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GENETIC INFORMATION AND THIRD PARTY ACCESS TO INFORMATION: NEW JERSEY'S PIONEERING LEGISLATION AS A MODEL FOR FEDERAL PRIVACY PROTECTION OF GENETIC INFORMATION

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Our genes determine who we are: our physical characteristics, our predispositions to and fortifications from particular diseases, and, as many researchers now believe, our individual personality traits.1 Although there has been great progress in the field of genetics,2 only recently have

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   Genes are located in the nucleus of each of the one hundred thousand billion cells in the human body. See Janet A. Kobrin, Comment, Confidentiality of Genetic Information, 30 UCLA L. Rev. 1283, 1286 (1983). Genes are comprised of nucleic acids, Ribonucleic Acid and Deoxyribonucleic Acid, and are carried by chromosomes. See id. at 1286 n.23. Twenty-three pairs of chromosomes comprise the human genome, one set inherited from the mother and the other set from the father. See Richard A. Bornstein, Note, Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes, 4 J.L. & Pol'y 551, 555 & n.19 (1996); see also Suter, supra, at 1856 & n.12. Chromosome pairs contain the identical number and sequence of genes as its partner. See Kobrin, supra, at 1256. The genes carried within these chromosomes dictate a person's genetic structure and physical appearance. See Suter, supra, at 1856-57. Each body or human cell performs a specific function, thereby utilizing only a specific portion of the genetic information contained within its nucleus. See id. at 1856.

   Genetic defects can occur in several different ways. See Kobrin, supra, at 1287. For example, a genetic sequence transmitted from a parent that lacks the proper genetic coding can affect the chromosomes. See id. A mutation in a parent's gene can cause a single gene disorder, which scientists now know causes disorders like sickle cell anemia and cystic fibrosis. See id. The interaction of more than one miscoded gene can cause a polygenic disorder such as spina bifida. See id. at 1288-89. Finally, variations in number or structure of the chromosomes can cause a disorder such as Down's Syndrome. See id. at 1289.

   Scientific research indicates that more than 5,000 disorders are genetically related. See Bornstein, supra, at 557-58. Many disorders are caused by the genetic defects as described above, but others may result from a genetic predisposition to the disease. See id. An inherited genetic disorder carries a greater probability than a mere predisposition to genetic disease that the disease will develop. See id. at 558 n.31. Beyond genetic diseases, personality traits, such as alcoholism and shyness, have been linked to particular genes. See id. at 559 n.37.


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scientists begun to unravel the mystery of the human genome, which contains the genetic information of an individual's past and future.\textsuperscript{3} Answers to elusive questions and ties between human genetics and disease are today discovered on almost a daily basis.\textsuperscript{4} Modern research concentrates on sequencing the human genome and unraveling the genetic code to discover information about the causes of genetic defects and diseases.\textsuperscript{5}

\begin{footnotesize}
\begin{enumerate}
\item See Catherine M. Valerio Barrad, Comment, \textit{Genetic Information and Property Theory}, 87 NW. U. L. REV. 1037, 1041 n.16 (1993). In 1983, scientists knew the locations of only 606 genes; however, by 1993, the location of more than 5,000 more genes had been determined. \textit{See id.}

Discovering the location of individual genes is essential in developing a map of the human genome, which is the compilation of a person's total genetic information. \textit{See LEROY WALTERS & JULIE GAGE PALMER, THE ETHICS OF HUMAN GENE THERAPY 4 (1997); see also infra notes 18-23 and accompanying text (discussing the Human Genome Project, an attempt to decode the human genome).}

\item See Charles Craig, \textit{Genomes Progressing Rapidly, But to What End?}, BIOWORLD TODAY, May 22, 1997, available in LEXIS, Nexis Library, Curnews File (discussing the rapid advancements in human genomics science). From 1986 to 1992, sixteen disease genes were located, and in 1993 alone, seventeen disease genes were found. \textit{See id.; see also} Burk Burnett, Comment, \textit{Genetic Discrimination: Legislation Required to Keep Secrets}, 21 SETON HALL LEGIS. J. 502, 512 (1997) (stating that “[r]apid advancements in genetic technology compelled redefinition of many of the initial goals” of the human genome project). This evolving source of knowledge will most likely change the entire course of modern medicine. \textit{See id.; Snowe, supra note 2 (“Who could have predicted 20 years ago that scientists today could accurately identify the genes associated with cystic fibrosis, cancer, and Alzheimer’s disease? Today, scientists can, and as a result doctors are increasingly able to identify predispositions to certain diseases based on the results of genetic testing.”).}

Genetic “linkage studies” are helping to increase the pace of genetic information by allowing more individuals to learn about their predispositions to certain diseases. \textit{See Alexander Morgan Capron, \textit{Which Ills to Bear?: Reevaluating the “Threat” of Modern Genetics, 39 EMORY L.J. 665, 686-89 (1990) (discussing the current practices of genetic screening); see also} Bornstein, \textit{supra} note 1, at 558-59 (highlighting the utility of genetic testing as well as the recent advances in genetic science).

\item See Alexandra K. Glazier, \textit{Genetic Predispositions, Prophylactic Treatments and Private Health Insurance: Nothing Is Better Than a Good Pair of Genes}, 23 AM. J.L. & MED. 45, 45-46 (1997); \textit{see also} J. Madeleine Nash, \textit{To Know Your Own Fate}, TIME, Apr. 3, 1995, at 62 (commenting on the need for improved testing for Alzheimer’s disease because there is not yet a medical cure). Although currently more than four million people in the United States suffer from Alzheimer’s disease, scientists developed solid theories about the progression of the disease only recently. \textit{See id.} Alzheimer’s has no cure yet, and presently only one drug, Tacrine, is FDA approved for use against the disease. \textit{See id.} However, even Tacrine only temporarily eases symptoms and is not intended as a long-term treatment. \textit{See id.}

Scientists have also identified a genetic link to the cause of allergies, which presently affect 40 to 50 million Americans each year. \textit{See Charles W. Henderson, \textit{Allergy: Scientists}}
Through genetic sequencing techniques, scientists are deciphering patterns of genetic information contained within deoxyribonucleic acid (DNA), which encodes proteins and physical processes within the human body.\textsuperscript{6} Scientists already are able to explain the origin of a disease such as breast cancer, by identifying the specific genetic defect which causes it.\textsuperscript{7} A direct link between Alzheimer's disease and the Apo E4 gene has also recently been discovered.\textsuperscript{8} Most genetic defects, however, do not yet have cures, leaving individuals with difficult decisions about genetic testing, which could give them an early indication of an incurable disease.\textsuperscript{9}

\textit{Identify a Strong Genetic Link to Allergies, GENE THERAPY WKLY.,} Jan. 5, 1998, available in LEXIS, News Library, Curnews File. The genetic mutation found will make it easier to identify individuals susceptible to allergies and will eventually aid in the development of more effective treatments. \textit{See id.}

6. \textit{See James D. Watson, The Human Genome Project: Past, Present and Future,} 248 SCI. 44, 44 (1990). Once the DNA can be completely deciphered, scientists hope to gain a better understanding of the underpinnings of human existence. \textit{See id.} The Human Genome Project's ultimate goal is to facilitate scientific understanding of disease progression. \textit{See id.; see also James D. Watson & Robert Mullan Cook-Deegan, The Human Genome Project and International Health,} 263 JAMA 3322, 3322 (1990).

The main benefit of the Human Genome Project will be revolutionary knowledge about the diseases that affect humankind on a global level. \textit{See id.} Currently, however, medical technology cannot effectively detect disease or increased susceptibility to disease. \textit{See ASSESSING GENETIC RISKS} 1 (Lori B. Andrews et al. eds., 1994). Therefore, there is an increased pressure to broaden both the screening programs and genetic tests. \textit{See id. at 2.}

7. \textit{See Gina Kolata, Research Links Single Gene to Almost All Breast Cancers,} N.Y. TIMES, Nov. 3, 1995, at A1 (discussing the isolation of the breast cancer gene as a new discovery resource); \textit{see also Breast Cancer in Young Tied to Faulty Gene,} N.Y. TIMES, Jan. 18, 1996, at A19 (stating that a defect in the gene BRCA1 is linked to breast cancer in women with a family history of breast cancer, as well as, those women in their later twenties and early thirties without a family history of breast cancer); \textit{cf.} Barbara L. Weber et al., \textit{Familial Breast Cancer: Approaching the Isolation of a Susceptibility Gene,} 74 CANCER 1013, 1018 (1994) (commenting that the identification and isolation of the BRCA1 gene will soon lead to the widespread availability of screening, allowing for women to detect their risk of developing the disease).

Women who are genetically tested for breast cancer need to remain cautious because a negative result does not erase the possibility of developing breast cancer. \textit{See Charlene Laino, Should You Be Genetically Tested?} (visited Jan. 24, 1998) <http://www.msnbc.com/news/116977.asp>. According to the Chief of Clinical Genetic Services at Memorial Sloan-Kettering in New York, "a negative breast-cancer test result will give women a false sense of security." \textit{See id.} The reason for this is that the majority of breast cancers are not caused by a defective gene. \textit{See id.}


9. \textit{See Glazier, supra note 5, at 45 n.1} (explaining that early detection is deceptive because instead of prolonging life, it merely increases the length of time the individual is aware of the illness). Studies comparing the survival percentages from the time of diagno-
As technology advances, courts and legislatures lag behind, unprepared to answer the innumerable legal questions raised by genetic research. Although legislative proposals to regulate the use of genetic information and genetic testing have arisen in both the United States

sis have been conducted to determine the effectiveness of early detection. See id. The developing genetic technology can potentially confuse or harm the public by creating the belief that an early diagnosis eradicates disease. See William C. Black & H. Gilbert Welch, Advances in Diagnostic Imaging and Overestimations of Disease Prevalence and the Benefits of Therapy, 328 NEW ENG. J. MED. 1237, 1237, 1239-42 (1993). In reality, for most diseases, early detection garners little benefit. See id.

Studies on early genetic defect diagnosis have revealed a phenomenon known as “lead time bias.” See Glazier, supra note 5, at 45 n.1. Lead time bias denotes the fact that one's life span after early detection of disease is typically the same as if it were detected later in its progression; the individual usually will die at the same age. See id.; see also Black & Welch, supra, at 1239-42 (defining “lead-time bias” in genetic disease detection).

A recent Johns Hopkins University study showed “that doctors misinterpreted the genetic test results in nearly one-third of patients who were tested for a colon cancer gene.” See Charlene Laino, Protect Against Gene Discrimination—Group Calls for Patient Safeguards (visited Jan. 24, 1998) <http://www.msnbc.com/news/63631.asp>. The results of this study have led to calls for patient safeguards from the National Action Plan on Breast Cancer (NAPBC). See id. The NAPBC's position is that the medical community cannot wholly rely on information from the genetic researchers, but rather must participate in the synthesis of the information when forming their own understanding. See National Action Plan on Breast Cancer & American Society of Clinical Oncology, Hereditary Susceptibility to Breast and Ovarian Cancer: An Outline of the Basic Fundamental Knowledge Needed by All Health Care Professionals (visited Jan. 24, 1998) <http://www.napbc.org/napbc/lisedcurr.htm#potential>.

10. See Kathy L. Hudson et al., Genetic Discrimination and Health Insurance: An Urgent Need for Reform (visited Jan. 24, 1998) <http://www.edoc.com/aaas/policy/genetics.html>; see also Michael M.J. Lin, Note, Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act, 22 AM. J.L. & MED. 109, 110 (1996) (stating that courts and legislatures have failed to establish a national policy for regulating the use of genetic information and biological materials); cf. Kobrin, supra note 1, at 1284 (claiming that genetic screening legislation has not been successful and suggesting that courts have confused genetic information issues with the principles of tort law).
House of Representatives\textsuperscript{11} and the United States Senate,\textsuperscript{12} Congress has failed to enact any substantial legislation.\textsuperscript{13} The passage of the Health In-

\textsuperscript{11} See Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997); see also Why We Need H.R. 306 (on file with author) (finding that H.R. 306 was proposed in response to concerns that genetic information will be used to prevent people from obtaining health insurance). H.R. 306, proposed by Representative Slaughter, attempts to ensure that the public has access to their genetic information without encountering discrimination by their insurance companies. See Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997). This legislation is intended to close the legal loopholes remaining after the passage of the Kennedy-Kassenbaum health care reform bill. See Letter from John Edward Porter & Louise McIntosh Slaughter, Members of Congress, to Members of Congress (Sept. 12, 1996) (on file with author); see infra note 14 and accompanying text (discussing the shortcomings of the Kennedy-Kassenbaum bill). The following are among the provisions included in H.R. 306: (1) amendments to the Employee Retirement Income Security Act of 1974 (ERISA); (2) amendments to the Public Health Service Act; and (3) amendments to the Internal Revenue Code. See Why We Need H.R. 306, supra. The combined purpose of these amendments is to restrict health care plans from discriminating against those with genetic defects. See id.

According to the proposed legislation, federal law is necessary to protect this information because state laws can affect only state-regulated insurance companies, thereby excluding large, multi-state employers regulated under ERISA. See id. Because it only addresses genetic discrimination in health insurance, this legislation is not intended to impact clinical trials or clinical research. See id.; see also Bornstein, supra note 1, at 579 (noting that legislation protecting genetic information from insurers has not been enacted). On January 7, 1997, H.R. 306 was referred to the Commerce, Ways and Means Committee, and the Education in the Workforce Committee for consideration. See Bill Summary & Status for the 105th Congress (on file with author) [hereinafter H.R. 306 Bill Summary & Status]. As of the date of this article, H.R. 306 remains in committee, with hearings and mark-ups yet to be scheduled. See id. There have been six bills proposed to Congress which would protect this information from insurers, yet congressional action has not been forthcoming. See Bornstein, supra note 1, at 587.

\textsuperscript{12} See Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105th Cong. (1997). The Act is the pending Senate legislation which prohibits discrimination against individuals on the basis of genetic information. See id. This bill, introduced by Senator Snowe from Maine, has been read twice, as of the date of this article, and referred to the Committee on Labor and Human Resources. See Bill Summary & Status for the 105th Congress (visited Jan. 24, 1998) <http://thomas.loc.gov>. Little progress has been made on the legislation, as it has been pending in the Senate since the 104th Congress. See Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 1694, 104th Cong. (1996); see also Snowe, supra note 2 (urging the Senate Labor Committee to support the Senate bill, S. 1694).

\textsuperscript{13} See Genetic Information Nondiscrimination in Health Insurance Act of 1997; H.R. 306, 105th Cong. (1997); supra note 11; see also supra note 12 and accompanying text (discussing the status of proposed protective genetic legislation in the U.S. House and Senate). It is likely, however, that the 105th Congress could address the issue of human cloning, an issue that is closely related to the use of genetic information and testing, as early as 1998. See Human Cloning Research Prohibition Act, H.R. 922, 105th Cong. (1997).

Representative Ehlers (R-Mich.) introduced the Human Cloning Research Prohibition Act to the House of Representatives on March 5, 1997. See id. This bill prohibits the use
Insurance, Portability and Accountability Act in 1996, more commonly known as the Kennedy-Kassenbaum Bill, marks the indirect beginning of congressional involvement with genetic information regulation.\(^4\) Although this Act contains a provision which prohibits the classification of genetic predispositions as preexisting conditions by insurance companies, the provision is narrow in scope and neglects many of the present and developing concerns about the use and abuse of genetic information.\(^5\) Notably, the provision fails to address important issues, such as mandatory genetic testing by insurance companies used to determine eligibility for coverage and the maintenance of confidentiality of the results of genetic testing.\(^6\) The provision also leaves many avenues of genetic discrimination unprotected.\(^7\)

\(^{14}\) of federal funding for conducting or supporting research on the cloning of humans. \textit{See id.}

Presently, the bill has been referred to committees on Science and Commerce for hearings and revisions. \textit{See Bill Summary & Status for the 105th Congress} (visited Jan. 17, 1998) <http://thomas.loc.gov>.


Internationally, nineteen nations signed a treaty outlawing human cloning. \textit{See id.} A medical ethicist in Paris described human cloning as a “an insult to human rights.” \textit{See id.} In Britain, where sheep were cloned, leaders refused to sign the treaty claiming that it was too harsh. \textit{See id.} By contrast, Germany refused to sign the treaty claiming it was too lenient. \textit{See id.}

\(^{14}\) \textit{See The Health Coverage Availability and Affordability Act of 1996, H.R. 3103, 104th Cong., § 101 (1996) (prohibiting health care eligibility decisions to be based on health-status-related conditions and stating that genetic information cannot be considered in the absence of an actual diagnosis of the genetic disease).}

Many critics believe that this bill is insufficient because it is too limited. \textit{See Karen Rothenberg, Genetic Testing Raises Real Fears of Molecular Discrimination, THE TAMPA TRIBUNE-TIMES}, Aug. 3, 1997, at 1. The Health Insurance Portability and Accountability Act of 1996 prohibits insurers from using genetic information to establish rules for eligibility and it prevents the use of genetic information about a person’s predisposition to a disease as a basis for finding that the person has a preexisting condition. \textit{See id.} However, it does not prevent insurers from raising rates, excluding coverage altogether, or imposing unlimited caps on coverage. \textit{See id.} Moreover, the Act does nothing to prevent insurers from requiring genetic testing, nor does it protect the confidentiality of the test results. \textit{See id.}

\(^{15}\) \textit{See Rothenberg, supra note 14, at 1 (discussing the shortcomings of the Kennedy-Kassenbaum bill with respect to the use of genetic information regarding predisposition to disease).}

\(^{16}\) \textit{See id.}

\(^{17}\) \textit{See H.R. 3103, supra note 14 (attempting to “improve portability and continuity}
Congress has failed to produce legislation regulating genetic information; however, it currently funds a program to facilitate genetic research. The Human Genome Project is a three billion dollar federally funded, international program to decode the human genome. Sequencing the human genome is the primary goal of the project, yet mechanisms also must be created to help society assimilate the information obtained from such genetic research. In an attempt to develop
these assimilation mechanisms, the Human Genome Project's researchers analyze the practical effects of genetic information in our society.\textsuperscript{21} The ethical, legal, and social implications of the project's work are studied contemporaneously as the scientific data is synthesized.\textsuperscript{22} Monitoring the implications of sequencing the human genome is a necessary first step in preparing social institutions, such as health care providers and insurers, to use this information.\textsuperscript{23}

As opposed to Congress, traditionally courts have relied on the use of genetic information as a sentencing guideline in both civil and criminal litigation, providing a narrow body of case law on the issue.\textsuperscript{24} Genetic in-

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  \item Prohibit insurers from establishing rates based on genetic information;
  \item Prohibit insurers from making coverage decisions based on genetic information;
  \item Prohibit insurers from requesting or requiring collection or disclosure of genetic information;
  \item Prohibit any holder of genetic information (including insurance companies) from releasing that information without prior written consent from the individual.
\end{enumerate}

See id.

21. See Ethical, Legal and Social Implications (ELSI): High Priority Areas, (visited August 28, 1997) <http://www.nhgri.nih.gov/AboutNHGRI/Des/Elsi/high-priority.html#Research> (detailing the "high priority" areas for current ELSI research). There are several areas of concern include: (1) promoting privacy and fairness in the use of genetic information; (2) education of health care professionals in the use of genetic technologies; (3) targeting issues surrounding genetic research such as informed consent; and (4) promoting public and professional education. See id.

22. See id. Mapping the human genome raises questions as to how medicine will be practiced in the future and how to balance the immense capability of reading the human body while maintaining autonomous choice and protecting a "genetically bare" and vulnerable human body. See John C. Fletcher & Dorothy C. Wertz, Ethics, Law, and Medical Genetics: After the Human Genome Is Mapped, 39 EMORY L.J. 747, 747-48 (1990).

23. See Coble, supra note 20 (listing the American Medical Association's recommendations as to the means by which state and federal policy makers should protect individuals against genetic discrimination).


In DNA forensic analysis, portions of the DNA structure take different forms in different individuals creating areas called polymorphism. See Jakobetz, 955 F.2d at 791. Polymorphisms are significant in DNA forensic testing because, by focusing on specific portions of them, scientists establish a percentage of individuals who are likely to have the same DNA structure. See id. Scientists unravel the DNA structure, thereby breaking it into shorter fragments, and eventually splitting into two single strands of DNA. See id. at 792. A single strand is attracted to other complimentary strands, which then gravitate toward each other and connect to form a double helix model. See id. This process is called "hybridization." See id. A genetic probe is constructed by scientists during hybridization, which seeks out and locks onto complimentary strands, thereby locating the polymorphic
Genetic information also has been used in criminal law as a mitigating factor in determining punishment. Courts have viewed defendants genetically predisposed to commit crime as purportedly lacking free will. Thus, some courts take a defendant’s genetic make-up into account during sentencing.

Outside of the sentencing proceedings, courts have provided little guidance on the use or regulation of genetic information. Modern case strands of DNA. Once this process is complete, the FBI calculates the statistical significance of a match between two DNA profiles using tools from the field of human population genetics. This technique has been deemed reliable evidence in judicial proceedings. See id. at 799-800 (finding forensic analysis acceptable where it is shown to be reliable).

25. See Nelkin, supra note 24, at 2120. In Daubert v. Merrell Dow Pharmaceuticals Inc., the United States Supreme Court dealt with admissibility standards regarding the use of scientific information in the courtroom. 509 U.S. 579 (1993). In Daubert, the Court defined some indicators of scientific reliability, including whether the evidence has been tested, subjected to peer review and publication, derived through a set of standards with a known error rate, and is generally accepted in the scientific community. See id. at 593-94. In the courtroom, genetic information is typically used for DNA forensic testing; however, its uses are increasing to family relationships and criminal responsibility. See Nelkin, supra note 24, at 2120.

In child custody cases, courts have shifted from focusing on “the best interests of the child” to a reliance on genetic information to dispute the importance of genetic and emotional bonds. See id. (exemplifying the use of genetic information in child custody disputes and noting the inconsistency of judicial decisions on the issue). Instead of relying solely on testimony establishing that one parent provides a better home for the child than the other, courts now also consider genetic testimony indicating personality traits. See id. at 2020-21.

26. See Nelkin, supra note 24, at 2121 (stating that genetic information is used as guidance in decisions concerning responsibility and punishment). Genetic information is used as the basis for a defense and in order to mitigate punishment under the claim that genetic predispositions preclude free will. See id. at 2021. For example, Positron Emission Tomography (PET) scans have been allowed in court as a way to determine sanity. See Cerisse Anderson, Brain Scan Deemed Admissible at Trial: Guilty Plea Follows Insanity Defense Ruling, 208 N.Y.L.J. 1 (1992) (recounting the trial of a man accused of strangling his wife and throwing her out the window of their twelfth floor apartment).

27. See Nelkin, supra note 24, at 2120. Genetic information often guides criminal cases because the growing body of research has suggested connections between genetic predisposition and violence. See id. at 2123. Therefore, genetic information provides a background for decisions regarding responsibility and punishment. See id. at 2120. A genetic explanation for behavior has relieved defendants from a degree of personal responsibility for their actions. See id. at 2121-22 (recounting a disbarment proceeding in which the court accepted a genetic predisposition to alcoholism defense as an excuse for misappropriation of funds and mitigated punishment based on the genetic predisposition).

28. See Lin, supra note 10, at 110 (noting that very few cases address property rights in a person’s genetic material); see also Bertram I. Rowland, Legal Implications of Letter Licenses for Biotechnology, 1 HIGH TECH. L.J. 99, 129 (1986) (stating that commerce related to biological material will proceed cautiously due to the legal instability in this area).
law does not address the concerns of access to and discrimination in the use of genetic information.\textsuperscript{29} A significant case related to the use of genetic information is \textit{Moore v. Regents of the University of California},\textsuperscript{30} where the California Supreme Court, in denying a claim for conversion of bodily tissue, held that cells were abandoned once they were removed from the plaintiff's body.\textsuperscript{31} There is little case law that directly addresses genetic information.\textsuperscript{32} However, in \textit{Mayfield v. Dalton},\textsuperscript{33} the Ninth circuit was asked to determine the constitutionality of a requirement that United States marines provide blood and tissue samples to the federal government for future DNA testing.\textsuperscript{34} The District Court below granted the government's Motion for Summary Judgment on the theory that stored DNA would help to identify a soldier's remains.\textsuperscript{35} The appellate court denied the appeal as moot and both plaintiffs were honorably discharged.\textsuperscript{36}

Apart from the legislative and judicial forums, much of the apprehension regarding the use of genetic information arises from possible discrimination fears, such as higher insurance premiums, increased risk of employment termination, and public disclosure of genetic information.\textsuperscript{37}

\begin{thebibliography}{99}
\bibitem{29} See Lin, \textit{supra} note 10, at 110.
\bibitem{30} 793 P.2d 479 (Cal. 1990).
\bibitem{31} See \textit{id}. at 488-89. John Moore, suffering from hairy cell leukemia, underwent surgery for the removal of his enlarged spleen. See \textit{id}. at 480-81. Moore recovered from the cancer, but continued to return for evaluations at the request of his doctor, who used Moore’s tissue, blood, bone marrow, and other samples in order to continue research on his cancer. See \textit{id}. at 481. A cell line, worth $3.01 billion, was established from the use of Moore’s samples and the Regents of the University of California obtained a patent. See \textit{id}. at 481-82. Moore brought suit against the doctors and the University claiming unlawful conversion of bodily property and lack of informed consent. See \textit{id}. at 482. The California Supreme Court ruled against Moore on the ground that allowing him to retain an interest in the cells would hinder scientific research. See \textit{id}. at 494-95.
\bibitem{32} See Lin, \textit{supra} note 10, at 110.
\bibitem{33} 109 F.3d 1423 (9th Cir. 1997).
\bibitem{34} See \textit{id}. at 1424; see also Lori Andrews, \textit{Body Science}, 83 A.B.A. J. 44, 46 (1997) (stating that the Marines argued that the mandatory testing constituted a Fourth Amendment search and seizure violation); \textit{Concerns About Privacy of Military Specimens Are Addressed, Court Says}, \textit{BIOTECHNOLOGY}, Apr. 11, 1997, available in LEXIS, Nexis Library, Curnews File (highlighting the 9th circuit opinion in Mayfield and stating that the Marines feared that the military would abuse their genetic information);
\bibitem{35} See \textit{Mayfield v. Dalton}, 109 F.3d 1423, 1425 (9th Cir. 1997).
\bibitem{36} See \textit{id}.
\bibitem{37} See \textit{Why We Need H.R. 306, supra} note 11; see also Leslie P. Francis, \textit{Recent Developments in Genetic Diagnosis: Some Ethical and Legal Implications}, 1986 \textit{UTAH L. REV}. 483, 488 (discussing concerns about abuse of genetic information by employers, insurers, and the health care system); Steven Brostoff, \textit{Clinton Calls for Ban on Using Genetic Test Data; Health Insurance Groups Differ in Reaction to President Clinton's Proposal}, \textit{NATIONAL UNDERWRITER LIFE & HEALTH-FINANCIAL SERVICES ED.}, July 21,
Genetic discrimination is defined as discrimination against an individual based solely on the differences between the "defective" genetic composition of the individual and the perceived "normal" gene. An informal, 1996 study determined that nearly half of the respondents suffering from various forms of genetic disease experienced some form of genetic discrimination. Health care insurance and employment discrimination are among the immediate concerns related to the expanded knowledge of genetic information; however, the list has evolved to now include blanket societal discrimination. Psychological stress caused by the option of genetic testing and the growing potential for familial conflicts are other effects of the advancing technology.

Without federal or judicial guidance, state legislatures have taken the initiative by protecting the use of genetic information and genetic testing. Unfortunately, most state legislation fails to address both present and potential legal ramifications, thereby increasing the need for national

1997, at 3 (recounting statements of President Clinton calling for legislation barring health insurers from using genetic information to deny coverage or increase premiums). The Health Insurance Association of America opposed Clinton's plan because it would adversely affect healthy individuals by increasing rates across the board. See id. The Association's president, Karen Ignagni, stated, "it is critically important to guarantee that health care services for people with genetic illnesses are effectively coordinated and that those providing health care to these individuals have the information needed for the highest quality of care." Id; see also Patricia King, The Past as Prologue: Race, Class and Gene Discrimination, GENE MAPPING: USING LAW AND ETHICS AS GUIDES 94, 95-108 (George J. Annas & Sherman Elias eds., 1992) (analyzing the correlation between race and genetic discrimination). In order for all of society to benefit from emerging genetic information, there must be a massive overhaul of our existing health care system and the "policy implications of differences among human beings" must be taken into account. Id. at 107.


39. See Rosemary Orthmann, Study Reveals Cases of Genetic Bias, LAW & POLICY REPORTER, June 1996, at 85. Four genetic disorders, were the focus of this study to which roughly 455 people responded. See id. The most common sources of discrimination: health and life insurance companies. See id.; see also Snowe, supra note 2; Poll Shows Dark Side of Genetic Research, HOUSTON CHRON., Oct. 25, 1996, at A5.

40. See Hudson, supra note 10 (giving examples of health care and employment discrimination, as well as societal discrimination).

41. See Suter, supra note 1, at 1855-56 (discussing the psychological effects of genetic testing).

legislation. State legislation also exemplifies the increasing confusion concerning the level of constitutional protection genetic information should receive. Specifically, the controversy involves the issue of whether genetic information is or should be classified as a privacy right or a property right.

The Genetic Privacy Act of 1996, passed by the New Jersey Legislature, is an exception to the general inadequacy of state legislation. Commentators have heralded the New Jersey legislation as one of the broadest state measures that offers protection on a variety of levels and acknowledges the political, moral, and social significance of genetic information. Due to its comprehensiveness, New Jersey's legislation has also been labeled by commentators as a model for other states and the nation.

This Comment examines the classification of genetic information as a property and privacy right. Specifically, this Comment provides a practical analysis of New Jersey's Genetic Privacy Act to determine whether it is a model for a national policy. Part I examines the abbreviated legislative history of the Act, focusing on the deletion of property rights in genetic information. Part I also demonstrates the breadth of New Jersey's statute by way of illustrations of how this information is misused. Part II analyzes the competing property and privacy interests involved in access to genetic information, focusing on the ramifications of these interests in a national policy. This Comment then suggests that the classification of genetic information as a property or privacy right should not be the focus of a national policy. Rather, it suggests that Congress should enact leg-

43. See Philip Reilly, New Jersey Genetic Privacy Act, 1 THE GENE LETTER 1, ¶3 (July 1, 1996) <http://www.geneletter.org/0796/njprivacyact.html> (stating that the majority of law concerning genetic testing and information focuses on preventing health insurance discrimination and does not include protection against other forms of discrimination).

44. See infra notes 83-89 and accompanying text (discussing the dilemma facing state legislatures as they attempt to protect genetic information while maintaining a high level of scientific research).

45. 1996 N.J. ch. 126; §17B:30-12.

46. See Burnett, supra note 4, at 525-26; see also infra notes 82-89 and accompanying text (discussing the breadth of the New Jersey statute in relation to more restrictive statutes enacted in other states).

47. See New Jersey: Governor Signs Genetic Privacy Act, HEALTH LINE, Nov. 20, 1996, available in LEXIS, Nexis Library, Curnews File; see also Burnett, supra note 4, at 525 (claiming that New Jersey's Genetic Privacy Act is "one of the most comprehensive measures in protecting against genetic discrimination in the nation"). New Jersey's legislation surpasses protective bills pending in other states because of its heightened standards. See Burnett, supra note 4, at 526 (footnote omitted).

48. See supra note 47 (describing the comprehensive nature of the legislation).
islation that adequately addresses the complexity and uniqueness of genetic information without limiting its focus to classifying the nature of the right. This Comment also asserts that issues surrounding genetic information transcend science and medicine, and travel to the core of what it means to be human. This Comment concludes that these issues are politically, ethically, morally, and practically significant and should not be addressed piecemeal by the courts or indiscriminately by state legislatures.

I. GENETIC DISCRIMINATION

Controlling the use of genetic information is essential because genetic discrimination affects all aspects of society, revealing fundamental components of what differentiates one human from another and thereby opening the door to numerous forms of discrimination. The most obvious and perhaps the most active areas of discrimination are insurance coverage and employment. Social discrimination potentially may result from unfair insurance and employment practices. As research progresses, the potential for discrimination similarly heightens.

A. Insurance Discrimination

Presently, insurance companies are free to charge higher premiums or even to cancel coverage for individuals with preexisting health conditions

49. See Why We Need H.R. 306, supra note 11; Phil Bereano, Don’t Take Liberties with Our Genes, THE SEATTLE TIMES, July 17, 1997, at B5 (discussing the effects of the public “discourse” on genetic information). Science and technology are not “value-neutral.” Id. It is feared that “predictability will replace a tolerance for natural variation and diversity.” See id. Further, society’s growing fascination with genetic research and human health has the potential to cause the neglect of other health factors. See id. For example, a connection between environmental factors and cancers had been established. See id. However, if cancer becomes recognized as a purely genetic disease, efforts to improve the environment may be completely disregarded. See id. Social conditions such as poverty, which contribute to high mortality rates, will also become less important as people are faulted for having defective genes. See id.

50. See Allen, supra note 18 (naming employment discrimination and health insurance barriers as outgrowths of human genetic research); see also infra notes 53-66 and accompanying text (exploring the health care and employment issues surrounding the use of genetic information).

51. See King, supra note 37, at 95 (expressing skepticism as to whether the information obtained from the Human Genome Project will be beneficial to all members of our society). As correlations between genetic diseases and race are discovered, there is a possibility that racial discrimination and stereotyping will increase. See id.; see also infra notes 67-76 and accompanying text (elaborating on the growing fear of societal discrimination resulting from the abuse of genetic information).

52. See King, supra note 37, at 95.
as a “cost-control” measure. In the absence of laws governing the use of genetic testing, and making mandatory testing illegal, cost-control measures may soon impact those inflicted with genetic illnesses or with histories of genetic problems. Stories about parents who are unable to obtain insurance for their children because of a hereditary genetic defect and insurance companies threatening to cancel insurance based on the results of prenatal testing are surfacing with great frequency. Eventually, the entire population will have access to their genetic information and as a result will be sorted into a particular genetic category. Since no individual is genetically flawless, every person will be subjected to a

53. See Glazier, supra note 5, at 46 (stating that it is common practice for private health insurance companies to refuse coverage for preexisting conditions).

The definition of “preexisting condition” has been expanded by state and federal law to include conditions for which there is no affirmative diagnosis. See id. at 60. This insurance exclusion has frequently been litigated in cases of workers’ compensation claims. See id. at 59. This litigation has created a trend toward expanding the definition of “preexisting condition.” See id. For instance, courts have held that even preexisting illnesses which are diagnosed after insurance policies become effective are excluded from coverage. See Kirk v. Provident Life and Accident Ins. Co., 942 F.2d 504, 508 (8th Cir. 1991).

54. See Catherine Arnst, Concerns Grow About Insurance Bias Based On Genetic Testing, REUTERS NORTH AMERICAN WIRE, Sept. 11, 1991, available in LEXIS, Nexis Library, Curnews File (reporting that larger companies in the United States and Europe presently eliminate job applicants whose genetic screens indicate a high risk for disease). Scientists are concerned that expectant parents will be forced to allocate risks when they learn that an unborn child has a genetic predisposition for disease. See id. Another fear is that coverage will be denied before pregnancy on the basis of the parents’ genetic testing. See id.

55. See Bornstein, supra note 1, at 566. A woman with a family history of Huntington’s disease was unable to obtain health insurance for herself or her children until she tested negative for the gene. See id. The protein HAP1 is thought to interact with the Huntington’s disease gene which triggers the reactions that kills brain cells. See id. Huntington’s disease results in brain atrophy, eventually causing loss of bodily functions and ultimate death. See id. at 559 n.37.

56. See Ted Peters, In Search of the Perfect Child: Genetic Testing and Selective Abortion, THE CHRISTIAN CENTURY, Oct. 30, 1996, at 1034, 1035. A couple’s insurance company threatened to withdraw coverage for their children if they did not abort their fetus, whose prenatal testing divulged the gene-causing cystic fibrosis. See id. Cystic Fibrosis is a single-gene disorder caused by a mutation in a parent’s gene and which is characterized by chronic pulmonary disease, pancreatic insufficiency, and elevated levels of sodium and chloride in sweat. See Jan L. Breslow et al., Distinguishing Homozygous and Heterozygous Cystic Fibrosis Fibroblasts from Normal Cells by Differences in Sodium Transport, 304 NEW ENG. J. MED. 1, 1 (1981).

57. See Paul Nuki, Insurers Fight for Access to Results of Genetic Tests, SUNDAY TIMES, Sept. 5, 1993, LEXIS, Nexis Library, curnews file (fearing that as genetic testing becomes more accessible, insurance companies will conditionally “insist” that everyone undergo testing before obtaining coverage). Mandating genetic testing as a prerequisite to obtaining insurance would create risk groups into which the population would be placed: a “genetic super-class” would be at one extreme with a “genetic sub-group” at the other. Id.
mandatory genetic test to determine where the imperfections lie. In-
surance premiums and coverage will then be based on the degree of any
flaw, leaving individuals at the mercy of their own genetic information.

B. Employment Discrimination

Advancing genetic technology has provided certain benefits to em-
ployees, which at the same time has increased the potential for employ-
ment discrimination. Although employers have both a right and re-
sponsibility to maintain a safe work environment, the development of
genetic testing raises issues about the scope of information to which em-
ployers are entitled, confidentiality, and third-party access to informa-
tion. Concerns about insurance coverage and increased premiums al-

58. See id.; see also Recommendations on Genetic Information and the Workplace: Ethical, Legal and Social Implications of Human Genome Research, (visited Feb. 2, 1998) http://www.napbc.org/napbc/recommend.htm> (discussing how the ability to identify genetic disease raises concerns that the information will be used to discriminate against individuals). Accordingly, comprehensive legislation should be adopted to protect all sensitive medical information. See id.; see also Arnst, supra note 54 (discussing the use of genetic testing by employers to weed out job applicants); Bereano, supra note 49, at B5 (discussing the downside of the rapid pace of genetic testing, including increased employment and insurance discrimination). See generally Rothenberg, supra note 14, at 1 (noting specific instances of genetic discrimination and stating that the public concern about the exploitation of testing results is legitimate).

59. See Nuki, supra note 57 (discussing the potential use of genetic information to classify people for insurance purposes).

60. See Lori B. Andrews & Ami S. Jaeger, Confidentiality of Genetic Information in the Workplace, 17 AM. J.L. & MED. 75, 75-76 (1991). Benefits such as the ability to avoid jobs which may trigger the onset of a genetic illness and the knowledge of abnormal chromosomes resulting from exposure to toxins such as asbestos are realized by employees through genetic testing. See id. at 76. Many states have laws granting employees access to records about exposure to toxins, and several mandate that the employer specifically notify the employee if the exposure exceeds threshold levels. See, e.g., N.J. STAT. ANN. § 34:6A-40(c) (West Supp. 1997); N.C. GEN. STAT. § 95-143(c) (1993); W.VA. CODE § 21-3A-8(c)(3)(1996). Among those interested in the results of genetic testing in the workplace include occupational health care providers, managers, other employees, unions, and the government. See Andrews & Jaeger, supra, at 76; see also Poll Shows Dark Side of Genetic Research, supra note 39, at A5.

61. See CONGRESS OF THE UNITED STATES, OFFICE OF TECHNOLOGY ASSESSMENT (OTA), GENETIC MONITORING AND SCREENING IN THE WORKPLACE 3 (1990) (reporting that employers historically have been allowed to require medical testing to ensure a safe work environment). Recent advances in genetic technology expand an employer's ability to medically monitor employees. See id. at 55-136 (discussing various medical procedures now available to employers). A 1989 OTA study determined that out of 1500 United States companies surveyed, one in twenty conducted some form of genetic monitoring or screening within the prior nineteen years. See id. at 22-23.

Confidentiality issues in the workplace involve managing the interests of those at risk. See Andrews & Jaeger, supra note 60, at 95-96. For instance, one question employers are struggling with is whether or not employees potentially at risk for an adverse genetic con-
ready interplay with employment decisions. For instance, if a prospective employee’s genetic testing reveals a condition which may require extensive health care coverage, an employer may not hire that individual for fear that insurance will no longer be affordable. Those individuals suffering from HIV infection or full-blown AIDS have experienced this conflict. Employers, citing the risk of increased health care premiums, have been cautious about hiring or maintaining employees who suffer from the HIV infection or AIDS.

Although many states have attempted to legislate the health care issue, many employers and health care programs are exempt from such statutory measures. The Employee Retirement Income Security Act of 1974 preempts state regulation of many health care plans, thus, state legislation is less effective in preventing genetic discrimination.

C. Societal Discrimination

Analogous to African Americans who suffer from sickle cell anemia and persons who suffer from HIV infection or AIDS, societal discrimination also has become a determinant for those seeking to regulate the use of genetic information. All individuals potentially carry a genetic defect have the right to know the results of another employee’s genetic testing. See id. at 95.

62. See Rothenberg, supra note 14, at 1. States have passed legislation prohibiting insurers from genetic discrimination; however, ERISA exempts self-funded employer plans from these state laws. See id.; see also Employee Retirement Income Security Act of 1974 (ERISA), 29 U.S.C. § 1144 (b)(2) (1994). Therefore, many employees remain unprotected and open to insurance discrimination based on their genetic composition. See Rothenberg, supra note 14, at 1.

63. See Gerald M. Oppenheimer & Robert A. Padgug, AIDS: The Risk to Insurers, the Threat to Equity, 16 HASTINGS CTR. REP. 18, 21 (1986). Since the inception of the AIDS epidemic, employers have often attempted to fire employees with AIDS or to exclude coverage of AIDS from their insurance policies. See id.

64. See id.

65. See Rothenberg, supra note 14, at 1 (discussing the affects of ERISA on state regulation efforts).

66. See id.

67. See Kobrin, supra note 1, at 1287 n.29 (stating that one in every 500 black children is born with sickle cell disease). Sickle cell anemia occurs when the hemoglobin forms an “S” shape at the onset of reduced oxygen levels in the blood stream. See id. The cells do not flow throughout the bloodstream like normal cells; therefore “sickling” occurs, eventually causing early death. See id. During the 1970s, there was a surge of screening legislation for sickle cell anemia which was poorly drafted and ineffective, leading to misuse of the information and discrimination. See id. at 1292.

68. See Fletcher & Wertz, supra note 22, at 748-49 (hypothesizing that, considering the discrimination evidenced against those suffering from HIV, AIDS, and various other disorders, society will not trust geneticists to use this information responsibly). “The dangers of isolation, loss of insurance, educational, and job opportunities for persons diag-
of some form, so unlike other diseases that affect certain races or that are theoretically preventable, genetic defects are beyond an individual's control. Therefore, genetic discrimination has the potential to affect the entire population at one time or another.

In the 1970s, legislative efforts to mandate screening for sickle cell anemia failed because of scientifically inaccurate programs, lack of genetic counseling, and lack of confidentiality provisions. As a result, employment and insurance discrimination was rampant, as was abuse of the private information. Societal discrimination, partially founded in racial discrimination, also increased. These legislative inadequacies cannot be forgotten when regulating the use of genetic information in order to avoid repeating past mistakes.

Psychological stress related to family histories of genetic diseases or to the decision of whether to undergo testing for such diseases is rapidly surfacing. Simultaneously, the potential for familial conflict is also growing as disputes as to whether immediate or extended family have the

69. See Nuki, supra note 57 (asserting that the entire population should be concerned with the progress of genetic research).

70. See id.; see also Peters, supra note 56, at 1034 (stating that those who stand to benefit from genetic testing will be the ones who suffer from the worst consequences, such as increased insurance premiums. See Poll Shows Dark Side of Genetic Research, supra note 39, at A5 (discussing research which indicates that those who suffer from genetic defects are discriminated against on a variety of levels).


72. See id. at 72-73.

73. See id. at 67. During the 1970s, airlines grounded black employees indiscriminately due to fears that a "sickling crisis" might occur if the plane depressurized. See id. at 74. In addition, insurance companies charged higher premiums without any reliance on mortality rates. See Rothenberg, supra note 14, at 1.

74. See Reilly, supra note 71.

75. See Richard M. Glass, AAAS Conference Explores Ethical Aspects of Large Pedigree Genetic Research, 267 JAMA 2158 (1992). Carrying a defective gene affects the individual physically and psychologically. See id. at 2159. It affects one's perception of oneself and one's relationship to family and the world. See id.; see also Rothenberg, supra note 14, at 1 (recounting the story of a forty-year-old woman with a history of breast cancer who underwent genetic testing only to lose her employer-based health insurance and her job after testing positive for the BRAC1 gene). People are afraid because genetic testing will not only reveal their predispositions to disease, but because it will also adversely affect the future of their families. See id.
right to know about potential genetic defects remain unresolved.  

II. NEW JERSEY'S GENETIC PRIVACY ACT

A. The Proposed Genetic Privacy Act: New Jersey's Expansive Legislation

New Jersey's genetic legislation, although largely focused on health insurance and employment discrimination, addresses some of the greater social ramifications of the increased use of genetic information by creating a privacy right in an individual's genetic information.  

This legislation has the potential to influence a national policy on genetic information because of its breadth and because of the debate over whether this information should be protected through a property or privacy right.  

The Genetic Privacy Act was introduced to the New Jersey legislature on February 15, 1996.  

The legislation was to provide a comprehensive regulatory framework to protect against unwarranted genetic testing, genetically based discrimination, and disclosure of genetic information without consent.  

An express property right in genetic information was established as the vehicle of protection and the use of genetic information was left to the discretion of the individual.

76. See Suter, supra note 1, at 1856 (arguing that mandatory disclosure of genetic information should be banned and that mandatory third-party access to genetic information is unconstitutional). Regarding familial conflicts, the person who has been tested may want to “avoid harm” from disclosure and keep the results private while a relative may want to know the results in order to prevent harm to herself or her family. See id. at 1855. “When genetic testing of one person can benefit another family member, privacy and autonomy interests of the former may collide with the relative’s interests in protecting her health or planning her future.” Id.  

77. See 1996 N.J. Sess. Law Serv. 126; see also infra notes 79-82 (discussing the purposes and various provisions of this proposed legislation).  

78. See Reilly, supra note 43, ¶¶ 2-4, 7-8 (discussing the scope of New Jersey's legislation in comparison with legislation passed by other states); see also Lin, supra note 10, at 133-34 (concluding that a federal property right should be conferred in DNA); cf. Suter, supra note 1, at 1907-08 (concluding that an individual's genetic information is protected by his or her constitutional privacy and autonomy interests).  


80. See Memorandum from Assemblywoman Rose Heck to Marvin Jiggetts (Oct. 26, 1995) [hereinafter Heck Memorandum] (noting that the New Jersey bill was based on similar legislation enacted in California, Colorado, Minnesota, New Hampshire, Ohio, Oregon, and Wisconsin).  

81. See Senate Health Committee Statement to Senate Committee Substitute for Senate, Nos. 695 and 854, 207th Legis. Reg. Sess. 1 (N.J. 1996) [hereinafter Senate Committee Substitute] (noting "an individual's genetic information is the property of that individual and prohibits any person from retaining an individuals genetic information without
lature passed the Genetic Privacy Act and sent it to Governor Whitman in June of 1996.82

Unlike statutes passed in other states,83 the New Jersey Genetic Privacy Act is landmark legislation due to its comprehensive coverage of issues raised by the progress of genetic research.84 Many state statutes, such as those enacted in Oregon, California, and New York, provide extensive protection of genetic information but are limited in their scope to insurance companies and employers.85 Although the potential for discrimination permeates our society, these state legislatures did not protect society from the use of genetic information, but instead narrowly focused on issues of genetic testing in health care insurance and employment.86 State legislatures, however, are not alone because legislation proposed in

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82. See id.; cf. Why We Need H.R. 306, supra note 11 (stating that the intent of the proposed Genetic Nondiscrimination in Health Insurance Act of 1997 is to ensure access to genetic information without the fear of discrimination on behalf of insurance companies).

83. See supra note 42 (citing genetic legislation which has been enacted in many states, including New Jersey).

84. See Burnett, supra note 4, at 526 (noting the magnitude of New Jersey's Genetic Privacy law); see also Reilly, supra note 43, at ¶ 3 (discussing the limited focus of genetic legislation passed before the New Jersey law).

85. See CAL CIV CODE § 56.17 (West Supp. 1997); CAL HEALTH AND SAFETY CODE § 1374.7 (West 1990); CAL. INS. CODE § 10140(c) (West Supp. 1998); CAL INS CODE § 10123.3, (West 1993); N.Y. LAW § 296 (McKinney Supp. 1997-98) (prohibiting employers, labor organizations, and licensing agencies from requesting genetic tests or the disclosure of test results from employees or on job applications); OR. REV. STAT. § 659.036 (1995) (establishing a property right in genetic information and limiting the circumstances in which third parties may obtain an individual's genetic information); see also GA. CODE ANN. §§ 33-54-1-6 (1997); OHIO REV. CODE ANN. § 1751.64 (Anderson 1997); WIS. STAT. ANN. § 111.372 (West 1997).

Although the property right was omitted from New Jersey's legislation, interest groups such as the Pharmaceutical Research and Manufacturer's Association (PhRMA) are still concerned because the Oregon law creates a precedent for protecting genetic information with a property right. See Whitman Signs Comprehensive Genetic Privacy and Anti-Discrimination Bill, HEALTH LEGISLATION & REGULATION: WASHINGTON POLITICS, POLICIES & REGULATION, Nov. 27, 1996, at 2 [hereinafter Whitman Signs Bill]. PhRMA is concerned with the potential consequences this will have on scientific research. See id.

86. See Andrews, supra note 34, at 47. There is a substantial difference between carrying the gene for a genetic disease and actually developing the disease. See id. at 48. Modern research has enabled scientists to more efficiently determine who carries the genes for specific traits; however, the mere knowledge that a child possesses the trait for a learning disability does not mean that the disability will manifest itself. See id. But its consequences may be placing "normal" children into specialized learning in anticipation of a disorder from which the child will never suffer. See id. The ramifications of this newfound knowledge transcend science and medicine, but it does not appear as if the legislatures or courts are prepared to realize this. See id. at 48-49.
the United States House of Representatives also focused solely on issues related to health care insurance and employment.\textsuperscript{87}

The proposed New Jersey Legislation broadens the protection available to individuals with genetic abnormalities by amending the State's antidiscrimination laws.\textsuperscript{88} New Jersey's legislative purpose in regulating genetic information was to protect individuals with genetic diseases and those at risk of inheriting genetic diseases from general societal discrimination as well as from insurance and employment discrimination.\textsuperscript{89}

\textbf{B. Conflicting Perspectives on the Legal Classification of Genetic Information: The Conditional Veto of the Genetic Privacy Act}

New Jersey's proposed Genetic Privacy Act was never enacted into law.\textsuperscript{90} On September 19, 1996, Governor Christine Todd Whitman conditionally vetoed the Act.\textsuperscript{91} Specifically, Governor Whitman redacted the provision creating a property right in genetic information, replacing it with a privacy right.\textsuperscript{92}

A property right in genetic information establishes the individual's ownership of the material.\textsuperscript{93} Under American property law, an owner-
ship interest is comprised of a "bundle of rights" which sets apart an individual's right to the material from anyone else's. Property law has developed from the case law of the individual states. Therefore, although classifying an object as "property" implies the owner has autonomous control over the object, the legal definition recognizes restrictions on a person's actions with regard to their property.

A privacy right, in comparison, attaches substantive due process rights to the information which triggers heightened judicial scrutiny and requires the state to proffer a compelling interest to obtain the information. Moreover, the United States Supreme Court has recognized the right to privacy as a fundamental right that is essential to individual liberty. Privacy rights thus hold a more constitutionally stable position than do property rights.

The establishment of a property right in genetic information was rejected by Governor Whitman because of its potentially negative impact on scientific research. Governor Whitman opined that the goals of the legislation, protecting privacy and preventing discrimination, did not require a property right protection. Governor Whitman's other concerns focused on research; creating a property right, according to Governor

94. See First Charter Land Corp. v. Fitzgerald, 643 F.2d 1011, 1014-15 (4th Cir. 1981) (stating that property refers to the actual physical object and the various incorporeal ownership rights, such as the right to possess and the right to alienate); see also infra notes 136-50 and accompanying text (discussing limitations on property rights).


97. See Barrad, supra note 3, at 1049 (explaining the legal nature of property rights in American law and specifically discussing the alienability of property).

98. See NOWAK & ROTUNDA, supra note 95, § 11.7 (analyzing the development and classification of fundamental rights in constitutional law).

99. Compare Governor Vetoes, supra note 90, at 160 (establishing the bases upon which Governor Whitman vetoed the initial version of the Genetic Privacy Act), with Moore v. Regents of the Univ. of Cal., 793 P.2d 479, 494 (Cal. 1990) (holding that Moore's conversion of bodily tissue claim on the basis that he abandoned his interest during the surgery was disallowed, and to hold otherwise would significantly impede scientific research).

100. See Senate Committee Substitute, supra note 81 (relaying Governor Whitman's opinion to the state legislature that "[t]he bill is designed to avoid [t]he danger [of improper harm to those with genetic defects] by clarifying privacy rights and prohibiting discrimination based on information obtained through genetic testing"). Governor Whitman continued to convey her concern that the original drafting of the bill would create further problems with harmful consequences, such as the "establishment of a new property right is a fundamental change from current practice that will have unintended but troubling consequences for research." Id.
Whitman, would drastically hinder research efforts by forcing scientists to obtain permission to use genetic information and complicate research by creating royalty issues for those whose genetic information led to significant discoveries. If an individual owns their genetic material in the same manner as any other material possession, compensation would have to be offered in exchange for its use. Accordingly, research would halt while these issues are resolved, thereby costing the scientific community valuable time and money.

As a result of these concerns, the bill was sent back to the New Jersey Senate for reconsideration. The final version of the bill, less any mention of property rights, was signed into law by Governor Whitman in November 1996.

The current Genetic Privacy Act states that an individual's genetic information contains "uniquely" private information about the individual and offers protection against unwarranted disclosure of such information. Therefore, deleting the property protection did not deter the intent of the bill to protect against improper uses of genetic information.
While the method of protection has been revised, the unique characteristics of the legislation, mainly its comprehensiveness, remain intact.108

C. New Jersey Law Regarding Privacy Rights and Medical Information
   Before the Passage of the Genetic Privacy Act

Prior to the enactment of the Genetic Privacy Act, New Jersey law failed to provide adequate protection against the abuse of medical information.109 The draft Act set a precedent because medical information never had been protected as a personal property right before.110 For instance, New Jersey insurance practice law defines personal information without any mention of property rights.111 The regulation of insurance information does not address the individual’s relationship with their insurance information.112 Rather, it focuses on how the insurance company may utilize an individual's information. This statute fails to provide a satisfactory level of protection for individuals because there are other statutes under which insurance companies can easily obtain and communicate information from or to a third party.113

1. Doctor-Patient Confidentiality

Another method of protection under New Jersey common law, which was codified in 1968, is the privileged and confidential relationship be-

108. See supra notes 86-90 and accompanying text (describing the Genetic Privacy Act in further detail).
109. See Senate Committee Substitute, supra note 81 (discussing the inadequacy of existing laws related to genetic information). Prior to the Genetic Privacy Act, there were no express provisions for the protection of genetic information and statutory law cohesively codified in the New Jersey code. See id.; see also N.J. STAT. ANN. § 17:23A-1 (West 1994) (covering insurance information practices); N.J. STAT. ANN. § 2A:84A-22.1 (West 1994) (defining the patient-physician privilege); N.J. STAT. ANN. § 47:1A-2 (West 1989) (addressing the right to inspect public documents); N.J. STAT. ANN. § 17B:30-12 (West 1985) (prohibiting discrimination in the insurance industry).
110. See Senate Committee Substitute, supra note 81 (stating that the property right established by the original version of the Genetic Privacy Act was a “fundamental change from current practice”).
111. See N.J. STAT. ANN. § 17:23A-2(t) (West 1994) (defining personal information as “any individually identifiable information gathered in connection with an insurance transaction from which judgments can be made about an individual's character, habits, avocations,” etc); cf. Whitman Signs Bill, supra note 85, at 2 (defining a property right in genetic information as ownership of the material and the research resulting from it).
113. N.J. STAT. ANN. § 17:23A-13 (West 1994) (describing the limitations and conditions related to the disclosure of information and providing for the means by which an insurance company can gain access to an individual’s genetic information).
tween a doctor and a patient.\textsuperscript{114} The doctor is protected from having to reveal any information related to his or her patients, including information obtained from physical exams and confidential communications.\textsuperscript{115}

The New Jersey Superior Court confronted the issue of doctor-patient confidentiality when deciding whether a doctor has a duty to warn family members of a potentially genetically transmitted illness in \textit{Safer v. The Estate of Pack}.\textsuperscript{116} In \textit{Safer}, Dr. Pack and the plaintiff's father had a doctor-patient relationship.\textsuperscript{117} Dr. Pack unsuccessfully treated the plaintiff's father for colon cancer and multiple polyposis of the colon.\textsuperscript{118} When the plaintiff was thirty-six years old, she underwent surgery to resolve a cancerous blockage and multiple polyposis of the colon.\textsuperscript{119} The daughter brought suit against Dr. Pack, contending that her condition was hereditary and alleging that Dr. Pack was negligent in not informing the family of the risk of contracting the condition.\textsuperscript{120} The New Jersey Superior Court held that the standard of care owed by a physician to his patient creates a duty to warn third parties only when these third parties are identifiable, such as siblings and children.\textsuperscript{121} The court limited its holding by stating that this duty is satisfied by warning the patient, who can inform those who are at risk.\textsuperscript{122}

Although \textit{Safer v. The Estate of Pack} has not been overruled, the passage of the Genetic Privacy Act affected or altered its holding.\textsuperscript{123} A doctor's obligation to inform a patient of any disease he or she may carry remains intact.\textsuperscript{124} A doctor's duty to warn third parties, however, either has been overruled, or at least modified.\textsuperscript{125}

\begin{itemize}
\item \textsuperscript{114} N.J. STAT. ANN. § 2A:84A-22.1 (West 1994).
\item \textsuperscript{115} See id.
\item \textsuperscript{116} 291 N.J. Super. 619 (1996).
\item \textsuperscript{117} See id. at 622-23.
\item \textsuperscript{118} See id. at 621-22.
\item \textsuperscript{119} See id. at 622.
\item \textsuperscript{120} See id. at 623. Plaintiff also asserted that the hereditary nature of the condition was known at the time the plaintiff's father was treated by Dr. Pack. See id.
\item \textsuperscript{121} See id. at 625-26.
\item \textsuperscript{122} See id.
\item \textsuperscript{123} See N.J. STAT. ANN. § 17B:30-12(2)(b) (West 1996) (stating that genetic information is personal and prohibiting collection or disclosure of such information without the express consent of the individual). Therefore, Dr. Pack would no longer be permitted to inform the plaintiff or any other family members of Mr. Safer's genetic disease without the consent of the original patient.
\item \textsuperscript{124} See id. This statute does not prevent a doctor from informing the patient of any defect. See id. It only prevents the doctor from informing anyone outside of that relationship about the patient's condition. See id.
\item \textsuperscript{125} See id. Due to the enactment of this statute, it is hard to imagine that a doctor would be permitted to bypass a patient's consent to inform the family of that patient's
\end{itemize}
2. The Common Law Right-to-Know Doctrine

Under New Jersey common law, the public has the right to inspect any public documents. In Home News v. New Jersey Department of Health, a New Jersey statute limiting public access to public records was challenged by a newspaper seeking to determine the cause of death of a missing five-year-old boy. By codifying this right, the New Jersey legislature conflicted with the state’s statute protecting the privacy interests of those individuals afflicted with certain diseases.

The statute limiting public access to death certificates was intended to effectuate the confidentiality provisions of the Cancer Registry Act, the Acquired Immune Deficiency Syndrome Assistance Act, and the Registration of Vital Statistics Act. Limiting cause of death information, according to the Home News Court, was the final step in protecting the privacy of those who die from diseases which carry a social stigma, such as AIDS or cancer.

The right-to-know law, in contrast, grants citizens an “absolute right” to access public records, including death certificates. Therefore, the court was forced to determine whether individual privacy concerns outweighed the right to information. The court held that despite the valid condition, regardless of any genetic factors. See id.

128. See id. at 197.
129. See N.J. ADMIN. CODE. § 8:2A-1.2(a)(2)(1996) (requiring that information concerning the cause of death be omitted from death certificates unless the applicant is a close relative or the decedent’s executor).
130. See N.J. STAT. ANN. § 26:2-107 (West 1996) (requiring confidentiality under the Cancer Registry Act); N.J. STAT. ANN. §§ 26:5C-7 to 13 (West 1996) (maintaining confidentiality under the Acquired Immune Deficiency Syndrome Assistance Act); N.J. STAT. ANN. §§ 28:8-40.22 to 40.23 (West 1996) (providing confidentiality under the Registration of Vital Statistics Act); see also Home News v. New Jersey Dep’t of Health, 667 A.2d 196, 196-97 (N.J. 1996) (stating that each of these regulations require that cases of cancer, AIDS, and birth defects be reported to the Department of Health and that each regulation provides that personal information will be kept confidential).
131. See Home News, 677 A.2d at 197.
132. See id. at 198. The codified right to inspect public documents is not as broad as the common law rule. See id. Although death certificates irrefutably fall within the category of public records, access under the right to know statute is restricted to those who have an interest in the subject matter of the material sought. See id. But see N.J. ADMIN. CODE § 8:2A-1.2(a)(2) (1996) (restricting access to death certificate information to those who are immediate family, executors, or those who have the consent of the immediate family).
privacy concerns expressed through the confidentiality statute, the newspaper's interest in receiving information outweighed the need to maintain confidentiality as a matter of individual privacy.\footnote{134}{See id. In reaching this holding, the court balanced the public need for access to information against the need for confidentiality and concluded that since the death in question was likely a homicide, the need for the information was greater than the need for confidentiality. See id. at 200.}

D. The Constitutional Significance of Property and Privacy Classifications

The United States Constitution provides that: "[n]o state shall . . . deprive any person of life, liberty, or property, without due process of law."\footnote{135}{U.S. CONST. amend. XIV, § 1.} Beyond that, however, property and privacy rights are not defined within the United States Constitution.\footnote{136}{See Ronald Krotoszynski, Jr., Fundamental Property Rights, 85 GEO L.J. 555, 625 (1997) (concluding that the Supreme Court must "reestablish symmetry between property and liberty in its substantive due process jurisprudence"). According to Krotoszynski, the failure to establish a fundamental property right is illogical. See id. at 624; see also Harry Kalven Jr., Privacy in Tort Law—Were Warren and Brandeis Wrong?, 31 LAW & CONTEMP. PROBS. 326, 327 (1966) (discussing the nonexistence of a privacy right at early common law).} The law is particularly unclear when dealing with property rights, since the Supreme Court has never classified them as "fundamental."\footnote{137}{See Krotoszynski, supra note 136, at 555-57 (noting that although there are many property rights, the Supreme Court has refused to grant them more than minimal protection). Substantive Due Process protects personal interests that are created by the Constitution. See Craig Hillwig, Comment, Giving Property All the Process That's Due: A "Fundamental" Misunderstanding About Due Process, 41 CATH. U. L. REV. 703, 710 (1992). A right is deemed fundamental under the incorporation doctrine when the right is "implicit in the concept of ordered liberty." Id. at 711. Courts have granted "fundamental" status to rights of privacy, interstate travel, and voting. See id. at 712. When a state infringes on these fundamental rights, the court uses strict judicial scrutiny to determine the constitutionality of the state action. See id. Griswold v. Connecticut is heralded for reviving substantive due process as a method for protecting integral rights not mentioned in the Constitution. See Griswold v. Connecticut, 381 U.S. 479, 485 (1965) (holding that there is a fundamental right to privacy in reproductive decisions); see also Krotoszynski, supra note 136, at 557 (arguing that property rights should not be treated differently under substantive due process jurisprudence). Because both property and liberty interests are in the Due Process Clauses of the Fifth and Fourteenth Amendments, they should be treated similarly by the courts. See id.}

1. Property

The status of property rights has fluctuated since this country was founded. The framers of the Constitution strongly believed in broad property rights; for instance, James Madison described property rights as
defining the human identity, in that they distinguish people from one another. This principal has been narrowed over time. Although access to genetic information was not an issue confronted by the framers of the Constitution, early American property rights did include the right to one's physical characteristics, which are determined by genetic information.

An often-ignored United States Supreme Court opinion delivered in 1921 addresses the fundamental nature of property rights. In *Truax v. Corrigan*, unionized cooks and wait staff of the Truax Restaurant went on strike to contest unfair wages. The strikers picketed in an attempt to affect patronage of the restaurant, causing a substantial loss in business to Truax. Truax unsuccessfully attempted to enjoin the picketers due to Arizona's statute prohibiting the courts from taking such action. Truax raised a property claim before the United States Supreme Court, alleging that his business was a property which the State had failed to protect. The Court held that a business is a property right and that a state is obligated to recognize and protect certain fundamental property interests from restriction. Arizona could not enforce a law which deprived a citizen of property rights without due process of law. The Supreme Court has yet to revisit this issue, thereby leaving property rights relatively open ended.

According to American property law, property ownership is a bundle

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138. *See Barrad, supra* note 3, at 1053-54 (quoting J. Madison, *PROPERTY* (1792), in 6 *THE PAPERS OF JAMES MADISON* 101 (G. Hunt ed., 1906) (asserting that individuals have property interests in their identity, comprised of characteristics and traits differentiating one human being from another)).
139. *See id.*
140. *See id.*
141. *See Krotoszynski, supra* note 136, at 558 (stating that the Supreme Court has not recently "spoken" to whether property rights are fundamental).
142. 257 U.S. 312 (1921).
143. *See id.* at 321.
144. *See id.*
145. *See id.* at 322. The statute created an exception to the general rule against inhibiting property rights by allowing courts to issue an injunction when necessary to prevent irreparable injury to the property or property right of another. *See id.*
146. *See id.* Truax also alleged that the statute denied him equal protection of the law by withholding injunctive relief available to citizens in non-labor situations. *See id.*
147. *See id.* at 328; *see also* Krotoszynski, *supra* note 136, at 558-59 (claiming that although the *Truax* Court was cited favorably during the past seventy years, its holding never has been addressed by the courts and that *Truax* was the "high-water mark" for substantive due process protection of property rights).
149. *See Krotoszynski, supra* note 136, at 624-25.
Property ownership, however, is not an absolute concept. It can be controlled by both state and federal regulations, as well as by the possessory interests of the individual. A property interest can arise and be extinguished according to the actions of the legislatures or individuals.

2. Privacy

In contrast to property rights, privacy rights are clearly recognized as "fundamental" by the Supreme Court. In Griswold v. Connecticut, the Supreme Court launched a revival of modern substantive due process jurisprudence and created a privacy right not enumerated in the Constitution. In Griswold, a challenge was brought against a state statute prohibiting the use of contraceptives by married couples. The Court held that individuals have a fundamental liberty interest in the decision of whether or not to have a child, with which the state cannot interfere without a compelling reason or interest.

Since Griswold, the Court consistently has held that reproductive decisions involve fundamental privacy rights, thus requiring the State to prove that a law is necessary to promote a compelling state interest in order to divest an individual of the right to make such decisions. The Court recently modified this dictum with regard to abortion rights when it adopted the "undue burden" on the woman test to determine an infringement of the right to abortion. Today, the right to privacy encompasses much of what originally was conceived of as a right to property, and is thought of as the broadest individual protection not enumerated in

150. See Barrad, supra note 3, at 1049 (stating that property interests include exclusive possession, control over use of the property, alienability, devisability, and length of ownership). For a more detailed discussion of ownership concepts in American property law, see ROGER A. CUNNINGHAM, THE LAW OF PROPERTY (1984).

151. See Barrad, supra note 3, at 1049.

152. See id. Since property is alienable, new property interests are created through gifts and donations as well. See id.


154. 381 U.S. 479 (1965).

155. See id. at 485.

156. See id. at 480.

157. See id. at 485.


159. See Planned Parenthood v. Casey, 505 U.S. 833, 869-75 (1992) (rejecting the trimester framework of Roe v. Wade and adopting a test which disallows the State to impose an "undue burden" on the woman's right to make an abortion decision).
III. PROPERTY VERSUS PRIVACY: PROTECTING THE USE OF GENETIC INFORMATION

A. The Nature of Property Rights in American Jurisprudence and Their Relationship to Scientific Research and Genetic Information

Although the recognition of a property right in genetic information is not a complete solution, it is worthy of consideration. American jurisprudence always has treated property rights somewhat precariously, and although many believe a property right would not adequately protect genetic information, there are strong arguments to the contrary. The lack of express treatment of property rights has created an opportunity for clarification and definition. Indeed, the re-birth of substantive due process has hindered this development by transforming many former property rights into privacy rights and by focusing on fundamental liberty.

Genetic information can reasonably be classified as property from a legal standpoint. For example, the Genetic Privacy Act, introduced to Congress in 1995, confers a property interest in an individual's DNA molecules. The enactment of such a law would have established a clear

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160. See Krotoszynski, supra note 136, at 555 (discussing the historic perspective of what a right to property should encompass).

161. See id. at 588-89 (discussing the Framers' view that property rights encompass a broad range of human rights); see also Barrad, supra note 3, at 1048-53 (analyzing whether genetic information is characteristic of property and concluding that it may be because not all property characteristics need be present in an object to deem it a property interest).

162. See E. RICHARD GOLDF, BODY PARTS: PROPERTY RIGHTS AND THE OWNERSHIP OF HUMAN BIOLOGICAL MATERIALS 2-3 (1996) (defining "property" as rights given to individuals which allow them to make value judgments in relation to specific objects); see also Barrad, supra note 3 at 1049 (defining "property" as a state-protected collection of interests that a person may have incident to ownership).

163. See Krotoszynski, supra note 136, at 605-07 (discussing the revival of the substantive due process doctrine and its emphasis on fundamental liberties and privacy rights).

164. See Barrad, supra note 3, at 1086 (concluding that the courts should recognize a property interest in genetic information); see also Lin, supra note 10, at 134 (suggesting that Congress adopt the original version of the Genetic Privacy Act, thus creating a property right in genetic information). The Genetic Privacy Act discussed by Lin was drafted by George J. Annas, J.D., M.P.H., Leonard Glantz, J.D., and Patricia Roche, J.D., and the manuscript is available from the Health Law Department of the Boston University School of Public Health. See id. at 111 n.17. This Act was introduced to Congress in 1995, where it was subsequently referred to committee, but not enacted into law. See id.

165. See Lin, supra note 10, at 111. This proposal is a first step toward the protection of genetic information. See id. However, the act fails to address the existence of property rights in the genetic materials themselves and the apportionment of benefits from research.
national standard, protecting individual and societal interests.\textsuperscript{166} It would have furthered scientific research in genetics.\textsuperscript{167} Another alternative with the potential for clearly defining a national policy, or at least serving as a model for one, is New Jersey's version of the Genetic Privacy Act.\textsuperscript{168}

1. The Nature of Scientific Research and the Implications of Establishing a Property Right in Genetic Information

Reservations about the creation of a property right in genetic information are rooted in the nature of scientific research.\textsuperscript{169} Human tissue always has had a monetary value in Europe,\textsuperscript{170} but not in the United States until organ transplants flourished in the 1940s.\textsuperscript{171} The National Organ Transplant Act (NOTA) banned the sale of human organs.\textsuperscript{172} NOTA was enacted to maintain an equitable system of distribution of organs for transplants and to eliminate the "trade" of organs.\textsuperscript{173} Despite the enactment of NOTA, the human body has since become recognized as a "good" worth some value on many different levels.\textsuperscript{174} Therefore, pro-

\textsuperscript{166}See id.
\textsuperscript{167}See id. at 128-29 (claiming that the adoption of the Genetic Privacy Act would encourage dissemination of information, protect and facilitate scientific research, and support the donation of raw materials for scientific research).
\textsuperscript{168}See Reilly, supra note 43, ¶¶ 2-4.
\textsuperscript{169}See Moore v. Regents of the University of California, 793 P.2d 479, 487-88 (Cal. 1990) (finding that allowing conversion for scientific use of bodily tissue would have tremendous ramifications for scientific research); cf. Senate Committee Substitute, supra note 81 (describing the governor's reasons for vetoing the property right created by the original version of New Jersey's Genetic Privacy Act).
\textsuperscript{170}See RUSSELL SCOTT, THE BODY AS PROPERTY 1-3 (1981) (noting that the intrinsic value of the human body was recognized in Europe decades earlier than in the United States).
\textsuperscript{171}See id. at 3 (describing the modern transplantation era in the United States).
\textsuperscript{172}National Organ Transplant Act (NOTA), 42 U.S.C. §§ 273-274 (1994) (making it illegal for anyone to buy or sell human organs for transplantation).
\textsuperscript{173}See Congress of the United States, Office of Technology Assessment, (OTA), NEW DEVELOPMENTS IN BIOTECHNOLOGY: OWNERSHIP OF HUMAN TISSUES AND CELLS 31, 31-46 (1987) (discussing policy issues and options for congressional action regarding the uses of human tissue and cells).
\textsuperscript{174}See GOLD, supra note 162, at 12 (discussing the various reasons for valuing the human body: for its diversity, for individual personalities, and for the ability to recognize others as different from ourselves). In modern times, body products such as blood and semen are readily available for sale. See SCOTT, supra note 170, at 190-91. Historically, property rights in the human body have been recognized through the practice of slavery and through the former notion that a wife was the property of her husband. See Stephen A. Mortinger, Comment, Spleen for Sale: Moore v. Regents of the University of California and the Right to Sell Parts of Your Body, 51 OHIO ST. L.J. 499, 503 (1990).

State statutes and the common law also have limited the property interests that people have in their bodies. See id. at 505. For example, in Schmerber v. California, the Supreme
Protecting the human body and the information contained therein revolves around societal expectations and morality, as much as it does around legislation and case law. 175

Genetic research, a growing element of modern scientific study, relies on a steady supply of raw biological material. 176 Included in this material are cells, tissues, and organs derived from living human donors. 177 Among those affected by genetic research and the need for raw material are donors, researchers, and the public. 178 Therefore, legislating to protect genetic information keeps or maintains such interests in mind. 179 Creating a property right in genetic information may hinder the maintenance of a steady flow of available raw material because a new focus will be placed on actual possession of the information. 180 This new focus will not only morally affect the nature of scientific research, but it will also complicate the functions of the patent and royalty system. 181

2. Property Rights in Genetic Information and the Potential Effects on Genetic Discrimination

Classifying genetic information as a property right also requires an examination of its effect on genetic discrimination. Recognition of genetic information as a property right would protect individuals from intrusions into their genetic information and prevent public abuse of the information. 182 Pursuant to statutes such as New Jersey's confidentiality statute, Court held that the State may legally remove a person's blood for blood-alcohol testing without consent. 175 See id.; see also Schemerber v. California, 384 U.S. 757, 771-72 (1966).

175. See GOLD, supra note 162, at 5 (stating that "through the allocation of rights of control, society implicitly sanctions certain modes of valuing the human body and its materials, and discourages others"). For example, policy and legislation against selling organs and body parts is largely derived from societal sanctioning of the concept. See id.

176. See Lin, supra note 10, at 109-10 (discussing the plethora of economic, social, and ethical issues arising from the ever increasing need for raw biological materials).

177. See id.

178. See id. (analyzing the various conflicting interests affected by the need for raw materials). For instance, the donors are largely concerned with the resolution of their particular ailment, whereas the researchers and those who support them are typically focused on the "fruits" of their research and the advancement of science. See id. The public is generally concerned with the knowledge and improved health care resulting from the raw material donations and scientific research. See id.

179. See id.

180. See Barrad, supra note 3, at 1074 n.239 (claiming that critics of creating a property right in genetic information raise arguments about improper motives for donating materials and the potential negative impact on the poor, who may feel pressure to participate in scientific experiments unwillingly).

181. See Lin, supra note 10, at 121-22 (discussing the implications of a royalty system for genetic information).

a property right would also limit public access to information about causes of death. Statutes such as the one implicated in Home News serve to protect the confidentiality of victims of AIDS and cancer; an express property right would strengthen the confidentiality of genetic information. Additionally, this classification would create a proprietary interest in one's identity, which is essentially one's DNA.

Relinquishing control of genetic information to the individual would halt concerns about insurance companies setting higher premiums based on mandatory genetic testing results and employers terminating employees due to fear of increased health care costs. A property right alone, however, is not a complete solution because issues dealing with scientific research are left unattended. If the progress of research is halted, scientists will never realize their capacity to understand the human body.

3. The Shortcomings of Establishing a Property Right in Genetic Information

Governor Whitman believed that an express property right in genetic information would stagnate scientific research, therefore she requested its deletion from the bill. Governor Whitman supplanted a privacy right. Unfortunately, due to the lack of federal legislation and judicial case law there is no easy solution to this issue, and the creation of a privacy right does not automatically quell the rising concerns related to the use of genetic information. A privacy right, as discussed below, provides protection to the individual, but does not resolve the concerns about insurance, employment, or societal genetic discrimination.

183. See Home News v. New Jersey Dep't of Health, 677 A.2d 195, 198 (N.J. 1996) (discussing the rationale behind the confidentiality statutes and analyzing the court's holding justifying the public's need for access to cause of death information).
184. See id.
185. See Barrad, supra note 3, at 1070 (claiming that the "[c]haracteristics of identity, such as one's voice or face, are protected elements of personality because they are distinctive, personal, and a palpable manifestation of identity").
186. See supra notes 50-85 and accompanying text (detailing the concerns about discrimination that surround the use of genetic information).
187. See supra notes 53-59 and accompanying text (linking increased research efforts to genetic discrimination).
188. See Governor Vetoes, supra note 90, at 160 (discussing Governor Whitman's concerns about the property right included in the original draft as the reason for her veto).
189. See id.
190. See Why We Need H.R. 306, supra note 11 (noting the lack of adequate statutes or case law to deal with the confidentiality issues raised by genetic research).
191. See supra note 136 and accompanying text (suggesting that property rights are more stable because of their constitutional position, but that they do not adequately pro-
B. Privacy Rights: Their Relationship to Scientific Research and Genetic Information

The fundamental right to privacy, well founded in American jurisprudence, may be a more stable approach to regulating the use of genetic information. As with the creation of a property right, however, privacy protection does not completely resolve the issues surrounding the scientific use of genetic information.

1. The Fundamental Status of Privacy Rights Under Supreme Court Jurisprudence

American courts have provided more substantial case law regarding the status and treatment of privacy rights than property rights. In Planned Parenthood v. Casey, the Supreme Court held that the Due Process Clause of the Fourteenth Amendment applies both to substantive and procedural law, and that fundamental rights within the term "liberty" are constitutionally protected from state interference. Although not precisely defined, fundamental rights include personal decisions related to rearing children, procreation, and marriage.

2. The Inherent Connection Between Privacy Rights and Genetic Information

Privacy rights are strongly implicated in protecting the use of genetic information. Genetic data determines identity, from physical appearance to the ability to have healthy children, thereby linking it automatically to the concept of "personhood." Mandatory genetic testing and

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192. See supra notes 100-02 and accompanying text (discussing why Governor Whitman opted for the express privacy right in genetic information).

193. See infra notes 197-208 and accompanying text (discussing the potential complications an express privacy right in genetic information can create).


195. See id. at 846-47.

196. Compare Suter, supra note 1, at 1892 (quoting the Planned Parenthood v. Casey statement that "[a]t the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life"), with Barrad, supra note 3, at 1053-54 (defining "property" as an individual's interest in identity and character).

197. See Suter, supra note 1, at 1892-93.

198. See Glass, supra note 75, at 2158 (suggesting that knowledge of carrying a disease gene affects an individual's perception of and relationships with the world); see also Marlene Huggins et al., Predictive Testing for Huntington Disease in Canada: Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk, 42 AM. J. MED. GENETICS 508, 514-15 (1992) (discussing psychological difficulties experienced by individuals receiving decreased risk reports in cases in which other family members were less
various intrusive methods of obtaining genetic information violate individuals rights to control their own destiny.\textsuperscript{199} Testing reveals an individual’s genetic disposition but it should not, and does not, dictate the way in which the individual or third party uses the information.\textsuperscript{200}

The decision to undergo genetic testing involves weighing many factors\textsuperscript{201} that could affect not only the individual, but that individual’s entire family.\textsuperscript{202} This should be a personal decision, free from encroaching legislation and unwanted influence from third parties.\textsuperscript{203} These decisions are often spurred by the results of prenatal testing after the parents learn that the fetus has a genetic deficiency.\textsuperscript{204} Ironically, it was the debate over the right to bear a child that initiated the revitalization of the substantive due process doctrine.\textsuperscript{205}

3. \textit{Addressing Concerns about Insurance, Employment, and Societal Genetic Discrimination Through Privacy Rights}

A privacy right also addresses concerns about insurance, employment, and societal discrimination.\textsuperscript{206} If access to an individual’s genetic information is restricted, then logic dictates that the potential for abuse will be alleviated.\textsuperscript{207} This solution may not satisfy health insurance companies,
which argue that this information is critical in providing reasonably priced health care for all.\footnote{208} It may be necessary, however, in order to preserve individual freedoms.

4. The Shortcomings of a Privacy Right in Genetic Information

Legislation regulating the use of genetic information based on fundamental privacy rights may have a stronger constitutional position than legislation based on property rights. But this does not necessarily mean that the potential abuses or conflicts stemming from the use of genetic information are resolved.\footnote{209} For example, the progress of the Human Genome Project will halt unless the information learned may be disseminated.\footnote{210} Conflicts within families will increase over whether family members, who may be impacted by the presence of a disease gene, have the right to know that a genetic disease runs in the family.\footnote{211} Therefore, access to genetic information and scientific research can be hindered by the creation of a broad property right in genetic information in much the same way as if it were a property right. Similarly, privacy rights in genetic information can adversely affect scientific research and family relations in the same way as a property right.\footnote{212}

\footnote{208} See Nuki, \textit{supra} note 57 (discussing further the position of health care insurers as it relates to the use of genetic information).

\footnote{209} See Lin, \textit{supra} note 10, at 110 (discussing the public interest in information relating to the results of genetic research); see also Suter, \textit{supra} note 1, at 1907-08 (addressing the issue of familial conflicts arising over access to genetic information).

\footnote{210} See \textit{supra} notes 18-24 and accompanying text (discussing the Human Genome Project).

\footnote{211} See Suter, \textit{supra} note 1, at 1855; see also Safer v. The Estate of Pack, 291 N.J. Super. 619, 625 (1996) (holding that a doctor has an obligation to inform the patient that an illness is hereditary).

\footnote{212} See \textit{supra} notes 195-203 and accompanying text (discussing the negative implications of recognizing a right to privacy in genetic information).
C. Removing the Property Right from the New Jersey Genetic Privacy Act: Is the Creation of a Broad Privacy Right in Genetic Information the Appropriate Response?

Governor Whitman may be correct in asserting that controlling the use of genetic information interferes with scientific research.\textsuperscript{213} This may be a function of the various interest groups affected by control of this information and not of whether genetic information is classified as a property or privacy right.\textsuperscript{214} The creation of a property or privacy right in this information may not be the central issue in promulgation legislation—perhaps balancing these interests is the issue that should be addressed, although it remains to be seen whether the strength of the New Jersey statute will be affected by the deletion of the property right in genetic information.\textsuperscript{215}

Creating a privacy right in genetic information does not eliminate the potentially negative impact on scientific research. It does, however, provide constitutionally recognized protection for the information that extends beyond what a property right could provide.\textsuperscript{216} Property rights are not clearly defined in modern day jurisprudence, but this ambiguity can be advantageous because this leaves room for judicial maneuvering.\textsuperscript{217} Governor Whitman's concerns may be well founded, although not solely attributable to the nature of property rights, indicating that a more precise legislative definition is required.

IV. A LEGISLATIVE FRAMEWORK TO REGULATE THE USE OF GENETIC INFORMATION: CREATING A HAPPY MEDIUM

With the rate of scientific research increasing, a legislative solution to regulating the use of genetic information is the best alternative.\textsuperscript{218} Com-

\textsuperscript{213} See Governor Vetoes, supra note 90; see also Moore v. Regents of the University of California, 793 P.2d 479, 494-95 (Cal. 1990) (discussing the impact of recognizing legal ownership rights in genetic information).

\textsuperscript{214} See Lin, supra note 10, at 110 (discussing the various interest groups affected by the use of genetic information).

\textsuperscript{215} See McKUSICK, supra note 18 (establishing or providing the intention of Human Genome Project researchers to map the human genome by the year 2005). In the next ten to twenty years, this issue will be moot because the human genome will be sequenced and scientists will begin to discover cures to genetic diseases. See supra notes 18-24 and accompanying text (discussing the goals and progress of the Human Genome Project).

\textsuperscript{216} See supra notes 139-61 (describing the constitutional protection afforded genetic information).

\textsuperscript{217} See supra notes 161-62 (discussing the opportunity presented to a legislature attempting to define property rights).

\textsuperscript{218} See Barrad, supra note 3, at 1084 (claiming that courts may prefer to have a legislative solution to this problem; however, the judiciary is better equipped for assessing the
A comprehensive national legislation protecting the use of genetic information, is the easiest way to stop the growth of genetic discrimination in most of its forms.

A. A Judicial or Legislative Solution: The Debate

A judicial solution, resolving issues such as insurance and employment discrimination on a case-by-case basis, could never parallel the rate of scientific research. Allowing the common law to address conflicts arising out of the regulation of genetic information would be a tremendous struggle. The lag time of civil law suits alone poses problems, but when the individual defendant is positioned against the enriched interests of the biotechnological field, the outcome may not always be reasonable or fair. The legislature can address the most major issues, leaving the courts to refine the subtleties of these issues through case law.

In disagreeing with this approach, some scholars believe that the courts are adequately equipped to synthesize genetic information. Founded on the notion that genetic information is a property right and that defining property rights has traditionally always been the responsibility of
state legislatures, this view calls for reliance on the status quo.\textsuperscript{225} Unfortunately, reliance on property rights that are not precisely defined by the courts is a dangerous route to regulate the use of this information.\textsuperscript{226} The pace of scientific research, coupled with increasing discrimination, calls for a rapid response that cannot be found in a judiciary that since 1920 has ignored property rights.\textsuperscript{227}

\textbf{B. The Flaws in Establishing a Federal Property Right in Genetic Information}

A federal privacy right in genetic information, establishing both floor and ceiling limitations, may alleviate some of the insurance concerns, which cause both health insurance and employment discrimination.\textsuperscript{228} Similarly, informed consent laws are state regulated; thus, they vary widely from state to state.\textsuperscript{229} This variance causes confusion for patients who frequently relocate and it causes utter chaos for the multi-state insurance companies because they would have to comply with fifty different standards for informed consent.\textsuperscript{230}

Such a situation is developing with the increasing number of states enacting genetic information legislation.\textsuperscript{231} State legislation is inconsistent, with various states regulating health care or employment and others regulating only genetic testing and not general genetic information.\textsuperscript{232} Therefore, those who have an interest in this information have no stan-

\begin{itemize}
\item \textsuperscript{225} See id.
\item \textsuperscript{226} See supra notes 159-61 and accompanying text (discussing the unstable position of property rights in American jurisprudence).
\item \textsuperscript{227} See id.
\item \textsuperscript{228} See Nuki, supra note 57 (stating that insurance companies are concerned that they will be excluded from the "genetic revolution," thereby causing them to lose money due to the inability to select against those with costly genetic diseases). The conflict over the use of this information in many ways is not medical—it is driven by political and social forces. See Arnst, supra note 54.
\item \textsuperscript{229} Cf. Bergman, supra note 2, at 134 (stating that the Moore Court concluded that doctors have a general duty to inform their patients of research interests derived from their treatment). The court based its reasoning on the principle of informed consent which states that "a person of adult years and in sound mind has the right, in exercise of control over his own body, to determine whether or not to submit to lawful medical treatment." Id. at 134 (citing Cobbs v. Grant, 502 P.2d 1, 9 (Cal. 1972)).
\item \textsuperscript{230} See Lin, supra note 10, at 122 (discussing the inadequacy of the informed consent doctrine as a solution to the conflicts arising out of the use of genetic information).
\item \textsuperscript{231} See Why We Need H.R. 306, supra note 11 (discussing the fact that state regulation has no effect on large, multi-state insurance companies which are regulated under ERISA).
\item \textsuperscript{232} See supra notes 85-86 and accompanying text (referencing those states that have enacted legislation pertaining to genetic issues).
\end{itemize}
standard guidelines with which to comply. Further, states cannot regulate many of the larger, multi-state insurance companies because of ERISA, thereby leaving a large number of employees unprotected. The best solution is federal legislation which, at a minimum, would establish parameters for the use of genetic information.

C. New Jersey's Statute as a Congressional Model

Congress should model its legislation after New Jersey's Genetic Privacy Act. The comprehensiveness of the New Jersey legislation is proactive and insightful. Despite the legislation only addressing one interest involved in regulating genetic testing, the tension between property versus privacy rights should not be the focus because neither protection alone can adequately protect genetic information. Instead of manipulating genetic information to fit into one classification or another, the classifications should be tailored to the character of genetic information. If the ambiguous nature of a property right is used as an opportunity for definition and the constitutional protection afforded to privacy rights is used to stabilize the status of genetic information, a middle ground is achievable and the courts can address the remaining issues through common law.

V. CONCLUSION

Through continuing advances in genetic technology, scientists will have mapped the entire human genome by the year 2005, linking genetic de-

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234. See Why We Need H.R. 306, supra note 11.
235. See id. (discussing proposed legislation relating solely to health insurance discrimination, but emphasizing the need for federal legislation); see also Lin, supra note 10, at 126-27 (discussing why federal legislation provides a more feasible solution to the regulation of genetic information than state legislation).
236. See id. (discussing proposed legislation relating solely to health insurance discrimination, but emphasizing the need for federal legislation); see also Lin, supra note 10, at 126-27 (discussing why federal legislation provides a more feasible solution to the regulation of genetic information than state legislation).
237. See supra notes 105-113 and accompanying text (discussing the provisions of New Jersey's Genetic Privacy Act and stating that the purpose of the Act is to end insurance discrimination).
238. See News Release, supra note 104; see also Lin, supra note 10 (listing various interests involved in regulating the use of genetic information).
239. See supra notes 218-26 and accompanying text (discussing the attributes of property and privacy rights).
fects to all "abnormalities" ranging from Down's Syndrome to alcoholism. While it is unreasonable to expect the judiciary to develop legal precedent contemporaneously with all technological advances, it cannot remain a mere passive bystander. This is a task for the federal legislature rather than the state legislatures. The varying state legislation dealing with insurance or employment discrimination is based on variant theories and only further muddles the issue. The federal government must establish laws creating a framework within which insurance companies and employers can function while sufficiently protecting the individual.

The New Jersey Genetic Privacy Act provides an effective model on which to base a national policy. While Congress may elect to begin tackling this issue by dealing with the relationship between health care insurance and genetic information, New Jersey's legislation represents the trend which any federal legislation should follow. Sooner, rather than later, the legal system must integrate this phenomenal ability to discover new genetic information into a framework whereby society can accept its genetic defects without facing widespread discrimination.