is the initial response of insurance companies to HIV infection, which was to conduct their own HIV tests and to regard HIV as an uninsurable condition.<sup>155</sup> All of this information does not lend itself to a very bright outlook for the insurability of conditions which can be detected from our genes. Because everyone will most likely be predisposed to something, if insurance companies begin to rely on the data revealed by the human genome efforts and conduct their own genetic tests, the impact on our health care system could be immense. If people are limited or denied coverage for the major diseases that they are most likely to get, our country could foreseeably be forced into a system of nationalized health insurance.<sup>156</sup>

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<sup>149</sup>Christopher Hallowell, *Playing the Odds*, TIME, Jan. 11, 1999, at 60.

<sup>150</sup>*Id.*

<sup>151</sup>Gostin, *supra* note 117, at 135.

<sup>152</sup>*Id.*

<sup>153</sup>*Id.*

<sup>154</sup>*Id.*

<sup>155</sup>*Id.* at 136.

<sup>156</sup>While the majority of Americans rejected the Clinton Administration's proposals for a larger government role in managing health insurance five years ago, if that same majority begins to experience limitations or denials of coverage based on genetic test results, they may

The outlook may not be as ominous as it would first appear. The ADA's effect on insurers and employers is to prevent the use of underwriting as subterfuge for discrimination, meaning insurers cannot deny coverage completely on the basis of genetic predisposition, and employers cannot deny jobs because of the increased cost of insurance or a lack of insurance coverage of a particular disability.<sup>157</sup> Instead, discrimination among disabled applicants must be based on sound actuarial data that indicates a heightened risk of contracting an illness in the future.<sup>158</sup> Research to decipher the human genome, while nearing completion, is yet unfinished, and it presumably would take time to study and compile reliable data which predicts the likelihood of development of a disease in persons with the gene. As a result, there is still time to devise laws to best control the problem.

The proper approach to legislating the practices of the insurance industry requires consideration of the differing views of the social utility of health insurance and surrounding public policy. There are two ways to view the insurance industry. The first way is to look at the insurance industry from a strictly business perspective.<sup>159</sup> From that point of view, discrimination on the basis of actuarial data seems reasonable, because the "essence of underwriting" is classification according to risk, and it would not make sense to require an insurer to take what the data indicates to be a bad business risk.<sup>160</sup> If this were the pervading view, the government might be inclined to adopt a "hands-off" approach with regard to insurance companies, which would create a greater propensity for an alternative system of health care as more and more people lacked private insurance coverage.

The second view describes the insurance industry as an instrument of social policy.<sup>161</sup> This view encompasses the concept of spreading risk across groups for wider access to health care services. The practice of underwriting is threatening to this conception of purpose because, to those with genetic predisposition, health insurance may become unavailable or unaffordable to those most likely to become ill.<sup>162</sup> Even though embracing this view means sharing the increased cost of other people's illnesses, it may be preferable to the alternative. In a Time magazine survey, eighty-eight percent of people polled said a person whose genetic profile shows potential problems should not pay higher health insurance rates than someone whose profile does not.<sup>163</sup> Assuming this is the majority opinion, the appropriate legislative response would mandate control of underwriting practices in regard to genetic predisposition in light of the potential public willingness to share the risk

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seek refuge in a nationalized health care plan absent a free-market alternative. Hallowell, *supra* note 149.

<sup>157</sup>Gostin, *supra*, note 117 at 136. Also, few people purchase individual health coverage—most are insured by employers or government plans, which involve no individual underwriting thus pose little threat of genetic discrimination. Yesley, *supra*, note 133 at 663.

<sup>158</sup>Gostin, *supra* note 117, at 136.

<sup>159</sup>*Id.*

<sup>160</sup>*Id.*

<sup>161</sup>*Id.*

<sup>162</sup>*Id.*

<sup>163</sup>Frederic Golden, *Good Eggs, Bad Eggs*, TIME, Jan. 11, 1999 at 56, 59.

across groups rather than pay proportionately to personal risk based on actuarial data. On the state level, the actual approaches taken with respect to legislation vary from state to state and from the context of the prospective application (for example, whether the law applies to insurance or to employment discrimination). There has also been legislation on the federal level, although only applicable to health insurance. Drafting appropriate legislation is difficult and requires attention to competing legal theories in order to effectively control the acquisition, use, and dissemination of genetic information in the intended context.

## VI. CURRENT LEGISLATION

### A. Introduction

In 1997, the number of states that prohibit genetic discrimination by health insurers more than doubled to twenty-three states.<sup>164</sup> Additionally, four states joined those that have legislation prohibiting genetic discrimination by employers, for a total of eleven.<sup>165</sup> The only federal legislation enacted to date which prohibits genetic discrimination is the Health Insurance Portability and Accountability Act of 1996 (HIPAA).<sup>166</sup> HIPAA, signed by President Clinton on August 21, 1996, states that genetic information shall not be considered a preexisting condition in the absence of a diagnosis of the actual condition. The protection afforded by the HIPAA is limited, however, because it only covers group health plans, not individual policies, which cover ten to fifteen percent of those insured.<sup>167</sup> Another drawback of the federal legislation is that it does not prevent an insurance institution from raising an entire group's rates.<sup>168</sup> As a result, HIPAA is not broad enough to ensure full protection from insurance discrimination, and does not even cover discrimination by employers or other undesirable uses of genetic information.

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<sup>164</sup>Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653, 656 (1998). See 1997 Ala. Acts 97-721; CAL. HEALTH & SAFETY CODE § 1374.7 (West 1998); CAL. INS. CODE §§ 742.405, 10123.3, 10140 (West 1998); COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1998); 1997 Conn. Pub. Acts 97-95; 1997 Fla. Laws ch. 97-182; GA. CODE ANN. §§ 33-54-1 to 8 (1997); 1997 Haw. Sess. Laws 91; 1997 Ill. Pub. Act 90-25; IND. CODE ANN. §27-8-26-7 (Michie 1997); 1997 Kan. Sess. Laws 190; 1997 La. Acts 1418; MD. CODE ANN., INS. § 223.1 (1997); MINN. STAT. § 72A.139 (1997); 1997 Nev. Stat. 412; 1997 N.C. Sess. Laws 350; N.H. REV. STAT. ANN. § 141-H:4 (1996); N.J. STAT. ANN. §§ 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, 17B-27-36.2, 26:2J-15.1 (West 1998); OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50 (Banks-Baldwin 1997); OR. REV. STAT. § 746.135 (1996); 1997 Tenn. Pub. Acts 121; 1997 Tex. Gen. Laws 1215; VA. CODE ANN. § 38.2-508.4 (Michie 1997); WIS. STAT. § 631.89 (1996).

<sup>165</sup>Yesley, *supra*, note 164. See 1997 Ariz. Sess. Laws 229; 1997 Ill. Pub. Act 90-25; IOWA CODE ANN. § 729.6 (West 1997); N.H. REV. STAT. ANN. § 141:H-3 (1996); N.J. STAT. ANN. § 10:5-12 (West 1998); 1997 N.C. Sess. Laws 350; N.Y. EXEC. LAW § 296 (McKinney 1993 & Supp. 1997); OR. REV. STAT. §§ 659.036, 659.227 (1996); R.I. GEN. LAWS § 28-6.7-1 (1997); 1997 Tex. Gen. Laws 1215; WIS. STAT. § 111.372 (1996).

<sup>166</sup>Pub. L. No. 104-191, 110 Stat. 1936 (1996).

<sup>167</sup>Bryce A. Lenox, Comment, *Genetic Discrimination in Insurance and Employment: Spoiled Fruits of the Human Genome Project*, 23 U. DAYTON L.REV. 189, 208-9 (1997).

<sup>168</sup>*Id.*

State legislation, while broader in the coverage of protected interests, is inconsistent. Some states regulate health care or employment, some regulate only testing, while other states include protection of genetic information generally.<sup>169</sup> Given the state to state variability, this writing assumes the position that federal legislation is necessary as a comprehensive and uniform protection of various genetic interests. In determining the best approach to such a task, there are several considerations.

#### B. Impediments to Effective Legislation

There are two factors which impede effective legislation to successfully combat genetic discrimination.<sup>170</sup> First is the difficulty of defining “genetic information” for the intended statutory purpose, given the mass of information with genetic significance.<sup>171</sup> The states’ definitions vary. Some states define genetic information narrowly, limiting it to a laboratory test of human chromosomes or DNA.<sup>172</sup> The effect of laws that include these narrow definitions (limiting genetic information to direct tests for the purpose of discovering gene alterations) is a protection against the use of these types of tests by employers and insurers, but they do not prevent the use of indirect means of determining and discriminating on the basis of genetic predisposition.<sup>173</sup> Other states have chosen a broader definition which encompasses “all information about genes, gene products, inherited characteristics, or family history/pedigree that is expressed in common language.”<sup>174</sup> This definition is nearly all-inclusive because almost all clinical tests could be considered a test for gene products. While the context and purpose of the test may be determinative of whether the test is included in a broad definition, the NIH has noted that the contents of most medical records will soon have potential genetic significance.<sup>175</sup> In addition, laws with broader definitions may have a larger scope of protection, but may be impractical to implement.<sup>176</sup>

The second impediment to effective legislation is the limited usefulness of laws narrowly focused on prohibiting genetic discrimination, and the possibility of unintended “perverse results.”<sup>177</sup> For example, New York’s employment anti-discrimination law does not protect individual privacy as to genetic information.<sup>178</sup> An employer may still require a genetic test, and may deny employment for refusal

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<sup>169</sup>Natalie Anne Stepanuk, Comment, *Genetic Information and Third Party Access to Information: New Jersey’s Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U. L. REV. 1105, 1142 (1998).

<sup>170</sup>Yesley, *supra* note 164, at 653.

<sup>171</sup>*Id.*

<sup>172</sup>*See, e.g.*, MD. CODE ANN. INS. § 223.1 (1997).

<sup>173</sup>Yesley, *supra* note 164, at 661.

<sup>174</sup>LA. REV. STAT. ANN. § 213.7(A)(8) (West 1998).

<sup>175</sup>Yesley, *supra* note 164, at 661.

<sup>176</sup>*Id.*

<sup>177</sup>*Id.* at 653.

<sup>178</sup>*Id.* at 659.

to be tested, but the employer cannot discriminate on the basis of the information obtained from the test.<sup>179</sup> One might wonder, then, why New York allows employers to demand genetic tests at all. The purpose is to allow employers to determine any increased risk of disease as a result of the work environment, however, the individual has the choice whether or not to be subjected to the risk.<sup>180</sup> The result of this type of narrowly focused legislation is perverse if the desired end is protection of privacy because the law only precludes discrimination, not revelation of genetic information as a condition of hiring. Perhaps the limited utility of narrowly focused laws are not really an impediment to effective legislation, but rather only to comprehensive legislation which attempts to prohibit or control all undesirable uses of genetic information by all possible sources. The most effective laws, then, should not attempt a broad, impractical scheme, but instead tailor legislation specifically to address each problem individually.

### C. *Privacy Theory Versus Property Theory*

The preceding discussion demonstrates that there is a distinction between prohibiting genetic discrimination and protecting genetic privacy, and there are different approaches to protecting each interest. Most state legislation fails to address both present and potential legal ramifications, and the state laws are confused as to the necessary level and type of protection to provide.<sup>181</sup> The main issue is whether to classify genetic information as a property right or a privacy interest.<sup>182</sup> Nearly all of the state genetic discrimination laws involve the protection of genetic privacy, but four states declare that genetic information is the individual's property.<sup>183</sup>

Whereas the right in property establishes an individual's ownership of material in relation to other people with respect to that property, creating a "bundle of rights,"<sup>184</sup> a privacy interest attaches substantive due process rights to the information, triggering a heightened judicial scrutiny and requiring the state to show a compelling interest in order to infringe upon the protected sphere.<sup>185</sup> Privacy and property rights have followed different paths of evolution in American law. Property rights have developed from the common law of the individual states, and are accordingly not uniform and may be open to interpretation in the context of the proper application to genetic information.<sup>186</sup> On the other hand, the Supreme Court has recognized the

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<sup>179</sup>*Id.*

<sup>180</sup>Yesley, *supra* note 164, at 659.

<sup>181</sup>Stepanuk, *supra* note 169, at 1115-6.

<sup>182</sup>*Id.*

<sup>183</sup>Yesley, *supra* note 133, at 657. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West 1998); GA. CODE ANN. § 33-54-1(1) (1997); 1997 La. Acts 1418; OR. REV. STAT. § 659.715(1) (1996) (as amended by 1997 Or. Laws 780).

<sup>184</sup>Stepanuk, *supra* note 169, at 1125. *See also* BLACK'S LAW DICTIONARY 508 (pocket ed. 1996) (defining private property as property protected from public appropriation, over which the owner has exclusive and absolute rights).

<sup>185</sup>Stepanuk, *supra* note 169, at 1125.

<sup>186</sup>*Id.*

right to privacy as fundamental and essential to individual liberty, inferring the possibility that privacy rights may hold a more constitutionally stable position.<sup>187</sup> The background and current interpretations of each of these rights merits attention in order to determine which is a more feasible basis for the protection of genetic information. The analysis will show that the best choice is dependent on the persons and activities that the legislation is intended to protect or regulate.<sup>188</sup>

#### D. The Privacy Interest

In 1977, before the need to protect genetic information was even within the Court's cognizance, the Supreme Court upheld a New York statute which required the establishment of a state database with the names and addresses of all persons who had obtained, by prescription, drugs with both lawful and unlawful markets.<sup>189</sup> In *Whalen v. Roe*, the Supreme Court specifically held that individuals have a constitutionally protected "zone of privacy," and the privacy interest against the disclosure of personal matters falls within this zone.<sup>190</sup> The law was upheld because the statute did not pose a "grievous" threat due to the extensive security measures afforded to protect the patients' identities.<sup>191</sup> The decision emphasized that the confidentiality provisions of the statute kept it within constitutional bounds, a determination the court made after an extensive investigation of the reporting system involved and a comparison with other states.<sup>192</sup>

*Whalen* provides a sound basis for predicting the fate of potential state databases established for the purpose of obtaining genetic information. Whereas the current databases contain the identifying DNA of convicted felons, and are held to a less stringent standard of justification given the diminished privacy rights in comparison with the state interest in preventing and solving crimes,<sup>193</sup> citizens at large could claim the constitutionally protected privacy interest against disclosure of personal matters with regard to genetic information if a state attempted to establish an all-inclusive database. If the court adhered to *Whalen*, researchers could establish such databases for purely scientific purposes, so long as donors' anonymity was protected, and statutes permitting the discovery of genetic information without the donor's

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<sup>187</sup>See, e.g., *Whalen v. Roe*, 429 U.S. 589 (1977) (holding the individual privacy interest against disclosure of personal matters is within the constitutionally protected "zone of privacy"); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (holding the state law which prohibited the use of contraceptives unconstitutional on the ground that the specific guarantees of the Bill of Rights create "penumbras" of implied rights which include marital privacy as a "fundamental right"). See also *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998) (remanding and holding that genetic testing of prospective employees could violate Constitutional rights of privacy if employees did not authorize the tests and had no reason to know that the tests were part of the routine physical).

<sup>188</sup>Stepanuk, *supra* note 169, at 1135 (Those affected by genetic research, and hence, genetic legislation include donors, researchers, and the public).

<sup>189</sup>*Whalen*, 429 U.S. at 591.

<sup>190</sup>*Id.* at 598-600.

<sup>191</sup>*Id.* at 600.

<sup>192</sup>*Id.* at 600-603.

<sup>193</sup>See *infra* pp.6-11.

permission would certainly be considered a “grievous” threat if identity was unprotected and the information could be used to adversely discriminate against the donor.

Unfortunately, the creation of a privacy interest in genetic information is not without drawbacks when it comes to implementation. It has been pointed out that laws with privacy measures will not necessarily guard against discrimination.<sup>194</sup> For example, the requirement of informed consent does not prevent an employer or insurer from conditioning acceptance on submission to a genetic test; the applicant may refuse, but he or she will not be eligible for coverage or employment.<sup>195</sup> In order to achieve protection against discrimination, legislation must either prohibit such tests directly or control the use of the results.

#### E. Property Rights

Proponents of property theory as the proper mechanism for protecting the individual’s interest in genetic information have asserted that property rights are “fundamental,” in an effort to invoke constitutional protection.<sup>196</sup> One proponent argues that since the framers of the Constitution felt very strongly about property rights, which included the right to one’s physical characteristics, and since these are determined by genetic composition, they should be constitutionally protected.<sup>197</sup> The Supreme Court held in *Truax v. Corrigan*<sup>198</sup> that a state is obligated to recognize and protect certain fundamental property interests from restriction.<sup>199</sup> However, although *Truax* has since been cited favorably, it has been viewed as the “high-water mark” for substantive due process protection of property rights, and the Supreme Court has not since addressed whether property rights are fundamental.<sup>200</sup>

Human tissue has always had monetary value in Europe, but this was not the case in the United States until the 1940’s when organ transplants became widespread.<sup>201</sup> The National Organ Transplant Act (NOTA)<sup>202</sup> makes it illegal to buy or sell human organs for transplantation, yet human body tissues are valued as property in other contexts, and the sale of blood and semen is permissible.<sup>203</sup> Where, then, does genetic information fit into this scheme? One of the major criticisms and fears of attributing property rights to genetic information is the potential for creating conflict

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<sup>194</sup>Yesley, *supra* note 133, at 658.

<sup>195</sup>*Id.*

<sup>196</sup>*See, e.g.,* Ronald Krotoszynski, Jr., *Fundamental Property Rights*, 85 GEO. L.J. 555, 624 (1997) (failure to establish a fundamental property right is illogical); Catherine M. Valerio Barrad, Comment, *Genetic Information and Property Theory*, 87 Nw. U. L. REV. 1037, 1086 (1993) (courts should recognize a property interest in genetic information).

<sup>197</sup>Valerio Barrad, *supra* note 196, at 1053-55.

<sup>198</sup>257 U.S. 312 (1921).

<sup>199</sup>*Id.* at 328.

<sup>200</sup>Krotoszynski, *supra* note 196, at 558-59.

<sup>201</sup>Stepanuk, *supra* note 169, at 1134.

<sup>202</sup>42 U.S.C. 273-74 (1994).

<sup>203</sup>Stepanuk, *supra* note 167, at 1134.

over ownership rights that could impede research and development efforts and result in unnecessary litigation.<sup>204</sup> This was one concern of the court in *Moore v. Regents of the Univ. of California*, which held that the doctors/researchers who used John Moore's unique spleen cells without his knowledge or consent for research which led to the development of a new cell line were not liable for conversion.<sup>205</sup> Instead, the court concluded that informed consent was sufficient to protect the patient's interest in knowing what is being done and how his body tissues will be used, without creating a property interest in the bodily tissue.<sup>206</sup>

The *Moore* holding is likely good news to the research-oriented, such as biotechnology companies, who would have the greatest concern if people were able to recover the value of genetic data used for research to produce a marketable product.<sup>207</sup> Indeed, when New Jersey first introduced its Genetic Privacy Act of 1996,<sup>208</sup> the governor conditionally vetoed the Act, replacing the provision which created a property right in genetic information with a privacy right out of similar concerns of hindering research.<sup>209</sup> While protecting genetic information with a privacy interest carries its own criticisms, these have been demonstrated to primarily consist of problematic implementation, or non-exhaustive scope of protection. On the other hand, attaching a property right to genetic information may not establish a fundamental right, but it does threaten potentially fundamental interests, by possibly hindering the steady flow of available raw material, placing the focus on actual possession of the information, and complicating the moral nature of the research as well as the function of the patent/royalty system.<sup>210</sup>

#### F. Recommendations

One method of protecting genetic information is to expand the laws and regulations that protect privacy in medical records to include genetic discrimination.<sup>211</sup> This mechanism would allow legislators to avoid the problems of defining what information is considered "genetic" while also avoiding the need to find justification for specially protecting genetic information.<sup>212</sup> However, this does not provide a solution for protecting genetic information in non-medical contexts.<sup>213</sup> In addition, it would not remedy the hodge-podge of state laws and is contrary to a uniform scheme. This is why I urge that federal legislation is the best solution for

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<sup>204</sup>Yesley, *supra* note 164, at 657.

<sup>205</sup>793 P.2d 479 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

<sup>206</sup>*Id.*

<sup>207</sup>Yesley, *supra* note 164, at 663.

<sup>208</sup>N.J. Stat. Ann. 126; § 17B:30-12 (West 1996).

<sup>209</sup>Stepanuk, *supra* note 169, at 1124-26.

<sup>210</sup>*Id.* at 1135.

<sup>211</sup>Yesley, *supra* note 164, at 658.

<sup>212</sup>*Id.*

<sup>213</sup>*Id.*

the sake of uniformity and to prevent an influx into the courts, forcing them to attempt to keep up with the scientific research on a case-by-case basis.<sup>214</sup>

Rather than attempt to formulate a comprehensive scheme of legislation to cover all the threats, federal legislation should be narrowly tailored to the character of the genetic information- a concept of separate legislation for separate problems.<sup>215</sup> The legal theory used to protect the interest at stake could then change depending on the context of the use of the information. However, based on the prevalence of privacy theory in state law and the arguments on each side, a property interest would rarely be necessary to protect against discrimination or nonconsensual taking or disclosure of genetic information. The laws should directly prohibit undesirable practices whenever possible, rather than indirectly create a “privacy” interest which doesn’t prevent conditioning employment or insurance on a genetic test.

New Jersey’s legislation has been hailed as a “model” for genetic discrimination legislation.<sup>216</sup> Congress could use it for guidance in regard to many issues, because it is one of the broadest state measures so far, offering protection on a variety of levels, and acknowledging the political, social, and moral significance of genetic information, but focusing on health insurance and employment discrimination.<sup>217</sup> In addition, Congress should not overlook the goals of the ELSI Program funded as part of the Human Genome Project to address the implication of genetic research for individuals and society.<sup>218</sup> With narrow tailoring and careful examination of the “real” issues involved, research can continue uninhibited while still protecting individual rights.

## VII. CONCLUSION

Fingerprints require only a swirl of ink on paper, to be compared with countless other patterns which reveal no more about their source than the appearance of the pads of the fingertips. With the impending completion of the Human Genome Project, however, our DNA will provide not only a reliable source of positive identification in the form of a “genetic fingerprint,” but also a host of other information about the source. Some do not wish to relinquish this type of information without at least the most basic protection against discrimination and exclusion from some of the most basic needs in today’s society.<sup>219</sup> This writing has

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<sup>214</sup>Not everyone shares the view that the answer lies in legislation. See Valerio Barrad, *supra* note 196, at 1084 (asserting that the courts need to apply common law principles and prevailing property theories to resolve issues surrounding the use of genetic information).

<sup>215</sup>Stepanuk, *supra* note 167, at 1143.

<sup>216</sup>*Id.* at 1116.

<sup>217</sup>*Id.*

<sup>218</sup>ELSI is a partnership of biological and social scientists, health care professionals, historians, legal scholars, and others committed to the exploration of the implications of the Human Genome Project as it proceeds. See Collins, et al., *supra* note 17, at 687-88. Three or four percent of the federal investment in the Human Genome Project (\$90 million) is allocated to studies dedicated to the ELSI program. Frederic Golden, *Good Eggs, Bad Eggs*, TIME, Jan. 11, 1999 at 56.

<sup>219</sup>See generally text, *infra*, pp. 5-11, and *Mayfield v. Dalton*, 901 F. Supp. 300 (D. Haw. 1995), *vacated*, 109 F.3d 1423 (9th Cir. 1997).

not even addressed in detail the additional implications medically, morally and socially if genetic information were publicly available.

The states have made admirable efforts to foresee and prevent the discriminatory effects of genetic testing,<sup>220</sup> and the federal government has also recognized the need and put forth an initial restraint on health insurance group providers.<sup>221</sup> The next step is to move forward, and continue to legislate before the problem occurs. A good general rule would recognize that there is an individual privacy interest in DNA which must be afforded the Constitutional safeguards of due process and a heightened scrutiny standard of review for any encroachment on that interest. If an invasion of the protected interest is justified, then the permissible uses of the genetic information must be limited to preclude discrimination on that basis with a legislative scheme similar to current discrimination legislation. This will spare the courts unnecessary case-by-case adjudication. Instead, the infant legislation can be put to the test, interpreted and adapted to fit the fast-moving legal and social developments which are inevitable when science has advanced to the point of deciphering the human genetic code.

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<sup>220</sup>See, e.g., statutes cited *supra* notes 164-65.

<sup>221</sup>Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1992 (1996).