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DNA, GENETIC MATERIAL, AND A LOOK AT PROPERTY RIGHTS: WHY YOU MAY BE YOUR BROTHER'S KEEPER

*By: Colin McFerrin**

ABSTRACT

In 2003, the Human Genome Project completed a thirteen-year international project that yielded a sequencing of the human genome. During that time—and continuing today—advances in DNA technology grew exponentially, allowing society to reap the benefits of DNA and other genetic material in fields such as forensics, genetic engineering, medical treatment, and research. Inevitably, the availability of such technology opened the door to an individual's genetic secrets being readily accessible and potentially misused. With varying degrees of success, state and federal legislators responded to the concerns of genetic privacy.

Federal legislation such as the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") and the Genetic Information Nondiscrimination Act of 2008 ("GINA") addressed concerns of genetic privacy and genetic discrimination in healthcare and employment. But, the perceived shortcomings and limited applicability of federal legislation spawned state legislation seeking to strengthen genetic privacy. On January 21, 2011, the Massachusetts legislature introduced a Genetic Bill of Rights that seeks to ensure genetic privacy and establish genetic property rights that align with Massachusetts's current property law.

This Comment evaluates concerns regarding familial DNA testing, surreptitious genetic testing, and genetic privacy. Accordingly, this Comment looks at how various courts addressed these issues, legislative remedies at the state and federal level, and potential dangers of over-legislating. Finally, this Comment recommends a legislative solution.

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I. INTRODUCTION

Scientists identified the structure of deoxyribonucleic acid ("DNA") in 1953 and completed the sequencing of the human genome in 2003; however, shows like *CSI*, *Law & Order*, and *Forensic Files* brought the concept of DNA to the forefront of society. Advances in technology, coupled with a stronger understanding of DNA and other genetic material, extended genetic applications into an array of fields and disciplines. Yet, the benefits to society in areas such as law enforcement, medicine, and research must be balanced with the rights, if any, an individual may have to genetic privacy.

On a daily basis, every individual unknowingly creates a genetic footprint. The hair near the shower drain, a discarded coffee cup, skin cells sloughed off onto an office chair, the empty soda can placed in recycling, the fork left on the table at a favorite restaurant, the cigarette butt from an afternoon break, the gum stuck to the bottom of a conference room table—these are but a few common examples in which individuals abandon their genetic material. Considering the role DNA plays in heredity, its ability to reveal propensities for various conditions and diseases, and the fact that, except for identical twins, DNA is unique to every individual, the question of genetic privacy emerges.

Part II of this Comment evaluates the science, applications, and legal issues surrounding DNA and genetic material. After examining the roles of chromosomes, genes, and replication, the concepts of familial DNA, abandoned DNA, and surreptitious genetic testing will be viewed through the lens of criminal investigations and newborn screening programs. Finally, this Section will further examine abandoned DNA and surreptitious testing as it applies to the Fourth Amendment and the ubiquity of online DNA testing kits, respectively.

Part III explores the attempts by federal and state legislatures to protect genetic information, ensure privacy, and establish genetic property rights. The Health Insurance Portability and Accountability

Act of 1996 ("HIPAA") and the Genetic Information Nondiscrimination Act of 2008 ("GINA") strive to protect individuals against genetic discrimination; however, both are limited in scope and protection. Accordingly, in an effort to remedy the perceived limitations of federal legislation, states such as Alaska implemented genetic privacy laws, which prohibit the nonconsensual collection, testing, and disclosure of DNA. This Section concludes with Massachusetts's Genetic Bill of Rights, which the legislature proposed in 2011 in an effort to establish genetic property rights commensurate to property rights existing under current state law.

Legislation continues to transform, becoming more comprehensive in an effort to better define and protect individuals' genetic rights. In light of the recent proposal of a Genetic Bill of Rights by the Massachusetts legislature, Part IV looks at the pitfalls associated with over-legislating genetic property rights. Newly proposed legislation must consider exceptions not only for law enforcement, research, paternity and newborn testing, and emergency medical treatment, but, possibly, exceptions for family members.

Finally, Part V recommends a federally based legislative solution that seeks to balance the need for individual privacy and genetic property rights with the societal benefits that flow from the use of genetic material.

II. AN OVERVIEW OF DNA AND THE SURROUNDING LEGAL ISSUES

A. *Understanding the Structure and Replication of DNA*

In 1953, James Watson and Francis Crick discovered both the structural and chemical properties of a cellular substance[1] that revolutionized a multitude of disciplines ranging from medicine and nanotechnology to law enforcement and forensics. Watson and Crick proposed that this cellular substance, deoxyribonucleic acid—more commonly known as DNA—possessed a three-dimensional, double helix structure that functioned as the chemical foundation for inheritance and served as the carrier of genetic information.[2] This genetic information, or genome, is an organism's complete set of genetic information and results from the presence of DNA within cellular structures.[3]

The structure of DNA is comprised of two polynucleotide chains that are held together by hydrogen bonds forming the double helix structure of a DNA molecule.[4] A polynucleotide chain consists of a

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[1] NEIL A. CAMPBELL & JANE B. REECE, BIOLOGY 4, 82 (6th ed. 2002).

[2] *Id.*; *see also* BRUCE ALBERTS ET AL., MOLECULAR BIOLOGY OF THE CELL 192–93 (4th ed. 2002).

[3] CAMPBELL, *supra* note 1, at 216.

[4] *Id.* at 82; *see also* ALBERTS, *supra* note 2, at 193.

five-carbon sugar, a phosphate group, and nitrogenous base pairs.[5] The five-carbon sugar and phosphate group form the backbone of the polynucleotide chain, and the nitrogenous base pairs reside in the interior of the helix formation. The four possible nitrogenous bases that may be found within a DNA molecule are adenine, cytosine, guanine, and thymine.[6] Due to the chemical composition and shapes of each nitrogenous base, only certain bases are compatible with each other such that hydrogen bonds will form between the base pairs.[7] Thus, due to this limited base pairing resulting from each base pair's shape and composition, adenine and thymine bases always pair together, and guanine bases always pair with cytosine bases.[8]

In addition to DNA, chromosomes play a vital function within the biological role of heredity and genetic information. Within all human somatic cells are two sets of twenty-three chromosomes, for a total of forty-six chromosomes.[9] One set of twenty-three chromosomes is a maternal set and comes from the mother; the second set of twenty-three chromosomes is a paternal set and comes from the father.[10] Of the twenty-three pairs of chromosomes in humans, all but one pair is common to males and females alike.[11] The unshared pair of chromosomes are the sex chromosomes, which are represented by X and Y and determine a child's gender.[12] A female child receives an X chromosome from each parent and, thus, has a homologous pair of X chromosomes (XX).[13] In contrast, a male child receives an X chromosome from the mother and a Y chromosome from the father (XY).[14]

A chromosome's most important function is to carry genes, and each chromosome contains hundreds, or thousands, of genes.[15] In fact, humans are estimated to have as many as 30,000 genes.[16] Genes are segments of DNA and, together, comprise a specific part of a single, long DNA molecule on the chromosome.[17] Essentially, genes are segments of DNA that generally correspond to a single protein or ribonucleic acid, commonly referred to as RNA, and are responsible for a specific hereditary characteristic.[18] Each gene is determined by the order or sequence of the bases along the DNA strand, and this

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[5] CAMPBELL, *supra* note 1, at 82; *see also* ALBERTS, *supra* note 2, at 193.

[6] ALBERTS, *supra* note 2, at 193.

[7] CAMPBELL, *supra* note 1, at 82; *see also* ALBERTS, *supra* note 2, at 194.

[8] CAMPBELL, *supra* note 1, at 82; *see also* ALBERTS, *supra* note 2, at 194.

[9] CAMPBELL, *supra* note 1, at 235–36.

[10] *Id.* at 236.

[11] *Id.*; *see also* ALBERTS, *supra* note 2, at 198.

[12] CAMPBELL, *supra* note 1, at 235; *see also* ALBERTS, *supra* note 2, at 198; LEWIS WOLPERT ET AL., PRINCIPLES OF DEVELOPMENT 418 (2d ed. 2002).

[13] CAMPBELL, *supra* note 1, at 236.

[14] *Id.*

[15] *Id.* at 235; *see also* ALBERTS, *supra* note 2, at 198.

[16] ALBERTS, *supra* note 2, at 200.

[17] CAMPBELL, *supra* note 1, at 235; *see also* ALBERTS, *supra* note 2, at 198.

[18] ALBERTS, *supra* note 2, at 6, 9–10.

sequence is unique for each gene.[19] As a result, the specific base sequence along the DNA strand determines the role and function that each gene will play within the cell.[20] The genes that individuals inherit from their parents, which are subsequently present on our chromosomes, determine a person's genetic makeup; thus, genes serve as the "functional units of heredity."[21] Accordingly, DNA provides the genetic material necessary for the phenotypic expression of traits such as freckles, attached or unattached earlobes, eye color, and the presence or absence of a widow's peak, to name a few.[22]

In addition to the DNA that specifically encodes proteins and RNA, about 97% of each individual's DNA consists of noncoding DNA, some of which consists of repetitive DNA, or base sequences.[23] Of the repetitive DNA present in the genome, between 10–15% of each individual's genetic information includes tandemly repetitive DNA, or satellite DNA.[24]

Tandemly repetitive DNA are short, recurrent sequences of base pairs that are between one and ten base pairs in length, may be repeated several hundred thousand times at a site within the genome, and repeat in succession.[25] For example, ATTGCATTGCATTG-CATTGC could be an example of tandemly repetitive DNA, with the base sequence ATTGC being the recurrent sequence of base pairs on one strand of DNA. It is these sequences, or satellite DNA, in the genome that produce a DNA fingerprint, which is accomplished by using the differing lengths of satellite DNA as markers.[26]

In forensic science, microsatellites are the most useful because they are highly variable between individuals, they are generally ten to one hundred base pairs long, and their repeating base sequence involves very few base pairs.[27] For example, the base sequence TGA could exist in Person A thirteen times at one locus; one-hundred twenty-seven times at a second locus; and exist in varying lengths at many other loci; however, another individual is quite likely going to have a different number of repeated TGA units at the same loci.[28] It is this variability in the identified repeating base sequence, or short tandem repeats ("STRs"), that creates an individual's DNA fingerprint resulting in different banding within the electrophoresis gel.[29]

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[19] CAMPBELL, *supra* note 1, at 82.

[20] *Id.*

[21] CAMPBELL, *supra* note 1, at 235; *see also* ALBERTS, *supra* note 2, at 200.

[22] CAMPBELL, *supra* note 1, at 234–35, 260.

[23] *Id.* at 357.

[24] *Id.*

[25] *Id.*

[26] *Id.* at 396.

[27] *Id.*

[28] *Id.*

[29] *Id.*

Having presented a rudimentary explanation of DNA, chromosomes, and genes, this Comment will now examine the process of DNA replication, a method by which genetic information is passed from one generation to the next. Although DNA replication is a complicated process involving many steps and enzymes, this Comment addresses a basic understanding of the replication process. As such, this Comment will outline only the general premise behind DNA replication in order to provide the necessary framework to comprehend the role it plays in the passing of genetic information from parent to offspring.

Weak hydrogen bonds hold the base pairs (adenine—thymine; guanine—cytosine) together.[30] Due to the weakness of these hydrogen bonds, the base pairs, along with the two polynucleotide chains, can be pulled apart without damaging or breaking the covalent bonds that hold the sugar-phosphate backbone together.[31] Because adenine always pairs with thymine, and guanine with cytosine, the two polynucleotide strands are said to be "complementary" because each is the "predictable counterpart of the other."[32] Therefore, each of the two original parental strands, once separated, can serve as a template strand for the synthesis of a new complementary DNA strand, the daughter strand.[33] The replication process results in two identical copies of the original DNA complex, with each of the resulting DNA molecules containing one of the original parental strands and one of the newly created daughter strands.[34] Thereafter, two daughter cells each receive one of the new DNA molecules and the transmission of hereditary information occurs.[35]

B. *Applications and Uses of DNA and Other Genetic Material*

As technology and understanding expands, the uses and applications of DNA continually evolve into a variety of fields. DNA technology serves as an indispensable tool in areas such as environmental concerns, paternity testing, disease diagnosis and treatment, pharmaceutical development, forensics, agriculture, and art.[36]

1. Forensics: Identifications and Convictions

One of the most prevalent and well-publicized applications of DNA is its use within the field of forensics. More specifically, DNA testing allows for the identification or confirmation of a suspect's identity,

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[30] ALBERTS, *supra* note 2, at 5–6.

[31] BENJAMIN LEWIN, GENES VIII 7 (2004); *see also* ALBERTS, *supra* note 2, at 6.

[32] CAMPBELL, *supra* note 1, at 83.

[33] *Id.*; *see also* LEWIN, *supra* note 31, at 7; ALBERTS, *supra* note 2, at 6.

[34] LEWIN, *supra* note 31, at 7; *see also* ALBERTS, *supra* note 2, at 6.

[35] ALBERTS, *supra* note 2, at 6; *see also* CAMPBELL, *supra* note 1, at 83.

[36] CAMPBELL, *supra* note 1, at 393–99; *see also* DNA 11, http://www.dna11.com (last visited Mar. 3, 2013).

assists in the conviction of guilty parties, and aids in the exoneration of wrongfully convicted individuals. Forensic scientists create a DNA fingerprint by analyzing specific markers within satellite DNA, which is DNA comprised of "tandemly repeated base sequences."[37] Several factors account for the reliability and capability of DNA to accurately identify an individual.[38] First, every person, with the exception of identical twins, possesses a unique DNA sequence.[39] Factors such as polymorphism, mutation, and sexual recombination provide for genetic variations among individuals that, subsequently, result in the existence of DNA's uniqueness.[40] Additionally, forensic scientists typically examine five highly variable DNA markers that, depending upon the specific markers chosen, create a 1:100,000 to a 1:1,000,000,000 chance that two individuals will have identical banding, or DNA fingerprint, within the electrophoresis gel.[41] Furthermore, scientists take into account the commonality of certain markers within various ethnic populations as the frequency with which a certain marker may appear; for example, in the Hispanic population, the commonality is vastly different from its frequency within the overall population.[42] Bearing in mind the uniqueness of each individual's DNA fingerprint, and the safeguards that ensure the accuracy and integrity of results, DNA evidence serves as a useful tool for law enforcement, prosecutors, and defense attorneys.[43]

The cases of the "Bind, Torture, Kill" ("BTK") serial killer[44] and the "Grim Sleeper" killer[45] are two prolific examples of law enforcement and prosecutors using DNA evidence to identify—and eventually convict—suspects. In both cases, however, law enforcement identified their suspects using familial searching.[46] In familial searching, law enforcement examines criminal DNA databases in an effort

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[37] CAMPBELL, *supra* note 1, at 357, 396.

[38] *Id.* at 395–96.

[39] *Id.* at 395.

[40] *Id.* at 453–56.

[41] *Id.* at 396.

[42] *Id.*

[43] *Id.*

[44] Ellen Nakashima, *From DNA of Family, a Tool to Make Arrests*, WASH. POST, Apr. 21, 2008, http://www.washingtonpost.com/wp-dyn/content/article/2008/04/20/AR2008042002388.html; *see also Computer Disk May Have Cracked BTK Case*, MSNBC.COM (Mar. 3, 2005, 4:32 pm), http://www.msnbc.msn.com/id/6988048/ns/us_news-crime_and_courts/t/computer-disk-may-have-cracked-btk-case/.

[45] Maura Dolan, Joel Rubin, & Mitchell Landsberg, *DNA Leads to Arrest in Grim Sleeper Killings*, L.A. TIMES, July 8, 2010, http://articles.latimes.com/2010/jul/08/local/la-me-grim-sleeper-20100708; *see also* Jennifer Steinhauer, *'Grim Sleeper' Arrest Fans Debate on DNA Use*, N.Y. TIMES, July 8, 2010, http://www.nytimes.com/2010/07/09/us/09sleeper.html; Lauren Sher & Neal Karlinsky, *New Technique of Using Family's DNA Led Police to 'Grim Sleeper' Suspect*, ABCNEWS.COM (July 8, 2010), http://abcnews.go.com/Nightline/familys-dna-led-police-grim-sleeper-serial-killer/story?id=11116381.

[46] *See* Nakashima, *supra* note 44; Dolan, *supra* note 45.

to identify the suspect, or a close relative of the suspect, by comparing the DNA profile of known offenders–arrestees with genetic evidence recovered from a crime scene.[47] Familial searching recognizes the concept that individuals in a sibling or parent-child relationship share more genetic material with each other than with non-familial individuals due to the DNA replication process discussed above.[48]

Dennis Rader, the self-named BTK criminal, murdered ten people between the 1970s and 1990s and managed to elude police for over thirty years in spite of his sending taunting letters and word puzzles to police and media.[49] Police suspected Rader after he sent a computer disk containing an electronic imprint to a local Wichita, Kansas television station.[50] Police were unable to confirm Rader's identity by comparing DNA evidence left at several BTK crime scenes to a sample of Rader's DNA.[51] Instead, so as not to alert Rader that police suspected his involvement, investigators compared crime scene DNA to genetic information belonging to Rader's daughter.[52] Armed with a court order and without the daughter's knowledge or consent, police obtained her Pap smear tissue sample from a Kansas medical clinic.[53] The comparison between crime scene DNA and the daughter's DNA profile demonstrated that she was the daughter of the BTK killer, resulting in Dennis Rader's February 2005 arrest.[54]

Similar to the BTK killer, police investigators utilized DNA from a family member to identify and arrest Lonnie David Franklin, Jr., who was nicknamed the "Grim Sleeper," due to the long time lapse between his murders.[55] Although law enforcement conducted familial DNA testing, police further established Franklin's identity by comparing crime scene DNA evidence to DNA that Franklin left on a slice of discarded pizza.[56] For more than twenty years, police were unable to identify the individual responsible for at least ten murders and one attempted murder.[57] In 2008, investigators performed an unsuccessful

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[47] *Familial Searching*, FED. BUREAU OF INVESTIGATION, http://www.fbi.gov/about-us/lab/codis/familial-searching (last visited Mar. 3, 2013).

[48] *Id.*

[49] Nakashima, *supra* note 44; *see also Computer Disk May Have Cracked BTK Case*, *supra* note 44.

[50] *Computer Disk May Have Cracked BTK Case*, *supra* note 44.

[51] *Id.*; *see also* Nakashima, *supra* note 44.

[52] *Computer Disk May Have Cracked BTK Case*, *supra* note 44; *see also* Nakashima, *supra* note 44.

[53] *Computer Disk May Have Cracked BTK Case*, *supra* note 44; *see also* Nakashima, *supra* note 44.

[54] *Computer Disk May Have Cracked BTK Case*, *supra* note 44; *see also* Nakashima, *supra* note 44.

[55] Dolan, *supra* note 45; *see also* Steinhauer, *supra* note 45; Sher & Karlinsky, *supra* note 45.

[56] *See* Dolan, *supra* note 45; Steinhauer, *supra* note 45.

[57] *See* Dolan, *supra* note 45; Steinhauer, *supra* note 45; Sher & Karlinsky, *supra* note 45.

familial DNA search.[58] The California DNA familial search involved obtaining DNA samples from convicted criminals and then comparing those samples to DNA samples recovered at crimes scenes.[59] The DNA familial database contains genetic information obtained only from convicted felons[60] and seeks not only to identify whether the felons committed a crime, but whether their family members have as well.[61] Approximately eighteen months after the first DNA familial search, law enforcement officials performed a second familial search that returned a partial match.[62] In 2009, police arrested Franklin's son, Christopher, on a felony weapons charge and collected a DNA sample from him while in custody.[63] It was Christopher's sample that returned a partial match to DNA samples collected at the "Grim Sleeper" crime scenes, allowing police investigators to narrow their focus on Lonnie Franklin.[64] Thereafter, police placed Lonnie Franklin under genetic surveillance; subsequently, law enforcement recovered Franklin's DNA from a slice of discarded pizza and matched it to the "Grim Sleeper" crime scene evidence.[65]

Although DNA evidence provides a useful and effective tool for both identifying and convicting suspects guilty of criminal acts, the methods used in the BTK and "Grim Sleeper" serial murder cases create issues of genetic privacy, consent, and abandonment. Was Rader's daughter entitled to privacy rights relating to her Pap smear and, consequently, her genetic information? Moreover, unlike Franklin's son, who had a DNA sample collected and added to a criminal database while incarcerated as a felon, Rader's daughter was neither incarcerated nor a convicted felon at the time investigators appropriated her tissue samples from the medical clinic.[66] From this perspective, should there be a higher standard as to consent and confiscation of DNA samples or, in contrast, should law enforcement be permitted to take possession of genetic information unfettered? Finally, what rights, if any, does a person have to their DNA and genetic information on voluntarily discarded items? In other words, does dropping a cigarette butt on the ground, placing an empty soda can in the recycling bin, disposing of a band-aid or flavorless stick of chewing gum in the trash, or leaving a coffee cup on a table or countertop constitute abandonment such that another individual can confiscate that item and take possession of your genetic information? Or, in the alternative, should individuals retain inherent rights in their DNA and, ac-

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[58] *See* Dolan, *supra* note 45; Steinhauer, *supra* note 45.

[59] Steinhauer, *supra* note 45.

[60] Sher & Karlinsky, *supra* note 45.

[61] Steinhauer, *supra* note 45.

[62] *Id.*; *see also* Dolan, *supra* note 45; Sher & Karlinsky, *supra* note 45.

[63] Sher & Karlinsky, *supra* note 45.

[64] *Id.*; *see also* Dolan, *supra* note 45; Steinhauer, *supra* note 45.

[65] *See* Dolan, *supra* note 45; Steinhauer, *supra* note 45.

[66] Nakashima, *supra* note 44.

cordingly, expect a minimum level of privacy and protection in their genetic information?

2. State Programs for Newborn Screening

All fifty states require newborn testing for genetic disorders such as phenylketonuria ("PKU"), hypothyroidism, and sickle cell anemia.[67] Texas requires every newborn child be screened for PKU, "other heritable diseases, hypothyroidism, and other disorders . . . ."[68] To underscore the necessity for newborn screening, PKU affects approximately one out of every 10,000 to 15,000 newborns in the United States.[69] PKU is a recessive genetic disorder that prevents the body from correctly metabolizing phenylalanine, resulting in mental retardation due to toxic blood levels of this amino acid and its byproduct, phenylpyruvate.[70] However, newborn screening programs allow for the detection and early treatment of such diseases, many of which have high rates of morbidity and mortality.[71] Unfortunately, while such tests may provide for early diagnosis and treatment, they also further the realm of legal uncertainty because most states do not specify how residual blood samples may be used following newborn testing, nor do a majority of states require parental notification that a child's blood sample may be stored and used in the future.[72]

In *Higgins v. Texas Department of Health Services*, parents of children born in 2007 and 2008 brought suit alleging that the state of Texas kept and stored their infant's blood samples following the completion of testing under the state's newborn screening program.[73] The parents alleged that the Texas Department of Health Services (the "Department") "distributed, sold, bartered, and traded" newborns' blood samples to "private research companies, government agencies, and other third parties" without the parents' knowledge or consent.[74] Because blood samples contain genetic material, the parents were concerned that their children's genetic information may be misused

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[67] *Phenylketonuria*, MAYO CLINIC, http://www.mayoclinic.com/health/phenylketonuria/DS00514/DSECTION=tests-and-diagnosis (last visited Mar. 3, 2013); *see also* Alice Park, *Genetic Tests for Newborns Now Widespread*, TIME HEALTH (Feb. 19, 2009), http://www.time.com/time/health/article/0,8599,1880704,00.html (last visited Mar. 3, 2013); *Newborn Screening Tests*, MARCH OF DIMES, http://www.marchofdimes.com/professionals/bringinghome_screening.html (last visited Mar. 3, 2013).

[68] TEX. HEALTH & SAFETY CODE ANN. § 33.011 (West 2010).

[69] CAMPBELL, *supra* note 1, at 266.

[70] *Id.*

[71] *Position Statement on Importance of Residual Newborn Screening Dried Blood Spots*, AMERICAN COLLEGE OF MEDICAL GENETICS (Apr. 29, 2009), http://www.acmg.net/StaticContent/NewsReleases/Blood_Spot_Position_Statement2009.pdf.

[72] *Most States Unclear About Storage, Use of Baby Blood Sample, New Study Finds*, GENETICS & PUB. POL'Y CTR. (Mar. 30, 2011), http://www.dnapolicy.org/news.release.php?action=detail&pressrelease_id=143.

[73] Higgins v. Tex. Dep't of Health Servs., 801 F. Supp. 2d 541, 544 (W.D. Tex. 2011).

[74] *Id.* at 546.

and possibly result in discrimination against their children or other family members.[75] Although the court dismissed the parents' claims for lack of jurisdiction and their opposed motion for leave to file a motion to certify the class as moot, the alleged actions of the Department raised concerns of privacy and consent relating to stored genetic information resulting from the state's required screening of newborns.[76]

Similar to *Higgins*, the parents of children born between 1998 and 2008 brought suit against the Minnesota Department of Health in *Bearder v. Minnesota.*[77] In *Bearder*, the parents alleged that the Department of Health violated the state's Genetic Privacy Act by failing to acquire written consent from the parents before it stored and conducted research on the blood samples collected as part of the state's newborn screening program.[78] More than 800,000 newborn screening blood samples remained in storage at the end of 2008, and more than 50,000 of those samples were used for research and studies outside the scope of their original purpose.[79] Ruling against the parents, the district court granted summary judgment for the state on three grounds: (1) the Genetic Privacy Act applied only to children born after August 1, 2006; (2) the Act did not supplant the newborn screening statutes; and (3) the children's blood samples, as defined by the Act, were not considered "genetic information."[80] The parents appealed, and the Minnesota Court of Appeals affirmed the district court's holding, concluding that although the blood samples were considered "genetic information" under the Act, the parents failed to offer facts showing that the state used the blood samples improperly.[81] The court of appeals further held that the Minnesota Department of Health retained "broad statutory authority to operate the newborn screening program," and that the state's Genetic Privacy Act was not applicable in this situation.[82]

On appeal, the Minnesota Supreme Court found that the state's Genetic Privacy Act applied to the blood samples because the state statute's definition of "genetic information" included samples that contain "medical or biological information" and that "those samples unquestionably contain genetic information."[83] Because the state's Genetic Privacy Act applied, the Court stated that the Minnesota Department of Health must obtain "written informed consent to collect,

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[75] *Id.*

[76] *Id.* at 544.

[77] Bearder v. State, 806 N.W.2d 766, 769 (Minn. 2011).

[78] *Id.*

[79] *Id.* at 770–71.

[80] *Id.* at 770.

[81] *Id.*

[82] *Id.*

[83] *Id.* at 773.

use, store, or disseminate those samples."[84] Therefore, the Minnesota Supreme Court reversed the court of appeals and held that, aside from the testing and reporting of heritable and congenital disorders pursuant to state and federal law, the Department of Health retained no authority to use, store, or disseminate the blood samples it acquired as part of the state's newborn screening program.[85]

While most of society may arguably approve of using blood, tissue samples, and other sources of genetic information to identify and convict individuals guilty of criminal acts, many proponents of these uses would object to the surreptitious collection and testing of their children's genetic information. For instance, the parents in *Higgins*[86] and *Bearder*[87] both objected to third parties using their children's genetic information for research and study purposes completely unrelated to newborn screening. While many may herald the capture and conviction of individuals through the use of familial DNA and surreptitious genetic testing, does the sentiment for such techniques bleed over into other areas such as paternity testing, research and development, political espionage, or celebrity gossip?

C. *Genetic Testing and Abandoned DNA*

In addition to using familial DNA to identify suspects, law enforcement officials have capitalized on the opportunities to collect and analyze "abandoned" DNA for the purposes of identifying individuals suspected of committing various crimes. Abandoned DNA has been defined as "any amount of human tissue capable of DNA analysis and separated from a targeted individual's person inadvertently or involuntarily, but not by police coercion."[88] Therefore, the collection of abandoned DNA differs from samples obtained by force, consent, or on the basis of a "court issued warrant."[89]

For the purposes of comparing a suspect's DNA to genetic material left at a crime scene, law enforcement officials have obtained abandoned DNA samples from items such as skin cells that sloughed off

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[84] *Id.*

[85] *Id.* at 776.

[86] Higgins v. Tex. Dep't of Health Servs., 801 F. Supp. 2d 541, 546 (W.D. Tex. 2011).

[87] *Bearder*, 806 N.W.2d at 770–71.

[88] Elizabeth E. Joh, *Reclaiming "Abandoned" DNA: The Fourth Amendment and Genetic Privacy*, 100 Nw. U. L. Rev. 857, 859 (2006).

[89] *Id.*

onto the arm of a chair that a suspect occupied during questioning,[90] a cigarette butt,[91] a soda can,[92] discarded chewing gum,[93] and saliva.[94]

At this point, the question becomes whether an individual has a right to privacy in DNA and other genetic material, or, in the alternative, whether it may be assumed that an item with such inherent value may be abandoned. Once an individual voluntarily and intentionally abandons property, the Fourth Amendment no longer protects that item from seizure.[95] A defendant must demonstrate a legitimate expectation of privacy in the seized property to establish a Fourth Amendment violation.[96]

The Supreme Court outlined expectations of privacy and issues of abandonment in *California v. Greenwood*.[97] In *Greenwood*, law enforcement suspected the defendant of narcotics trafficking based upon frequent, late-night traffic at the defendant's home and receipt of a tip regarding an impending drug delivery.[98] Law enforcement requested the trash collector to retrieve the defendant's garbage bags, keeping it separate from other individual's garbage, and deliver it to them for inspection.[99] Upon examination of the defendant's garbage bags, law

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[90] Raynor v. State, 29 A.3d 617, 621 (Md. Ct. Spec. App. 2011) (holding that the defendant "had no objectively reasonable expectation of privacy in the chair in the police barracks and that he retained no objectively reasonable expectation of privacy in the identifying characteristics that could be gleaned from the normal biological residue he left behind").

[91] *See, e.g.*, People v. Gallego, 117 Cal. Rptr. 3d 907, 910 (Cal. Ct. App. 2010) (concluding that the DNA testing did not constitute a Fourth Amendment "search" and that because the defendant voluntarily discarded the cigarette butt, the item was abandoned and the defendant "did not have a reasonable expectation of privacy in the DNA testing of the cigarette butt . . ."); Commonwealth v. Perkins, 883 N.E.2d 230, 239 (Mass. 2008) (holding that the defendant abandoned the cigarette butts when he left them in the interview room and, thus, defendant abandoned "[w]hatever reasonable expectation of privacy he" had under the "State and Federal Constitutions").

[92] *See, e.g.*, Hudson v. State, 205 S.W.3d 600, 604–05 (Tex. App.—Waco 2006, pet. ref'd) (finding that the defendant abandoned the soda can when he intentionally and voluntarily discarded it in the trash).

[93] People v. LaGuerre, 815 N.Y.S.2d 211, 213 (N.Y. App. Div. 2006) (holding that law enforcement did not violate the defendant's rights when they obtained a sample of DNA from a piece of chewing gum that the defendant voluntarily discarded, and thus abandoned, at "a contrived Pepsi taste test challenge").

[94] Commonwealth v. Cabral, 866 N.E.2d 429, 433–35 (Mass. App. Ct. 2007) (holding that the defendant did not have a reasonable expectation of privacy in his saliva or DNA when he "expectorated on to a public street" and failed to retrieve the spittle).

[95] *See* Abel v. United States, 362 U.S. 217, 241 (1960) (holding that the defendant abandoned the property when he discarded it in the trash can of his hotel room and, thus, the property was subject to seizure by the F.B.I.); United States v. Lockett, 435 F. App'x 315, 317 (5th Cir. 2010) (finding that the defendant abandoned a gun when he threw it to the ground from a moving vehicle).

[96] State v. Christian, 723 N.W.2d 453, at *3 (Iowa Ct. App. 2006) (citing Minnesota v. Carter, 528 U.S. 83, 88 (1998)).

[97] California v. Greenwood, 486 U.S. 35 (1988).

[98] *Id.* at 37.

[99] *Id.*

enforcement discovered evidence indicative of narcotics use.[100] Subsequently, law enforcement officers executed a search warrant and discovered cocaine and hashish within the defendant's home.[101] The trial court dismissed the charges, and the court of appeals affirmed on grounds that "warrantless trash searches violate the Fourth Amendment and the California Constitution" and, absent the evidence gleaned from the search of the defendant's garbage bags, law enforcement lacked probable cause to search the defendant's home.[102]

The Supreme Court reversed, holding that "plastic garbage bags left on or at the side of a public street are readily accessible to animals, children, scavengers, snoops, and other members of the public."[103] Therefore, the defendant retained no expectation of privacy in the trash bags or their contents because he placed those items at the curb, open to public inspection, for the purpose of having a third party remove them.[104] The Supreme Court noted that for an individual to fall under the protection of the Fourth Amendment, not only must the individual have a legitimate expectation of privacy, but society must "accept that expectation as objectively reasonable."[105]

D. *Surreptitious Genetic Testing*

Despite Fourth Amendment and privacy concerns, courts seem reluctant to stymie law enforcement officials from surreptitiously obtaining and testing abandoned DNA. Thus, the concern shifts to the legality of non-law enforcement personnel collecting and testing genetic material for purposes such as political espionage, paternity testing, and other nefarious reasons.

In an article published in the New England Journal of Medicine during the 2008 presidential election, the authors stated that both Senator John McCain and President Barack Obama released medical records to the media to establish their fitness for office.[106] Because genetic testing may show correlations and genetic predispositions for various conditions and diseases, such as coronary artery disease, various groups or individuals opposing a particular politician may seek to acquire that candidate's genetic information for purposes of sabotaging his or her campaign.[107] Moreover, in what the authors term "genetic McCarthyism," an opponent to a candidate could overstate or embellish the actual risks or predispositions a candidate has in devel-

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[100] *Id.* at 37–38.

[101] *Id.* at 38.

[102] *Id.*

[103] *Id.* at 40.

[104] *Id.* at 40–41.

[105] *Id.* at 39–40.

[106] Robert C. Green & George J. Annas, *The Genetic Privacy of Presidential Candidates*, 359 NEW ENG. J. MED. 2192, 2192 (2008).

[107] *Id.* at 2192–93.

oping a particular disease.[108] This concern becomes further amplified when it involves personality traits or a psychiatric condition, such as bipolar disorder, because the associations between genetic markers and such conditions are less proven and substantiated.[109] Thus, opponents could easily gather a political candidate's DNA "from loose hairs, coffee cups, discarded utensils, or even a handshake" and publish damaging genetic information that may be based on limited research and invalidated markers.[110]

Paternity testing represents another facet of DNA testing that raises concerns of surreptitious collection and testing. The use of DNA to establish paternity can be mandated under a court order,[111] performed voluntarily,[112] or conducted without knowledge or consent.[113] In fact, it seems that DNA paternity testing gains national media attention annually involving individuals such as President Thomas Jefferson,[114] Larry Birkhead,[115] James Brown,[116] Mick Jagger,[117] and former United States Democratic Senator John Edwards.[118] But, such controversy is not limited to famous individuals; an internet search using the phrase "secret paternity test" yields an abundance of direct-to-consumer ("DTC") genetic testing companies that will accept a DNA sample and test it on the consumer's behalf.[119] One DTC genetic testing company, DNA Solutions, offers secret paternity testing that in-

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[108] *Id.* at 2193.

[109] *Id.*

[110] *Id.* at 2192–93.

[111] *E.g.*, TEX. FAM. CODE ANN. § 160.502(a) (West 2010); MASS. GEN. LAWS ch. 209c, § 17 (2011).

[112] TEX. FAM. CODE ANN. § 160.501(1) (West 2010).

[113] Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. REV. 665, 671, 678 (2011) (finding that several companies test DNA samples to determine or establish paternity, including a "secret DNA paternity test").

[114] *Thomas Jefferson and Sally Hemings: A Brief Account*, MONTICELLO.ORG, http://www.monticello.org/site/plantation-and-slavery/thomas-jefferson-and-sally-hemings-brief-account (last visited Mar. 3, 2013) (concluding that President Jefferson may have fathered six children with his slave, Sally Hemings).

[115] *DNA Tests: Larry Birkhead is the Father of Anna Nicole Smith's Baby*, FOXNEWS.COM (Apr. 11, 2007), http://www.foxnews.com/story/0,2933,264965,00.html (reporting that DNA tests confirmed that Birkhead was the father of Anna Nicole Smith's daughter).

[116] Brenda Goodman, *Godfather of Soul; Father Many Times Over*, N.Y. TIMES, Aug. 23, 2007, http://www.nytimes.com/2007/08/23/us/23james.html (reciting that DNA tests confirmed James Brown, the "Godfather of Soul," fathered LaRhonda Petit Brown).

[117] *Jagger Testifies in Paternity Case*, BBC NEWS, Mar. 15, 2000, http://news.bbc.co.uk/2/hi/entertainment/678659.stm (explaining that July 1999 paternity tests confirmed Jagger was the father of Luciana Morad's son).

[118] Julie Bosman, *Edwards Admits He Fathered Girl With Mistress*, N.Y. TIMES, Jan. 21, 2010, http://www.nytimes.com/2010/01/22/us/politics/22edwards.html (reporting that Edwards admitted to fathering a child with Rielle Hunter after repeated denials of paternity by Edwards).

[119] Joh, *supra* note 113, at 673.

volves surreptitiously collecting and testing a potential parent's DNA.[120] DNA Solutions promotes DNA testing at eighteen loci for $189, and for an additional $99, the company will perform the paternity test using a consumer-submitted "discreet sample."[121] Examples of "discrete samples" recommended by DNA Solutions include "a used toothbrush"; "Q-tip with ear wax"; "used bandage"; and "hairs with hair root."[122] Regarding whether permission is needed for the paternity tests, DNA Solutions states in its Frequently Asked Questions ("FAQ") section that while a person must be responsible for "reading, accepting, and signing" the terms and conditions, "there is no permission from anyone needed since the tests are for peace of mind only."[123] Consequently, an individual could easily procure follicles of hair from a hairbrush or bath drain, or confiscate an old toothbrush, and submit the item for DNA testing without the genetic owner ever granting consent or abandoning an item laden with residual DNA. Regrettably, as the Author will further discuss in Part III, very few states currently account for nonconsensual DNA collection and testing through legislation and statutes.[124] Additionally, federal legislation speaks to this issue only within the framework of employment and insurance discrimination.[125] This lack of oversight and regulation in the United States creates a situation where one's genetic information is, for the most part, left unprotected.[126]

III. LEGISLATIVE ATTEMPTS AT SECURING GENETIC RIGHTS

As this Comment demonstrates, genetic information can be gleaned from something as insignificant as a piece of chewing gum or empty soda can. Thus, genetic privacy concerns, coupled with the ubiquity of online genetic testing facilities, dictate the need for legislation prohibiting the nonconsensual collection, testing, and disclosure of genetic material by individuals, employers, and other business entities.

A. *HIPAA*

One of the first legislative attempts at protecting specific aspects of individuals' health information was the Health Insurance Portability

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[120] *Id.* at 678; *see also Secret Paternity Test*, DNA SOLUTIONS, http://www.dnanow.com/secret-dna-test.htm (last visited Mar. 3, 2013).

[121] *Secret Paternity Test*, *supra* note 120.

[122] *Id.*

[123] *DNA Testing Frequently Asked Questions*, DNA SOLUTIONS, http://www.dnanow.com/dna-testing-faq.htm (last visited Mar. 3, 2013).

[124] Joh, *supra* note 113, at 686–88.

[125] *Id.*

[126] *Id.* at 683, 686 (noting that a majority of jurisdictions in the United States fail to recognize "DNA theft" as an offense and "legislative attempts to protect genetic privacy have been sporadic and non-comprehensive").

and Accountability Act of 1996 ("HIPAA").[127] Federal legislators promulgated the HIPAA Privacy Rule to confront issues of privacy regarding the "use and disclosure of individuals' health information" as it applies "to health plans, health care clearinghouses, and to any health care provider who transmits health information in electronic form . . . ."[128] As a result, HIPAA prevents health care companies from denying coverage of an individual's preexisting conditions "based solely upon genetic information . . . ."[129] Furthermore, HIPAA sought to ensure that health care companies would not take into consideration an individual's genetic information when assessing coverage eligibility or calculating health plan premiums.[130]

But, HIPAA falls short in many respects and fails to adequately protect individuals' genetic information. For instance, DTC genetic testing companies such as DNA Solutions do not fall under the HIPAA umbrella because they are not one of the covered entities to which it is applicable, nor do they transmit claims or health information in electronic form.[131] This HIPAA shortcoming results in "limited coverage" and "weak protections" of individuals and their genetic information.[132] As if minimal protection and coverage were not enough, HIPAA further fails individuals by failing to create a private cause of action when their medical information is improperly disclosed.[133] In *Acara v. Banks*, the plaintiff filed suit against a physician for disclosing the plaintiff's medical information without consent during a deposition; however, the district court held that the plaintiff did not have a private cause of action under HIPAA.[134] On appeal, the Fifth Circuit affirmed and held that enforcement of HIPAA is limited "to the Secretary of Health and Human Services" and that "[e]very district court that has considered" the issue of "private enforcement of HIPAA" have been "in agreement that the statute does not support a private right of action."[135]

B. *Genetic Information Nondiscrimination Act of 2008*

Fortunately, Congress did not stop with HIPAA, and on May 21, 2008, President George W. Bush signed the Genetic Information Non-

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[127] U.S. DEP'T OF HEALTH & HUMAN SERVS., SUMMARY OF THE HIPAA PRIVACY RULE 1 (2003), http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/privacysummary.pdf.

[128] *Id.* at 1, 2; *see also* 45 C.F.R. § 160.102 (2009).

[129] *The Genetic Information Nondiscrimination Act of 2008 (GINA) Fact Sheet*, U.S. DEP'T OF LABOR (Sept. 2009), http://www.dol.gov/ebsa/newsroom/fsGINA.html.

[130] *Id.*

[131] Mark A. Rothstein, *Genetic Stalking and Voyeurism: A New Challenge to Privacy*, 57 U. KAN. L. REV. 539, 569 (2009); *see also* 45 C.F.R. § 160.102.

[132] Rothstein, *supra* note 131, at 577.

[133] Acara v. Banks, 470 F.3d 569, 571 (5th Cir. 2006).

[134] *Id.* at 570.

[135] *Id.* at 571.

discrimination Act of 2008 ("GINA").[136] The goal of further protecting genetic information and the importance of GINA was emphasized by Health and Human Services ("HHS") Secretary Kathleen Sebelius when, "[e]choing the late Senator Ted Kennedy," Ms. Sebelius stated that the "efforts to protect Americans undergoing genetic testing from having the results of that testing used against them by their insurance companies is one of the 'first major new civil rights' of the new century."[137]

GINA strives "[t]o prohibit discrimination on the basis of genetic information with respect to health insurance and employment."[138] Title I of GINA relates to genetic nondiscrimination within the field of health insurance and prevents health insurers from basing eligibility, coverage, and premiums on genetic information.[139] Title I further proscribes health insurers from requesting or requiring genetic testing of the plan member or the plan member's family.[140] Title II prohibits the use of genetic information by an employer as the basis for decisions such as hiring, termination, compensation, segregation, or classification.[141] Except in limited circumstances, Title II also precludes an employer from requesting, requiring, or purchasing genetic information of an employee or an employee's family member.[142]

GINA provides further protection for individual health insurance plans, and it limits group rate increases based upon genetic information.[143] Dr. Francis S. Collins, the director of the National Human Genome Research Institute, voiced expectations that GINA would protect all Americans from insurance and employment genetic discrimination when she stated that GINA could "be known as the bill to protect people with DNA, and that would be all of us!"[144]

Nevertheless, while GINA creates additional genetic safeguards, it fails to address concerns of surreptitious collection and testing of DNA,[145] and it also fails to bar genetic discrimination in areas outside

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[136] Kathy L. Hudson et al., *Keeping Pace with the Times — The Genetic Information Nondiscrimination Act of 2008*, 358 New Eng. J. Med. 2661, 2661 (2008).

[137] News Release, U.S. Dep't of Health & Human Servs., New Rules Protect Patients' Genetic Information (Oct. 1, 2009), http://www.hhs.gov/news/press/2009pres/10/20091001b.html.

[138] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

[139] *Id.*

[140] *Id.*

[141] *Id.*

[142] *Id.*

[143] Hudson, *supra* note 136, at 2662.

[144] Francis S. Collins, Director, Nat'l Human Genome Research Inst., On Passage of Genetic Information Nondiscrimination Act of 2008 by the U.S. House of Representatives (May 1, 2008), *available at* http://www.genome.gov/27026482.

[145] Joh, *supra* note 113, at 686.

of health insurance and employment.[146] It is further argued that GINA's goal of prohibiting health insurance discrimination is nothing but a "mirage" because HIPAA addressed genetic discrimination under group plans, making GINA useful only in situations involving those with "individual health insurance policies in the few states that did not" have laws proscribing genetic discrimination.[147] Moreover, GINA offers scant protection because it covers only asymptomatic individuals.[148] Where an individual exhibits evidence or symptoms of a disease, state insurance law—not GINA—governs the actions of the health insurance company.[149] As a whole, one could argue that GINA is limited to applicability within only the fields of employment and health insurance, is but a minor improvement on HIPAA protections, and fails to address the growing concerns surrounding abandoned DNA or the nonconsensual collection and testing of genetic material.

C. *State Legislation*

Just as GINA and HIPAA fail to adequately address surreptitious collection and testing of genetic material, most states lack legislation prohibiting the nonconsensual collection, testing, or disclosure of an individual's DNA.[150] In fact, the number of states that place such restrictions on genetic material, including acts of DNA theft, numbers only ten.[151] Of those ten states, only Alaska, Florida, New Jersey, New York, and Oregon characterize DNA theft as a criminal act;[152] however, no state currently characterizes it as a felony.[153] Nevertheless, Alaska has been recognized for the strength and breadth of its genetic privacy legislation.[154]

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[146] Hudson, *supra* note 136, at 2663 (noting that GINA fails to address other areas in which misuse of genetic information may take place, such as "life insurance, disability insurance," and "long-term-care insurance").

[147] Mark A. Rothstein, *GINA's Beauty is Only Skin Deep*, GENEWATCH, http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=184 (last visited Mar. 3, 2013).

[148] *Id.*

[149] *Id.*

[150] Joh, *supra* note 113, at 686–87.

[151] *Id.* at 686.

[152] Eriq Gardner, *Gene Swipe*, A.B.A. J., Aug. 2011, at 52.

[153] Joh, *supra* note 113, at 686.

[154] *Id.* at 687 (remarking that "Alaska's law is probably the most comprehensive"); *see also* Gardner, *supra* note 152, at 52 (stating that "Alaska has the toughest statute, prohibiting individuals from collecting DNA, performing an analysis, retaining a sample, or disclosing the results of an analysis without first obtaining the written consent of a person"); Sara Katsanis & Gail Javitt, *Surreptitious DNA Testing*, GENETICS & PUB. POL'Y CTR. (Jan. 21, 2009), http://www.dnapolicy.org/policy.issue.php?action=detail&issuebrief_id=48 (citing Alaska as one of "[o]nly a handful of states" that "have laws that broadly restrict surreptitious DNA testing for both health and non-health related purposes . . .").

1. Alaska's Genetic Testing Statute

Alaska's "Genetic Privacy" statute requires written consent before a person can collect, analyze, or retain an individual's DNA sample.[155] The statute further requires written consent for the disclosure of an individual's DNA analysis results.[156] In either instance, a "general authorization for the release of medical records or medical information" does not qualify as written and informed consent, thus failing to meet the statute's consent requirement.[157] These above-stated provisions, however, do not apply to DNA samples that are collected, tested, and retained under certain circumstances.[158]

The Alaska statute grants exceptions to the collection, testing, and disclosure requirements within fields previously discussed by this Comment. Specifically, the statute grants exceptions for paternity testing, newborn screening, and law enforcement purposes.[159] The law enforcement reservation is broadly stated in the statute and, because of its potential ambiguity, allows law enforcement agencies and personnel to capitalize on such opportunities as abandoned DNA and surreptitious collection and testing.[160] The statute grants two other exceptions: (1) administration of emergency medical treatment to an individual and (2) the collection of genetic samples for the state's DNA identification registration system.[161] As a whole, Alaska's Genetic Privacy statute enlarges genetic rights and protections beyond those contemplated and established under federal legislation such as HIPAA and GINA.

In addition to broadening the scope of genetic protections beyond GINA's areas of health insurance and employment, the Alaska statute creates a private cause of action against individuals who collect, analyze, or retain DNA samples without consent, or against individuals that release the results of DNA testing.[162] Individuals violating the Alaska Genetic Privacy statute are responsible for actual damages and "for damages in the amount of $5,000," or $100,000 if the liable party's "violation resulted in profit or monetary gain . . . ."[163] The protection of an individual's DNA from unauthorized "collection, analysis, retention, or disclosure" is further bolstered by the characterization of such

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[155] ALASKA STAT. § 18.13.010 (2011).

[156] *Id.*

[157] *Id.*

[158] *Id.*

[159] *Id.*

[160] *Id.* (stating that law enforcement exceptions to the statute include "the identification of perpetrators and the investigation of crimes and the identification of missing or unidentified persons or deceased individuals").

[161] *Id.*; *see also* ALASKA STAT. § 44.41.035 (2011) (requiring that genetic samples be taken from individuals such as those convicted of specific crimes, felonies, or those required to register as sex offenders).

[162] ALASKA STAT. § 18.13.020 (2011).

[163] *Id.*

actions as a criminal act; however, the violation is merely classified as a misdemeanor, not a felony.[164]

Interestingly, the Alaska statute states that the "DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed."[165] The concept of creating property rights in DNA runs counter to the holding of the California Supreme Court in *Moore v. Regents of the University of California*, a seminal case involving property rights in genetic material.[166]

In *Moore*, the University of California at Los Angeles Medical Center ("UCLA") treated the plaintiff, John Moore ("Moore"), for hairy-cell leukemia.[167] Dr. David Golde, Moore's attending physician, recommended a splenectomy as a necessary procedure for treatment of the leukemia.[168] Moore consented to the splenectomy and Golde, without obtaining consent or informing Moore, retained a portion of the spleen for research purposes.[169] During postoperative care, and unbeknownst to Moore, Golde and others performed research on Moore's cells for the purposes of financial gain through the development of a cell line.[170] Golde's research eventually culminated in a valuable cell line derived from Moore's T-lymphocytes upon which the University acquired a patent, listing Golde as one of the cell line inventors.[171] The cell line was commercially developed and, based upon existing policy, the Regents and Golde, along with others, were to share in the royalties and profits.[172]

Moore brought suit alleging, among other things, that the "unauthorized use of his cells constitutes a conversion" and that he was entitled to a proprietary interest in any products that delineated from the cell line.[173] Moore partially grounded his theory of conversion on the premise of privacy rights, citing wrongful publicity cases in which individuals are recognized as having both an interest in their own likeness and a cause of action against unauthorized uses.[174] Moore argued that an individual should have "a right in one's own genetic material" because it is more unique to an individual than one's name or face.[175]

The California Supreme Court pointed out that the defendants sought to manufacture lymphokines, which are not unique but share a

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[164] ALASKA STAT. § 18.13.030 (2011).

[165] § 18.13.010.

[166] Moore v. Regents of the Univ. of Cal., 793 P.2d 479 (Cal. 1990).

[167] *Id.* at 480.

[168] *Id.*

[169] *Id.*

[170] *Id.* at 481.

[171] *Id.* at 481–82.

[172] *Id.* at 482.

[173] *Id.* at 487.

[174] *Id.* at 489–90.

[175] *Id.* at 490.

universal molecular structure.[176] Furthermore, the Court stated that the genetic material responsible for lymphokine production is "the same in every person . . . no more unique to Moore than the number of vertebrae in the spine or the chemical formula of hemoglobin."[177] Finally, the Court bluntly addressed the issue of privacy within the physician-patient setting, remarking that it is not "necessary to force the round pegs of 'privacy' and 'dignity' into the square hole of 'property'" because patients are protected under the legal theories of informed consent and fiduciary duty.[178] The Court rejected Moore's claim and held that Moore's right, if any, did not include property and ownership rights.[179]

However, against the backdrop of *Moore's* denial of ownership or property rights in one's genetic material and Alaska's genetic privacy statutes seeking to inhibit nonconsensual collection and testing of DNA, new legislation has sprung forth in Massachusetts that goes further in creating and protecting one's genetic property rights with the intention of creating a "genetic bill of rights."[180]

2. Massachusetts's Genetic Bill of Rights

In 2011, legislators in Massachusetts, Vermont, and California introduced legislation that sought to establish property and privacy rights in one's genetic information and address growing concerns that current state and federal legislation is grossly inadequate to handle the potential for misuse that currently exists.[181] Although there are similarities and differences between the above-mentioned legislation that warrant discussion, this Comment will only evaluate the proposed Massachusetts legislation.

Massachusetts Senate Bill 1080 boldly declares an intent to create a "Genetic Bill of Rights," and in contrast to *Moore's* refusal to recognize genetic property rights, section 1 expressly states that it seeks to make "genetic information the exclusive property" of the individual to whom it belongs.[182] In addition to the creation of property rights, section 1, much like the Alaska statute, seeks to strengthen privacy rights by requiring an individual's written disclosure prior to the disclosure of genetic information.[183] But, where the Alaska statute stops, section 1(b) of the Massachusetts bill continues and aligns genetic property rights with the rights established in existing Massachusetts property

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[176] *Id.*
[177] *Id.*
[178] *Id.* at 491.
[179] *Id.* at 492.
[180] S.B. 1080, 187th Gen. Court, Reg. Sess. (Mass. 2011).
[181] *Id.*; *see also* H.R. 368, 2011 Leg., Reg. Sess. (Vt. 2011); S.B. 559, 2011 Leg., Reg. Sess. (Cal. 2011).
[182] Mass. S.B. 1080.
[183] *Id.*

law.[184] Accordingly, section 1(b) of the proposed bill (1) allows an individual's will to posthumously dictate the terms and use of their genetic information; (2) requires, within the context of commercial transactions, an individual to receive fair market value compensation for their genetic information and be made aware that such information may be used for commercial purposes; and (3) mandates an individual to be notified, orally and in writing, that their genetic information is a commodity with inherent value prior to the individual contractually agreeing to share his or her genetic information.[185]

The Massachusetts "Genetic Bill of Rights" has the potential not only to establish and expand genetic property rights, but to address perceived shortcomings found within GINA, specifically within the realm of insurance.[186] Recall that GINA prohibited genetic discrimination by two explicit classes: healthcare insurance providers and employers.[187] With the implementation of the proposed Massachusetts legislation, protections against genetic discrimination would expand into areas such as disability insurance, long-term care insurance, life insurance, and automobile insurance.[188]

In addition to creating and expanding upon the concept of genetic property rights, the Massachusetts bill imposes both civil and criminal penalties for violations.[189] Similar to the previously discussed Alaska statute, the Massachusetts bill also allows for civil penalties through a private cause of action.[190] Moreover, an individual or entity violating the proposed legislation incurs liability for actual damages, and for damages up to $5,000, or, if the violation yielded profit or monetary gain, $100,000.[191] The differences arise in the context of criminal penalties.[192] The Massachusetts "Genetic Bill of Rights" proposes to make the following changes to the existing criminal statutes: (1) an assault or battery upon a person or his property for the purpose of intimidation because of the person's "genetic information" may be punishable by a fine of $5,000, two and one-half years imprisonment, or both; if bodily injury results, punishment may increase to a fine of $10,000, five years imprisonment, or both;[193] (2) the "distinction, discrimination, or restriction" of an individual based on a "genetic marker or handicap" as it relates to the admission or treatment within a public accommodation may be punishable by a fine of $2,500, one

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[184] *Id.*

[185] *Id.*

[186] Susan Huber & Dan Vorhaus, *Genetic Bill of Rights Proposed in Massachusetts*, GENOMICS L. REP. (Feb. 14, 2011), http://www.genomicslawreport.com/index.php/2011/02/14/genetic-bill-of-rights-proposed-in-massachusetts/#more-5261.

[187] Genetic Information Nondiscrimination Act of 2008, 122 Stat. 881 (2008).

[188] Huber & Vorhaus, *supra* note 186; Mass. S.B. 1080.

[189] Mass. S.B. 1080.

[190] *Id.*

[191] *Id.*

[192] *Id.*; ALASKA STAT. § 18.13.030 (2011).

[193] Mass. S.B. 1080; MASS. GEN. LAWS ANN. ch. 265, § 39 (West 2011).

year imprisonment, or both;[194] and (3) in the context of identity theft, "genetic information" would constitute "personal identifying information" such that the misappropriation of genetic information, with the intent to defraud, may be punishable by a fine of $5,000, two and one-half years imprisonment, or both.[195] Thus, while the Alaska "Genetic Privacy" statute and the proposed Massachusetts "Genetic Bill of Rights" may share some commonality as to civil penalties, the latter seems to use criminal penalties as a conduit for broader protections of genetic information.

The evolution from limited protections under GINA to the creation of genetic property rights and expanded protections under the proposed Massachusetts legislation seems both inevitable and necessary in light of the potential for misuse. Nevertheless, future legislation must be crafted with the understanding that exceptions for the collection, testing, and retention of genetic material may be necessary.

IV. OVER-LEGISLATING GENETIC PROPERTY RIGHTS

Since the introduction of HIPAA, legislators have progressively expanded individuals' protections and rights in both their health information and genetic material, as evinced by GINA, Alaska's "Genetic Testing" statute, and Massachusetts's proposed "Genetic Bill of Rights." But, one could argue that increased protections and the potential creation of genetic property rights may result in various roadblocks, legal impediments, and civil or criminal liability in areas such as law enforcement investigations, research, and non-discreet family members, to name a few.

A. *Law Enforcement, Offenders, and DNA Profiles*

The federal government and all fifty states have provisions mandating the collection of DNA samples from individuals convicted of specified crimes, which are then stored and maintained in DNA databases.[196] Additionally, genetic samples may be collected from "individuals on probation, parole, and supervised release for federal offenses," and, at the states' discretion, arrestees.[197] From these DNA databases, law enforcement may then cross-reference offender DNA profiles with crime scene evidence in an effort to identify a suspect for both recent and cold-case crimes.[198] While a DNA match between the crime scene evidence and the DNA database identifies the previous

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[194] Mass. S.B. 1080; MASS. GEN. LAWS ANN. ch. 272, § 98 (West 2011).

[195] Mass. S.B. 1080; MASS. GEN. LAWS ANN. ch. 266, § 37E (West 2011).

[196] Jessica D. Gabel, *Probable Cause from Probable Bonds: A Genetic Tattle Tale Based on Familial DNA*, 21 HASTINGS WOMEN'S L.J. 3, 14–15 (2010).

[197] *Id.*

[198] *Id.* at 15.

offender as a suspect, a near match establishes a familial relationship between the suspect and the previous offender.[199]

Although familial searching offers another tool by which law enforcement can generate additional leads and identify suspects,[200] some have decried familial searches as being racially discriminatory.[201] In response to the arrest of the "Grim Sleeper" serial killer, some argued that African-Americans were "vastly overrepresented in the DNA databases"[202] because African-Americans represent a disproportionate amount of individuals arrested and convicted every year of crimes.[203] Thus, due to the high number of African-Americans within the DNA databases, a familial search for potential leads or suspects "extends the reach of databases . . . to the offenders' family," which results in a "genetic map of communities of color, and a law enforcement tool that is much more likely to solve crimes committed by black offenders than white offenders."[204]

In response to the racial equity concerns of familial DNA searching, Frederick Bieber, a medical geneticist and Harvard Medical School associate professor of pathology, points out that DNA "is race blind."[205] This position is strengthened by Bieber's argument that familial searches are performed on every genetic profile, regardless of race or ethnicity, and that the investigator does not "know or care whether the owner of that DNA is black, white, or green."[206]

In *United States v. Kincade*, the Ninth Circuit evaluated the constitutionality of requiring a California parolee to submit a blood sample for DNA profiling pursuant to the California DNA Act.[207] *Kincade* acknowledged the danger that DNA profiles could inevitably yield the race or sex of the individual due to "group variances . . . of various

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[199] Mitchell R. Morrissey, *A Tool to Protect Communities*, N.Y. TIMES, July 15, 2010, http://www.nytimes.com/roomfordebate/2010/7/14/how-far-should-the-dna-dragnet-go/familial-dna-searches-protect-communities (stating that a near match indicates the criminal "could be the father, brother or sister of the offender whose DNA is in the database").

[200] *Id.* (One study estimated that familial DNA searches "provide a 40 percent increase in the number of investigative leads generated from a DNA database search.").

[201] Jeffrey Rosen, *Privacy Risks and Racial Bias*, N.Y. TIMES, May 20, 2011, http://www.nytimes.com/roomfordebate/2010/7/14/how-far-should-the-dna-dragnet-go/discrimination-and-privacy-concerns-with-familial-dna-searches.

[202] Peter Bibring, *"Grim Sleeper" Case Doesn't Justify Expanding the Reach of DNA Databases*, AM. CIV. LIBERTIES UNION BLOG (July 15, 2010, 12:30 PM), http://www.aclu.org/blog/racial-justice-technology-and-liberty/grim-sleeper-case-doesnt-justify-expanding-reach-dna-data.

[203] Rosen, *supra* note 201 ("African-Americans represent about 13 percent of the United States population but 40 percent of the people convicted of felonies every year.").

[204] Bibring, *supra* note 202.

[205] Jessica Cerretani, *Whodunit?*, BOS. GLOBE, Oct. 31, 2010, http://www.boston.com/news/education/higher/articles/2010/10/31/whodunit/?page=3.

[206] *Id.*

[207] United States v. Kincade, 379 F.3d 813, 820–21 (2004).

alleles at the STR loci . . . ."[208] But, the court seemed to mitigate these concerns by stating that the variances in the alleles at the thirteen STR loci are such that the DNA profiles are highly individualized and "the chance that two randomly selected individuals will share the same profile are infinitesimal . . . ."[209] Once an individual's DNA profile is created, it is loaded into the Federal Bureau of Investigation's ("FBI") Combined DNA Index System, or CODIS.[210] Once again, the court addressed, and attempted to minimize, the concerns that DNA profiles contain personally identifying information, stating that "[b]eyond the STR-generated DNA profile, CODIS records contain only an identifier for the agency that provided the DNA sample, a specimen identification number, and the name of the personnel associated with the analysis."[211] Finally, the court pointed out that once convicted of a felony under the DNA Act, an individual's "identity has become a matter of state interest and he has lost any legitimate expectation of privacy in the identifying information derived from blood sampling."[212] Thus, while the court recognized that race or sex may be revealed through DNA profiles, it dismissed such concerns, noting that the implemented safeguards, the variance of genetic information at the tested loci, and the state's interest validated the collection, storage and maintenance of DNA profiles.

The constitutionality of DNA sampling will continue to be questioned by offenders,[213] irrespective of the fact that every federal circuit, as well most district and state courts, have "upheld the state and federal DNA indexing laws . . . ."[214] But, as legislators seek to bolster individual protections and establish genetic property rights, explicit exceptions for the non-consensual collection, analysis, and storage of DNA by law enforcement must be included within the statute. Otherwise, police officers and law enforcement agencies could find themselves liable under future genetic legislation the next time they retrieve and test a suspect's discarded coffee cup from the trash.

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[208] *Id.* at 818.

[209] *Id.*

[210] *Id.* at 819.

[211] *Id.*

[212] *Id.* at 837 (citing Rice v. Oregon, 59 F.3d 1556, 1560 (9th Cir. 1995)).

[213] *See, e.g.*, Haskell v. Brown, 677 F. Supp. 2d 1187, 1189 (N.D. Cal. 2009) (plaintiffs sought to enjoin a California statute requiring "DNA sampling of felony arrestees"); Segundo v. State, 270 S.W.3d 79, 96 (Tex. Crim. App. 2008) (offender argued that the acquisition of his DNA profile while in prison violated the Texas Constitution and the Fourth Amendment of the United States Constitution); United States v. Sczubelek, 402 F.3d 175, 186 (3rd Cir. 2005) (individual on supervised release refused to submit to DNA sampling on the grounds that it was an unconstitutional search and violative of the Fourth Amendment).

[214] United States v. Amerson, 483 F.3d 73, 78 n.3 (2nd Cir. 2007).

B. *Inhibiting the Cure for Cancer*

Deleterious effects on clinical, medical, and research activities represent another potential ramification of creating broad and overreaching genetic property rights. The proposed Massachusetts Genetic Bill of Rights creates exceptions for law enforcement, the state DNA database, and judicial orders; however, some argue that the Massachusetts legislation fails to adequately account for "legitimate scientific and research activities."[215] With the increasing costs and restrictions placed on genetic information under the Massachusetts bill, genetic research could potentially be obstructed or become cost prohibitive.[216]

The Massachusetts Society of Pathologists ("MSP"), in a letter to State Senator Harriette Chandler, requested an amendment to the proposed Massachusetts Genetic Bill of Rights.[217] The MSP argued that the bill contained "serious errors" because it failed to delineate what areas of genetic testing would be governed by the legislation's informed consent requirement.[218] Current state law exempts genetic testing used to diagnose or detect "existing disease, illness, impairment, or disorder" from the informed consent requirement.[219] And, without implementing the current statutory exemption into the Genetic Bill of Rights, the MSP argued that the proposed genetic testing prohibitions could serve as "an impediment to patient access to high quality healthcare" in areas such as cancer treatment and diagnosis.[220]

Because "[n]obody wants legislation that, for example, impedes the discovery of a cure for cancer,"[221] it is necessary to balance the quest for individual genetic property rights and protections with the societal benefits of "more meaningful commercial, scientific, and clinical innovation."[222] Failure to do so could, arguably, irreparably stifle advances in medicine and research. Accordingly, state and federal legislators must ensure that adequate exceptions for research and medical purposes are carved out of future genetic legislation, especially as it pertains to an informed consent requirement.

C. *Blood is Thicker than Water*

Another scenario that may be problematic for DNA privacy laws and a Genetic Bill of Rights involves the parent-child and sibling rela-

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[215] Huber & Vorhaus, *supra* note 186.

[216] *Id.*

[217] Letter from C. Dean Pappas, President, Mass. Soc'y of Pathologists, to Harriette L. Chandler, Mass. State Sen. (Mar. 14, 2011) (on file with author), *available at* http://www.cap.org/apps/docs/statline/pdf/chandler.pdf.

[218] *Id.*

[219] *Id.*

[220] *Id.*

[221] Gardner, *supra* note 152, at 55.

[222] Huber & Vorhaus, *supra* note 186.

tionship, which has seemingly been overlooked by existing legislation.[223] Because each of us receives half of our chromosomes from our mother, and the other half from our father,[224] individuals will share more genetic material with a parent, child, or sibling than they would with an unrelated individual.[225] Thus, if new legislation fails to account for the familial sharing of genetic information, an individual would have no recourse against a family member that intentionally or mistakenly shares "that person's genetic secrets."[226] Of course, the natural inverse to this dilemma is that future legislation could go too far, and be too stringent, such that family members find themselves subject to criminal or civil liability, or both, by releasing their genetic information.

Of the relatively few states that currently legislate the collection, testing, and disclosure of genetic material,[227] Oregon, unlike many of its counterparts, recognized and addressed the link between DNA and blood relatives.[228] This foresight on the part of the Oregon legislature resulted in genetic privacy statutes that define an individual's rights in their genetic information and the rights of that individual's blood relatives.[229] With limited exceptions,[230] the statute seeks to protect both the identity of individuals that undergo genetic testing and the blood relatives of the tested individual.[231] Oregon's "Genetic Privacy" statute protects these rights by allowing the individual or the individual's blood relative to bring private causes of action against a person whose

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[223] *See, e.g.*, ALASKA STAT. § 18.13.010(b)(1)–(5) (2011) (establishing disclosure exceptions for the state offender DNA database, law enforcement, paternity testing, newborn screening, and emergency medical treatment); FLA. STAT. ANN. § 760.40(2)(a) (West 2011) (exceptions for disclosing genetic information exists for criminal prosecutions, paternity testing, and the state offender DNA database); N.J. STAT. ANN. § 10:5-47(a)(1)–(10) (West 2011) (creating exceptions for disclosure of genetic information for law enforcement, paternity testing, court orders, the "DNA Database and Databank Act of 1994," written consent by the individual, use of decedent's genetic information for medical diagnosis of blood relatives, identifying deceased individuals, newborn screening, identification of persons pursuant to federal law, and disclosure by an insurer pursuant to statute).

[224] CAMPBELL, *supra* note 1, at 235–36.

[225] *Familial Searching*, *supra* note 47.

[226] Gardner, *supra* note 152, at 55.

[227] Joh, *supra* note 113, at 686.

[228] OR. REV. STAT. ANN. § 192.533(1)(a)–(f) (West 2011). The Legislative Assembly found that DNA testing provides information about both the individual and their family. *Id.* Failure to properly safeguard genetic information not only affects "family privacy," but can lead to "stigmatization and discrimination in areas such as employment, education, health care, and insurance." *Id.*

[229] *Id.* § 192.533(2)(a).

[230] OR. REV. STAT. ANN. § 192.539(1)(a)–(f) (West 2011) (permitting disclosure of the identity of genetically tested individuals, the identity of the tested individual's blood relatives, or the disclosure of genetic information that leads to the identity of such individuals for purposes of law enforcement, court orders for civil actions, paternity testing, medical diagnosis of the decedent's blood relatives, identification of bodies, or when the tested individual signs a consent form).

[231] *Id.* § 192.539(1).

actions are violative of specific sections of the statute.[232] Oregon's explicit recognition of blood relatives' rights in a family member's genetic material, however, creates ambiguity.

As previously noted, the Oregon statute expressly references an individual's blood relative with regards to a private right of action[233] and the protection against disclosure of that family member's genetic information or identity.[234] The remaining sections of Oregon's "Genetic Privacy" statute largely fail to expressly use the term "blood relatives," thus creating uncertainty as to a family member's liability for disclosing genetic information.[235] This question of "familial liability" seems readily apparent in section 192.535 of the statute. It states that "[a] 'person' may not obtain genetic information from an individual, or from an individual's DNA sample, without first obtaining informed consent of the individual or the individual's representative," absent a provisional exception.[236] Textually, this section requires a 'person' to obtain consent before acquiring genetic information *from an individual* or the individual's DNA. But what about the individual's blood relative? It would seem that the statute allows a 'person' to acquire that individual's genetic information *from a blood relative* without either party incurring liability.

Legislators must be aware of the scientific underpinnings of DNA and heredity when crafting future genetic legislation. States such as Alaska, Florida, and to a lesser degree, Oregon, failed to adequately consider the rights and liabilities associated with shared genetic information among blood relatives. Accordingly, new legislation must find

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[232] Or. Rev. Stat. Ann. § 192.541(1) (West 2011) (identifying violations of sections 192.535, 192.537, 192.539, and 192.547 as the basis for a civil action by an individual or their blood relative).

[233] *Id.*

[234] § 192.539(1).

[235] *See generally* Or. Rev. Stat. Ann. § 192.531 (West 2011) (citing Or. Rev. Stat. Ann. § 433.045 (West 2011), which defines "person" as "any health care provider, health care facility, clinical laboratory, blood or sperm bank, insurer, insurance producer, insurance-support organization, . . . government agency, employer, research organization or agent of any of them" and states that a "'person' does not include an individual acting in a private capacity and not in an employment, occupational, or professional capacity"); Or. Rev. Stat. Ann. § 192.543(1) (West 2011) (A "PERSON" COMMITS A CRIME IF THE "PERSON" OBTAINS, RETAINS, OR DISCLOSES GENETIC INFORMATION IN VIOLATION" OF THE STATUTE); § 192.541(1) ("AN INDIVIDUAL OR AN INDIVIDUAL'S BLOOD RELATIVE . . . MAY BRING A CIVIL ACTION AGAINST ANY 'PERSON' WHO VIOLATES" THE STATUTE); *id.* § 192.539(1) ("Regardless of . . . the source of genetic information, . . . a 'person' may not disclose or be compelled . . . to disclose the identity of an individual upon whom a genetic test has been performed or the identity of a blood relative of the individual, or to disclose genetic information about the individual or a blood relative of the individual in a manner that permits identification of the individual," absent an exception).

[236] Or. Rev. Sat. Ann. § 192.535(1) (West 2011) (authorizing exceptions for law enforcement purposes, anonymous research, identification of deceased individuals, newborn screening, paternity testing, and the use of a decedent's genetic information for medical diagnosis of blood relatives).

a solution to this familial dichotomy. Extremely protective and rigid genetic privacy laws could inhibit research, prevent individuals from examining their genetic background,[237] and expose family members to additional liabilities. In contrast, legislation that does not explore and address the familial sharing of genetic information may not sufficiently protect individuals from an unwitting or unscrupulous family member.[238]

V. CONCLUSION

As technology and scientific understanding of DNA evolves, so must legislation. Otherwise, the protections afforded to society become antiquated and meaningless because new discoveries and advances in testing methodologies could intentionally or inadvertently circumvent older statutes. Thus, diligence becomes an essential component to any genetic statute, requiring such legislation to recognize and account for these changes and advances.

Future legislation must prohibit both surreptitious and nonconsensual collection, testing, and disclosure of DNA and other genetic material by individuals, business entities, and in limited circumstances such as those present in *Higgins*[239] and *Bearder*,[240] government agencies. This necessity is presently dictated by three realizations: (1) the potential economic value of genetic material; (2) the inherently private and sensitive information encoded with DNA and other genetic material; and (3) the ubiquity and accessibility of DTC genetic testing and DNA test kits. Accordingly, a requirement of written consent from the genetic donor should serve as the first vital component of any proposed legislation. The written consent form shall inform the donor of the purpose and scope of testing; the length of time the sample and results will be retained; the potential corollary uses, if any, for which the donor's sample and results will be used; and identification of third parties that may conduct any testing or analysis of the sample or results. The form shall also include an "opt-out" provision in which the donor may elect to have the sample and results destroyed upon completion of the stated purpose and scope of testing. Additionally, a donor must be apprised of any pecuniary gain that may result from his or her genetic material or information; however, unlike Massachusetts's Genetic Bill of Rights,[241] compensation to the donor shall not be mandatory. Instead, the parties should be allowed to freely con-

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[237] Gardner, *supra* note 152, at 55.

[238] *Id.*

[239] Higgins v. Tex. Dep't of Health Servs., 801 F. Supp. 2d 541, 544 (W.D. Tex. 2011) (arguing that the Texas Health Department improperly distributed newborn samples for pecuniary gain).

[240] Bearder v. State, 806 N.W.2d 766, 769 (Minn. 2011) (alleging the Minnesota Health Department used misappropriated newborn samples for the purpose of research).

[241] S.B. 1080, 187th Gen. Court, Reg. Sess. (Mass. 2011) (requiring fair market

tract, as in other areas of property law, because of the uniqueness[242] and potentially differing intrinsic values of an individual's DNA. Moreover, genetic material and information shall not be used in any discriminatory manner by individuals or entities in the context of employment, or in the purchase or use of any product or service. Finally, because individuals share substantial amounts of their genetic information with family members,[243] an individual must procure written consent from parents, siblings, and non-minor children prior to submitting a genetic sample or disclosing genetic results to another person or entity. Exceptions to the familial consent requirement include, but are not limited to, the following: emergency medical treatment; court-ordered testing; newborn testing; genetic testing for law enforcement purposes; state and federal DNA databases; and testing for medical diagnosis and treatment. While future legislation may need to identify additional exceptions to the familial consent requirement, legislators must recognize that doing so will further dilute family members' genetic privacy rights and protections.

The creation of genetic property rights necessitates the creation of both civil and criminal penalties to ensure enforcement. Similar to the Alaska Genetic Privacy statute[244] and Massachusetts Genetic Bill of Rights,[245] an individual shall have a private cause of action against individuals or entities violating the above-stated provisions. Civil penalties shall include fines of $5,000 for each violation and, if the violation results in economic gain, $100,000 for each violation. Although no state currently classifies genetic misappropriation as a felony,[246] future legislation must define criminal penalties according to the *mens rea* of the individual violating the statute. An individual that purposely, knowingly, or recklessly violates the statute shall be guilty of a felony. In contrast, an individual that negligently violates the statute shall be guilty of a misdemeanor. This distinction recognizes the economic value of genetic material, reinforces the principle of genetic privacy, and more closely follows how states treat property crimes such as theft.[247] Moreover, the *mens rea* requirement ensures that individuals who mistakenly violate the statute, such as an unwitting family member,[248] are not unduly punished.

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value compensation when genetic material and information is collected for possible "resale, licensing, or transfer . . . for collateral gain").

[242] CAMPBELL, *supra* note 1, at 395.

[243] *Familial Searching*, *supra* note 47.

[244] ALASKA STAT. § 18.13.020 (2011).

[245] S.B. 1080, 187th Gen. Court, Reg. Sess. (Mass. 2011).

[246] Joh, *supra* note 113, at 686.

[247] *Id.* (noting that most jurisdictions classify various theft crimes as felonies and misdemeanors); *see, e.g.*, TEX. PENAL CODE ANN. § 31.03(e) (West 2011) (classifying theft as a misdemeanor or felony based upon the value of the property).

[248] Gardner, *supra* note 152, at 55.

Under limited circumstances, protections from civil and criminal liability represent another key component of future genetic legislation. First, exceptions must be established for law enforcement purposes and criminal DNA databases. During the course of a legal investigation, law enforcement shall have the ability to collect and test genetic samples pursuant to a warrant or court order. Furthermore, law enforcement shall be allowed to utilize familial DNA searching during the course of a legal investigation, provided that the source of the suspect's family member's DNA is obtained pursuant to a warrant or court order, or from the criminal DNA database; however, law enforcement shall not conduct surreptitious collection and testing of a family member's DNA or other genetic material. Law enforcement shall be allowed to collect and test genetic samples for criminal DNA databases from individuals arrested or convicted of statutorily-specified crimes. Additionally, samples collected, tested, and disclosed for newborn screening, emergency medical treatment, and court-ordered testing (i.e., paternity testing) must be exempted from liability. Finally, individuals and entities utilizing genetic material and information for medical, scientific, and research activities are shielded from liability, provided that the above-outlined written consent and familial consent requirements are satisfied.

The implementation of any future genetic legislation must necessarily come from the federal government. Currently, clinical research trials exist in every state and the District of Columbia.[249] Allowing states to independently establish genetic rights could result in fifty different genetic statutes, each containing separate variations in their breadth of genetic rights, exceptions, and liabilities. Permissible research activities in "State A" may require market-value compensation to a genetic donor in "State B," and be altogether prohibited in "State C." Consequently, research activities and clinical trials could present liability concerns, administrative inefficiencies, and increased costs. Similar liability concerns arise within the context of family members residing in different jurisdictions with contrasting genetic statutes. These examples highlight only two of the many potential conflicts that may arise from differing genetic legislation. Accordingly, the solution to avoiding a multitude of conflicting state proposals is the creation of a federal statute that clearly establishes and defines genetic property rights—while recognizing the need for statutory exceptions—and aggressively protects those rights by implementing and enforcing civil and criminal penalties. Anything less, and individuals are left with piecemeal protections of genetic rights that remain dependent upon jurisdictional limitations.

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[249] *Map of Clinical Trials*, ClinicalTrials.gov, http://clinicaltrials.gov/ct2/search/map/click?map.x=177&map.y=180 (last visited Mar. 3, 2013).