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The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy

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NOTE

THE HUMAN GENOME PROJECT: GENETIC SCREENING AND THE FUNDAMENTAL RIGHT OF PRIVACY

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I. INTRODUCTION

The law of the past cannot be eluded,
The law of the present and future cannot be eluded,
The law of the living cannot be eluded—it is eternal.

—Walt Whitman

The essence of the law finds expression in the many forms of statutes, cases, rules, regulations, and codes which serve as guides to the citizenry and ensure that societal order is maintained.

The essence of the physical human being finds expression in the elaborate molecular processes that direct the function and appearance of our bodies and minds. To unlock the secret of these processes and thus discover the specific makeup of the human being would truly be an extraordinary mark of achievement for the application of the human intellect.

This endeavor is precisely what hundreds of scientists are striving to accomplish under the rubric of an awesome worldwide effort—the Human Genome Project. The primary goal of the Human Genome Project is to locate and decipher approximately 100,000 genes which

2. The Human Genome Project is also commonly referred to as the Human Genome Initiative. Throughout this Note, Human Genome Project will be used to refer to both. See George P. Smith, II, Accessing Genomic Information or Safeguarding Genetic Privacy, 9 J.L. & HEALTH 121, 126 (1994-1995). The Human Genome Project is a cooperative undertaking which, when completed, will provide a complete map of all genes that make up the human being, in essence, a human “blueprint.” See ROBERT SHAPIRO, THE HUMAN BLUEPRINT: THE RACE TO UNLOCK THE SECRETS OF OUR GENETIC SCRIPT 105-10 (1991).
3. See Smith, supra note 2, at 126; see also The Nat'l Human Genome Research Inst., The
make up the human genome. Once completed, scientists hope to better understand the functioning of the human genome and apply this knowledge to the improvement of human health through the treatment and prevention of genetic disease.

In order to facilitate this goal, practical application of the technology includes the development and improvement of genetic screening capabilities. This Note addresses whether genetic screening for particular diseases should be mandatory or voluntary. A balancing analysis will frame the legal implications of this question and will include the following issues: (1) whether the state, under its police power to protect the public health, can use new genetic assessments to justify implementing a mandatory screening program; (2) the impact of such a program on individual privacy rights of freedom from unreasonable search and seizure, autonomous decision-making, and selective disclosure; and (3) whether a mandatory screening program is the least restrictive alternative under certain circumstances. The analysis will conclude with a balancing of these issues, revealing that a mandatory testing program is not the least restrictive alternative, even under circumstances where the state's interest rises to the level of compelling.

In order to provide a foundation for understanding the importance

Human Genome Project (visited Jan. 9, 1998) <http:www.nhgri.nih.gov/HGP/> [hereinafter Human Genome Project] (providing the most up to date information regarding the Human Genome Project).

4. ""The human genome is the complete set of instructions for making a human being."" Leon Jaroff, The Gene Hunt: Scientists Launch a $3 Billion Project to Map the Chromosomes and Decipher the Complete Instructions for Making a Human Being, TIME, Mar. 20, 1989, at 62 (quoting biochemist Robert Sinzheimer of the University of California at Santa Barbara). "The human genome refers simply to the twenty-three pairs of chromosomes that all humans carry within which all human genes reside—and, more specifically, those genes that contribute directly to traits such as height, eye color, the shape of body parts, and human behavior." George P. Smith, II & Thaddeus J. Burns, Genetic Determinism or Genetic Discrimination, 11 J. CONTEMP. HEALTH L. & POL'Y 23, 29 (1994); see also Michael Kirby, The Human Genome Project—Promise and Problems, 11 J. CONTEMP. HEALTH L. & POL'Y 1, 8 (1994) (discussing the broad and daunting scope of the Human Genome Project).

of scientific advancements yielded by the Human Genome Project and how this science supports the state’s interest in public genetic health, it is necessary to have a basic understanding of genetics and of the potential of advancements in genetic technology. The science of genetics provides the framework for the Human Genome Project and is the foundation for the development of accurate genetic testing methods. Part II of this Note explains the role that DNA plays in genome technologies and provides an overview of the Human Genome Project. Part III presents the legal foundation for the state’s interest in the public health and the Fourth and Fourteenth Amendment privacy interests of individuals. Here, the state’s broad police power to contain communicable disease⁶ is contrasted against the individual’s right to avoid unreasonable searches and to make autonomous decisions about personal health and family health matters. Examples of past and present screening provisions are examined in those instances where the state has successfully implemented mandatory testing. Similarly, those instances where the state interest in protecting the public health had to yield to individual fundamental rights of privacy and autonomy are also explored.

Part IV applies the legal framework to the question of whether the state may constitutionally mandate specific genetic screening tests at this time under its police power to protect the public health. Various state interests are addressed, including preventative care through early detection and reduction of the occurrence of inheritable diseases. The state’s interest in potential life is also considered because genetic diseases are transmitted through reproduction.⁷ Next, the implications on an individual’s privacy rights are addressed in the context of each of these state interests. Special attention is given to the necessity of confidentiality for genetic information and the fear of discrimination from the unauthorized release of such information to insurers or employers.

Part V of this Note balances the state interest against individual privacy rights in the context of mandatory screening. Examples of previous screening programs are referenced in order to ascertain the types of elements necessary to support a state-mandated testing program. Special consideration is given to the impact of genetic screening on re-

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⁶. A communicable disease is one which can be transmitted from one person to another. See Holly A. Rosencranz & Warren G. Lavey, Treating Patients with Communicable Diseases: Limiting Liability for Physicians and Safeguarding the Public Health, 32 St. Louis U. L.J. 75, 75 n.1 (1987).

⁷. There are many issues surrounding reproductive genetics, however, this discussion focuses on the implications of genetic technology as applied to the screening of the pregnant mother, fetus, or newborn.
productive decision-making as scientific advancements may change foundational notions that have been considered in past legal analyses. This section concludes that a mandatory testing program at this time is unlikely to withstand constitutional scrutiny because the mandatory nature of the screening program unduly interferes with an individual’s privacy rights and is not the least restrictive alternative.

Part VI suggests the implementation of a voluntary screening program as an alternative to mandatory testing for genetic disease. Necessary components and related services are outlined. This analysis concludes that a voluntary testing program achieves state goals while preserving the individual’s privacy in personal decisions regarding health.

II. THE HUMAN GENOME PROJECT

A. DNA—Crafting the Human Composition

The human body is comprised of millions of cells that perform a variety of functions. For example, some cells are responsible for growing hair, while others are responsible for fighting off disease. These cells work together, enabling our bodies to act as a single entity—the human being. But how do these cells know which tasks to perform and when? In 1953, James Watson and Francis Crick discovered that within the nucleus of each cell are chromosomes containing deoxyribonucleic acid, or DNA. This substance gives each cell the “directions” necessary to perform its specific functions as well as the directions necessary to coordinate those tasks within the larger workings of the body.

8. For example, scientific advancements may change the concept of viability, thereby altering a woman’s rights regarding abortion options. See Mark J. Buetler, Comment, Abortion and the Viability Standard—Toward a More Reasoned Determination of the State’s Countervailing Interest in Protecting Prenatal Life, 21 SETON HALL L. REV. 347, 362-63 (1991); cf. Michael J. Malinowski, Coming into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening, 45 HASTINGS L.J. 1435, 1484 (1994) (suggesting that in the case of an unhealthy fetus, the state interest in preserving potential life is lessened, and perhaps “the viability cut-off for abortion should be removed . . . since the parents of a severely impaired newborn generally are given the option of withholding aggressive health treatment” that might otherwise save the child (emphasis added)).


10. See id.

of the human body.12

The Watson-Crick Model13 gave insight into the formulation and functioning of the double-helix structure of DNA. According to the model, DNA is comprised of two components. The first is a sugar-phosphorus chain,14 and the second component is a group of four basic units called nucleotides, which extend horizontally from the sugar-phosphorus chain; the four bases are adenine (A), guanine (G), thymine (T), and Cystosine (C).15 There are two sets of the chain-base combination, and the bases from each chain attract each other and always pair up in the exact same way: (A) always pairs with (T), and (G) always pairs with (C). As the bases pair up, the chains wrap around one another, thus forming the familiar double-helix shape.

DNA’s base pairs are the language through which it communicates messages to cells. Because there are only four elements that comprise DNA, it is necessary for DNA to encode its detailed directions in very long sequences of base pairs.16 For example, it is estimated that a typical small gene contains at least 3,000 base pairs and that each human cell contains roughly three to six billion base pairs.17

DNA is important because it is the building block upon which the production and maintenance of many of our body’s essential elements, including proteins, occurs. For example, DNA bases group together to form amino acids which then combine to determine the function of proteins in our bodies.18 Proteins are responsible in large part for the formation of the human body, with some proteins serving as messengers delivering information from one part of our body to another.19 An understanding of DNA and its processes is therefore essential to a complete understanding of how the body functions. With an increasing un-

12. See LEVINE & SUZUKI, supra note 9, at 18.
16. See LEVINE & SUZUKI, supra note 9, at 18.
17. See id. In order for a DNA sequence to be “unique” in the human genome, “[t]he DNA sequence must have a probability of occurrence of less than once in three billion nucleotides.” Anita Varma & David Abraham, DNA Is Different: Legal Obviousness and the Balance Between Biotech Inventors and the Market, 9 HARV. J.L. & TECH. 53, 61-62 (1996).
19. See LEVINE & SUZUKI, supra note 9, at 19. For example, proteins are the foundation for our skin and many of our organs. They send messages “from head to toe” allowing us to move our arms, walk, and run. See id. The DNA itself does not create the amino acids necessary for the formulation of proteins, rather, DNA transcribes itself onto messenger ribonucleic acid (RNA) which carries the information into a ribosome where the directions are decoded and the appropriate molecular compositions are created. See id. at 20.
understanding of the processes through which DNA commands the body, scientists are aiming to construct a complete map of the human genome and graph the inter-relationships between cells, genes, and the functions of the human body.\textsuperscript{21}

Self-knowledge about the human genome is an important component in understanding the human’s place within the environment, as well as in sustaining our well-being within that environment by combating the genetic diseases which plague us. A deeper understanding of DNA and its functions gives humans the power to potentially recreate DNA or DNA-like functions\textsuperscript{22} and to use this power to account for any shortcomings and errors within the normal functioning of the human body.\textsuperscript{23} In fact, scientists today are already successfully manipulating DNA, albeit in a somewhat limited fashion.\textsuperscript{24}

As scientists continue to study DNA intelligence, they hope to understand how DNA composes its directions to all types of cells. This greater understanding will enable scientists to improve the human condition.\textsuperscript{25} With this goal in mind, the Human Genome Project was created.

**B. The Human Genome Project**

In 1990, the Human Genome Project officially commenced in the United States under the joint efforts of the Department of Energy ("DOE") and the National Institutes of Health ("NIH").\textsuperscript{26} The Human

\textsuperscript{20} “Mapping” is defined as locating a particular gene on a particular chromosome. See John C. Fletcher & Dorothy C. Wertz, Ethics, Law, and Medical Genetics: After the Human Genome Is Mapped, 39 EMORY L.J. 747, 754 (1990).

\textsuperscript{21} See Understanding Our Genetic Inheritance, supra note 5.

\textsuperscript{22} For example, scientists can recreate DNA-like functions by “cutting and pasting” DNA pairs together in order to replicate a desired sequence through the use of the enzyme reverse transcriptase. See LEVINE & SUZUKI, supra note 9, at 24-25. This process, whereby an enzyme on RNA assembles a complimentary strand of DNA, is of vital importance because it imitates the process by which many incurable retroviruses infect human cells and then quickly replicate. See id. Scientists can also clone certain genes through Polymerase Chain Reactions. See Norman A. Doggett, The Polymerase Chain Reaction and Sequence-tagged Sites, in THE HUMAN GENOME PROJECT: DECIPHERING THE BLUEPRINT OF HEREDITY 128, 128 (Necia Grant Cooper ed., 1994).

\textsuperscript{23} See LEVINE & SUZUKI, supra note 9, at 23-25.

\textsuperscript{24} See supra note 22.

\textsuperscript{25} “[K]nowledge [of the human genome] will undoubtedly revolutionize understanding of human development, including the development of both normal characteristics . . . and abnormal ones, such as disease. It will transform our capacities to predict what we may become and, ultimately, it may enable us to enhance or prevent our genetic fates . . . .” Daniel J. Kelves & Leroy Hood, THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT, supra note 5, at vii.

\textsuperscript{26} See Smith & Burns, supra note 4, at 29; Understanding Our Genetic Inheritance, supra
 Genome Project’s main goal is to comprise a thorough map of the human genome, which is comprised over three to six billion DNA base pairs, in order to "further our basic understanding of human genetics and of the role of various genes in health and disease.” This map will serve as “the source book for biomedical science in the 21st century and will be of immense benefit ... [in] understand[ing] and eventually treat[ing] many of the more than 4,000 genetic diseases that afflict mankind, as well as the many multifactorial diseases in which genetic predisposition plays an important role.”

This endeavor has been described by some as the “holy grail” of life because deciphering the human genome will reveal all there is to know about the biological composition of the human being. “Evolution, disease, everything will be based on what’s in that magnificent tape called DNA.” These ambitious results have likened the Human Genome Project to such past pioneering scientific programs as the lunar landing and the invention of the first nuclear weapon.

Two preliminary objectives need to be achieved before the Human Genome Project can reach its ultimate goal, that of mapping and understanding the human genome. First, the Human Genome Project aims to produce a high resolution genetic map of the genetic markers making up the twenty-three chromosomes of the human genome. In other words,

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note 5. The National Human Genome Research Institute, originally established in 1987 as The National Center for Human Genome Research, was formed by the NIH to manage and monitor the project’s goals, technology, funding, and public relations issues. See Jon Beckwith, Foreword: The Human Genome Initiative: Genetics’ Lightning Rod, 17 AM. J.L. & MED. 1, 3 n.15 (1991); Understanding Our Genetic Inheritance, supra note 5. This office is an outgrowth of the office of Human Genome Research also originally formed by the NIH. See Beckwith, supra; Understanding Our Genetic Inheritance, supra note 5.

27. See LEVINE & SUZUKI, supra note 9, at 30; Smith & Burns, supra note 4, at 24; Understanding Our Genetic Inheritance, supra note 5.

28. Understanding Our Genetic Inheritance, supra note 5; see generally Beckwith, supra note 26 (discussing the far-reaching impact of the Human Genome Project); Dan W. Brock, The Human Genome Project and Human Identity, 29 HOUS. L. REV. 7, 20 (1992) (same).

29. Multifactorial traits are those which depend on both genetic and environmental factors. See Vicki G. Norton, Comment, Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation, 41 UCLA L. REV. 1581, 1592 n.61 (1994).

30. Understanding Our Genetic Inheritance, supra note 5.

31. See LEVINE & SUZUKI, supra note 9, at 30; Beckwith, supra note 26, at 1.

32. Jaroff, supra note 4, at 63 (quoting George Cahill, a vice-president at the Howard Hughes Medical Institute).

33. See Beckwith, supra note 26, at 1; James D. Watson, The Human Genome Project: Past, Present, and Future, SCIENCE, Apr. 6, 1990, at 44, 44.

34. See LEVINE & SUZUKI, supra note 9, at 30.

35. A genetic marker is a specific set of base pair sequences which describes a particular "code" of directions for a cell. See id.

It is important to note that the “human” genes which are being mapped are not those of any
the three billion base pairs comprising the twenty-three human chromosomes will be identified as part of a linear pattern.\textsuperscript{36} Second, various physical "learning" maps of all human chromosomes and of the DNA of selected model organisms will be produced.\textsuperscript{37} These maps will be combined in order to aid scientists in understanding the "big picture" of the human genome. The integrated map will demarcate the location of individual genes within the genome, while correlating maps will illustrate the genetic linkages (how various pieces of DNA fit together) between these 100,000 genes.\textsuperscript{38} "Once this integrated map is available, locations can be established for genes with identified phenotypic expressions,\textsuperscript{39} including disorders or predisposition for genetic diseases.'\textsuperscript{40} As of 1993, approximately 2,736 of the targeted genes had been mapped,\textsuperscript{41} and the rest of the genes are scheduled to be completely mapped by 2005.\textsuperscript{42}

The Initiative's total cost is estimated to be about three billion

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\item one human but are a collection of samples that have been acquired and grown in laboratories over an extended period of time. See Fletcher & Wertz, supra note 20, at 754.


\item Scientists presume that functionally important DNA is present among humans as well as other organisms, and that by comparing these pieces of DNA among and between various organisms as against the standard set forth by the human genome map, greater insight into the workings of DNA sequences can be gained. See Understanding Our Genetic Inheritance, supra note 5.

\item Of course, a thorough map cannot be created until scientists determine the complete sequence of human DNA and the DNA of all of the model organisms chosen; so by necessity, this goal is inherent in the Human Genome Project's plan. It is important to note that some of the functions of human DNA have already been discovered through experimentation and research on yeast and other organisms. See LEVINE & SUZUKI, supra note 9, at 10-12. This fact buttresses the theory that the DNA found in all living organisms derives from one common ancestor and continues to enable scientists to link human life within the full panorama of life upon Earth. See id.

\item Overwhelming similarity at the molecular level testifies that life's information storage system appeared only once. Our genes resemble those of other organisms because the genes in all of us are descendants of the genes once carried by our common ancestor ... who lived more than 3.5 billion years ago. The line of descent is unbroken, the web of relationships irrefutable. See id. at 33.

\item A phenotype is the variant of inheritable traits of an individual; it includes observable features such as skin color, height, and eye color. See Robert P. Wagner, Understanding Inheritance: An Introduction to Classical and Molecular Genetics, in THE HUMAN GENOME PROJECT: DECIPHERING THE BLUEPRINT OF HEREDITY, supra note 22, at 1, 18-21.

\item Iles, supra note 36, at 30. In addition to the actual production of these maps, scientists are working with biotech companies and other computer programmers to improve the "informatics and DNA sequencing techniques with the hope that their cost, accuracy and facility of use will make the sequencing of the genome of any organism a relatively easy task." Beckwith, supra note 26, at 3-4 (emphasis added).

\item See Smith, supra note 2, at 126.

\item See Iles, supra note 36, at 29.
\end{enumerate}
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dollars. Many biotechnology companies, however, are contributing to defray the costs of the Human Genome Project in return for shared rights to the new information. For example, biotechnology companies are paying high prices for the rights to access valuable genome information which they can use in the development of gene therapy treatments for various diseases. Indeed, “[t]reatment of people with DNA-based gene therapy has . . . market potential: tests to detect DNA defects of such diseases as cystic fibrosis or colon cancer are predicted to become a multi-billion dollar industry . . .” In addition, as technology advances, long-term goals are likely to include the efficient production of personal genetic profiles. In order to reach such goals, the development and refinement of genetic screening techniques is necessary to identify the presence or predisposition of genetic disease within an individual’s genome. It would seem then that the development and use of genetic screening is a logical stepping stone in the application of advanced genetic technologies designed for the purpose of promoting or protecting the public health.

III. LEGAL FOUNDATIONS FOR SCREENING PROGRAMS

A. State Interest in Regulating the Public Health

It is well established that the police power of the states includes the power to regulate the public health and welfare. Specifically, the

43. See ROBERT N. PROCTOR, VALUE-FREE SCIENCE?: PURITY AND POWER IN MODERN KNOWLEDGE 5 (1991); Jaroff, supra note 4, at 63. The coordinators of the project, such as the DOE and NIH, are receiving federal funding as well as support from biotechnology companies. See id.

44. “The decision to continuously fund this Initiative, the largest biology project in the history of science, at a time of significant budgetary constraints suggests its political currency.” Rochelle Cooper Dreyfuss & Dorothy Nelkin, The Jurisprudence of Genetics, 45 VAND. L. REV. 313, 314 (1992). Based on such strong national support for the Human Genome Project and the new genetic technologies gained from it, states may claim to have a compelling interest in mandating genetic screening for the protection of the public health. See infra Part IV.A.

45. Varma & Abraham, supra note 17, at 54 n.1.

46. See PHILIP KITCHER, THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES 173-77 (1996). While Kitcher’s proposal for the genetic profiling of the entire population may not occur for some time, the use of genetic profiles in somewhat limited circumstances involving employment and insurance could transpire shortly. See infra Part IV.B.2.a.

47. See Village of Euclid v. Ambler Realty Co., 272 U.S. 365, 375 (1926). “The Powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved
power to regulate the public health has been described by the Supreme Court as the power to "enact quarantine laws and 'health laws of every description."

In addition, the Supreme Court has recognized regulation of public health as a matter of local concern which can be most efficiently and advantageously regulated by the state.

The leading case setting forth the underlying principles supporting the state's power to regulate the public health is Jacobson v. Massachusetts. There, the Supreme Court, in 1905, upheld a mandatory vaccination statute for smallpox on the ground that the state had the authority to enact the statute under its police power. Importantly, the Supreme Court declared that the states' police power to protect the public health is broad, and that it is not for the courts to consider whether the method employed by the legislature to effectuate this purpose was the best method; rather, the Court's sole inquiry was whether it was reasonably related to the state objective.

Courts in the early twentieth century continued to follow the example set forth in Jacobson and presumed legislation to be valid if a reasonable relationship existed between the statute and the government objective. In addition, courts allowed popular belief rather than scientific knowledge to determine the reasonableness of the legislative regulations.

Since Jacobson, advancements in medical technology have not been sufficiently reflected by cases involving the state interest in regulating public health, specifically with regard to the control of contagious disease. The following paragraphs present a survey of the various public screening measures that states have taken to control disease under the

to the States respectively . . . ." U.S. Const. amend X. For a thorough discussion on the origins, scope, and limits of the state police power, see Christopher G. Tiedeman, A Treatise on the Limitations of Police Power in the United States (Da Capo Press 1971) (1886).


49. See Walter E. Schuler, Note, The Erisa Pre-emption Narrows: Analysis of New York State Conference of Blue Cross & Blue Shield Plans v. Travelers Insurance Company and Its Impact on State Regulation of Health Care, 40 St. Louis U. L.J. 783, 786 (1996) (surveying Supreme Court cases which recognize the states' power to regulate health care).

50. 197 U.S. 11 (1905).

51. See id. at 25.

52. See id. at 25, 35.

53. See, e.g., Miller v. Wilson, 236 U.S. 373, 380 (1915) (upholding a California statute limiting the number of hours women could work in certain types of employment).

54. See Jacobson, 197 U.S. at 35 ("'[T]he Legislature has the right to pass laws which, according to the common belief of the people, are adapted to prevent the spread of contagious diseases . . . . [F]or what the people believe is for the common welfare must be accepted as tending to promote the common welfare, whether is does in fact or not.'" (quoting Viemeister v. White, 72 N.E. 97, 99 (N.Y. 1904))).
auspices of police power. These examples will illustrate the courts' efforts to expand judicial construction of the Constitution to afford citizens more constitutionally protected rights, such as privacy. The extension of constitutional rights gave rise to the strict scrutiny standard, under which the state must have a compelling interest supporting a statute which is narrowly tailored to effectuate its purpose.\textsuperscript{55} However, the survey will reveal that public opinion, rather than advancements in technology, still pervade much of legislative decision-making.

1. Sickle Cell Anemia Testing

In the 1970s, some states implemented compulsory sickle cell anemia ("SCA") testing on African-American adults.\textsuperscript{56} The effort was undertaken after medical assessment isolated African-Americans as the group most at risk for this disease. The goal of the mandatory testing program was to identify "carriers of a single copy of a mutated gene which poses no risk to them, but would pose a major risk to their offspring should two carriers marry."\textsuperscript{57} In distinguishing a particular social group by genetic disease, the screening program fostered discrimination against African-Americans, thereby reducing access to medical services, education, and higher paying jobs.\textsuperscript{58} For example, with racial tension contributing to the stigmatizing effects of such testing, many African-Americans, even those who were asymptomatic and merely predisposed to the anemia, lost their jobs or were denied adequate health care benefits.\textsuperscript{59} Although the states' interests were legitimate, the goals of mandatory testing were thwarted by its discriminatory effects.

\textsuperscript{55} See infra Part IV.A.

\textsuperscript{56} See Philip Reilly, Genetics, Law, and Social Policy 68-72 (1977). Some commentators have pointed out that one of the reasons why the compulsory testing failed was because the tests themselves were premature in that they were not developed enough to accurately test for the actual disease. See Cynthia Smith Adelman, Note, The Constitutionality of Mandatory Genetic Screening Statutes, 31 Case W. Res. L. Rev. 897, 912 (1981). "The SCA test could not differentiate between those persons afflicted with sickle cell disease and those individuals merely carrying the sickle cell trait." Id. In addition, testing during the 1970s was often performed without consent and with little or no regard for confidentiality of patients identity and results. See Levine & Suzuki, supra note 9, at 202-03.


\textsuperscript{58} See Iles, supra note 36, at 27.

\textsuperscript{59} See Levine & Suzuki, supra note 9, at 202-03. In addition, it is important to note that many of those tested suffered from detrimental psychological ramifications due to the lack of pretest counseling and education and the unavailability of post-test medical solutions. See id. at 203. Due to these and many other shortcomings of the program, the mandatory testing of adults has since been repealed; however, mandatory testing for newborns has withstood Constitutional scrutiny. See infra text accompanying notes 108-21.
Congress responded to these pressures by enacting the National Sickle Cell Anemia Control Act ("Control Act") in 1972. The goals of the Control Act were to "establish a national program for diagnosis, prevention, and treatment of sickle cell anemia" while providing the necessary counseling and education, as well as confidentiality of screening results. Most notably, the Control Act repealed the mandatory nature of any state SCA screening statute and made such testing voluntary.

2. Communicable Diseases

a. Vaccinations

Another area which the state has traditionally regulated is the prevention and spread of communicable diseases. As early as 1905, *Jacobson v. Massachusetts* recognized the right of the state, via the police power, to enact narrowly tailored public health laws deemed necessary to safeguard the public health and welfare, even though they infringed on individual rights. In *Jacobson*, Justice Harlan, writing for the majority, upheld a Massachusetts state statute which mandated vaccinations for smallpox. The plaintiff, who was in perfect health, refused the free vaccination on the grounds that submission to it violated his Fourteenth Amendment rights. The Court rejected this argument and recognized the authority of the state "to enact . . . 'health laws of every de-

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62. See id. at 2; National Sickle Cell Anemia Control Act § 3(c). Further refinements were made with regard to SCA testing. The Sickle Cell Anemia Control Act was repealed in 1976 and replaced with the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act, Pub. L. No. 94-278, § 401, 90 Stat. 407 (1976) (codified as amended at 42 U.S.C. § 300b (1994)). Finally, in 1978, Congress expanded this Act to include a broader scope of genetic diseases, including cystic fibrosis and "genetic conditions leading to mental retardation or . . . mental disorders." 42 U.S.C. § 300b-1 Congressional Declaration of Purpose (1994). The Control Act also provided for continued research and development of genetic "programs for diagnosis, treatment, . . . and screening." Id. § 300b-6. This goal was designed to be achieved through the provision of such services as "1. Early detection of disease: (a) Newborn Screening, (b) Prenatal Screening, (c) Prenatal Diagnosis, (d) Screening at later ages; 2. Carrier detection; 3. Counseling; 4. Diagnosis and monitoring effectiveness of treatment; and 5. Information and education." S. REP. No. 95-860, at 33-34, reprinted in 1978 U.S.C.C.A.N. 9134, 9166-67.
63. 197 U.S. 11 (1905).
64. See id.
65. See id.
66. See id. at 39.
scription" so long as they are not unreasonable, arbitrary or oppressive.68

b. Quarantine

Many courts after Jacobson continued to grant states broad power to regulate the public health based on a "reasonably related" standard,69 the power of the states to quarantine individuals fell under this power.70 In the most extreme example, the New York Court of Appeals upheld the quarantine of a woman who was not sick with a communicable disease but merely lived next-door to somebody who was.71 The court justified its holding on the premise that "[a]mong all the objects to be secured by governmental laws, none is more important than the preservation of the public health," and statutes conferring such an important power should be construed liberally to ensure that the ends for which the powers were granted be achieved.72

As late as the 1950s, courts continued to respect broad legislative authority to quarantine based on a reasonableness standard. For example, in Moore v. Draper,73 the court denied a writ of habeas corpus challenging involuntary confinement under a TB control act because

(1) laws and regulations regarding public health were a subject for the legislature; (2) appropriate measures intended and calculated to accomplish these ends were not subject to judicial review; and (3) the constitutional guarantees of life, liberty, and property do not limit the police power of the state provided that the exercise of police power is not arbitrary or unreasonable.74

3. Limitation on State Interest

During the 1960s and 1970s, the courts began to expand the scope of constitutionally protected interests,75 and as a result, more restrictions

67. Id. at 25 (quoting Gibbons v. Ogden, 22 U.S. (9 Wheat.) 1, 203 (1824)).
68. See id. at 27, 38.
69. See supra note 49 and accompanying text.
70. For a general discussion tracing judicial decisions regarding past and present legislative quarantine efforts, see Wendy E. Parmet, AIDS and Quarantine: The Revival of an Archaic Doctrine, 14 Hofstra L. Rev. 53 (1985).
72. Id. at 358 (citations omitted).
73. 57 So. 2d 648 (Fla. 1952).
75. See Note, The Constitutional Rights of AIDS Carriers, 99 Harv. L. Rev. 1274, 1278-79
were placed on the involuntary quarantine of individuals.\textsuperscript{76} For example, in \textit{O'Connor v. Donaldson},\textsuperscript{77} a patient was quarantined to a mental institution after a hearing before a county judge. The patient was held against his will in the mental hospital for over fifteen years, despite repeated requests for release. In ruling that a finding of mental illness alone could not justify involuntary confinement, the Supreme Court indicated the strength and importance of the patient's liberty interest.\textsuperscript{78}

During this period, the courts began to delineate the strict scrutiny and intermediate scrutiny standards. Strict scrutiny applies when fundamental rights are burdened by legislation and "requires the state to prove that the chosen action was the least restrictive alternative."\textsuperscript{79} Intermediate scrutiny applies when quasi-suspect classes are involved or when substantial, albeit not fundamental, rights are burdened by legislation.\textsuperscript{80} Under this standard, a state must prove that the legislation furthers an important government objective through means which are substantially related to that end.\textsuperscript{81} Recall that where neither strict scrutiny nor the intermediate standard applies, courts rely on the reasonableness test, wherein the legislative regulation or statute is upheld unless it does not further a legitimate state interest.\textsuperscript{82}

\subsection*{a. Washington State Tuberculosis Statutes}

A present day example of the state police power to protect the public health against disease is the recent revision of the Washington State tuberculosis ("TB") laws which incorporated notions of due process and thereby limit the scope of the state police power.\textsuperscript{83} The laws

\begin{itemize}
\item \textsuperscript{76} See Reilly, \textit{supra} note 74, at 117.
\item \textsuperscript{77} 422 U.S. 563 (1975).
\item \textsuperscript{78} See \textit{id.} at 575-76.
\item \textsuperscript{79} See \textit{Note}, \textit{supra} note 75, at 1277 n.24 (citing Dunn v. Blumstein, 405 U.S. 330, 343 (1972)); \textit{see also infra} Part IV.B. (discussing the fundamental rights which trigger strict scrutiny, focusing on privacy rights).
\item \textsuperscript{80} See, e.g., Craig v. Boren, 429 U.S. 190 (1976) (applying intermediate scrutiny to gender classification); Bell v. Burson, 402 U.S. 535 (1971) (applying intermediate scrutiny to a statute which deprived individuals of driver's licenses).
\item \textsuperscript{81} See \textit{Craig}, 429 U.S. at 197.
\item \textsuperscript{82} See Moore v. Draper, 57 So. 2d 648, 650 (Fla. 1952).
\end{itemize}
were reconsidered after medical and political assessments regarding the development of new, multidrug resistant strains of TB and because of the clinical relationship between TB and HIV. Due to the deterioration of the public health infrastructure and the increased resistance to TB treatment, Washington reformulated its TB laws so that non-compliant individuals can be required to submit to screenings in order to detect the presence of the disease. In addition, physicians are required to report to the name, sex, occupation, and residence of TB patients to the local Board of Health. The most significant change in the new law is the implementation of due process standards which now offset the state’s police power. This juxtaposition of explicit due process protection for the individual and the state’s broad police power signifies a recognition, in this instance, of the sanctity of an individual’s fundamental right to privacy, albeit one subordinate to the public health.

b. HIV and AIDS

The advent of AIDS and the rapid increase in the number of cases of this incurable disease has caused great public concern about controlling the spread of the contagion. In the early 1980s, as the public gained initial knowledge about the AIDS virus, legislative attempts to contain the situation included “proposals for the massive screening of large segments of the population and for the quarantining of all individuals who tested positive for the antibody.” Much of this legislative effort clearly reflected misconceived public perception rather than scientific proof regarding the communicability of the disease. Unlike TB, which is spread through the air as a result of continued casual exposure, AIDS

84. See Vincler & Gordon, supra note 83, at 990-91.
85. See id. at 992.
88. See Vincler & Gordon, supra note 83, at 1007.
90. For a thorough description of the AIDS virus, see Rosencranz & Lavey, supra note 6, at 95-101.
92. For example, over 25% of Americans favor putting people with AIDS into quarantine. See Note, supra note 75, at 1281.
can only be transmitted by sexual contact or a mingling of body fluids.93 Current testing programs now reflect accepted scientific principles about AIDS, HIV, and its transmission. As a result, most screenings for HIV and AIDS have been implemented on a voluntary nature due to concerns such as confidentiality, stigmatization, and discrimination.94 Due to these concerns, it is useful to determine whether a mandatory or voluntary screening program best serves the state’s purpose in controlling the spread of HIV and AIDS.

Professor Steven Eisenstat has provided the following guidelines in assessing whether a voluntary or mandatory testing program is preferable in the context of HIV and AIDS: (1) What is the goal underlying the testing scheme, and does the testing scheme help achieve that goal? (2) Does the testing scheme provide a sufficiently reliable indication of the HIV status of the subject? (3) Presuming that the testing scheme serves a public health purpose, does it require the expenditure of funds and resources which could be utilized in a more effective manner? (4) Will the testing program discourage individuals who would otherwise voluntarily seek HIV education and testing from doing so, due to their fear of the nonconsensual disclosure of their test results to third parties?95 The following two sections explore the contrast between mandatory and voluntary HIV and AIDS screenings and identify when it is appropriate to use each method based on the availability of relevant technologies.

i. Voluntary Testing

Professor Eisenstat’s framework reveals that, generally, voluntary testing is more appropriate with regard to the public at large when addressing the prevention and spread of AIDS. First, although the state interest in protecting the public would be almost invariably satisfied, there must be some nexus between the activities likely to spread AIDS and the subjects of the testing.96 A mandatory screening en masse would be irrational and invalid since the goal of the underlying testing scheme could not be achieved by testing random subjects. A voluntary screening program, by contrast, would be rational as those individuals present-

93. See Eisenstat, supra note 91, at 336.
94. See infra Part III.A.3.b.i.
95. See Eisenstat, supra note 91, at 340 & n.78 (citing Lawrence O. Gostin et al., The Case Against Compulsory Casefinding in Controlling AIDS—Testing, Screening and Reporting, 12 Am. J.L. & Med. 7, 21-24 (1987)).
ing themselves for testing would do so only if they thought they had been exposed to HIV or AIDS.

Second, voluntary testing presupposes the test subject’s recognition of the risk of exposure to the detrimental effects of the AIDS virus and the importance of being tested. Therefore, a voluntary program would provide a more reliable indication of the HIV status of a subject who is, presumably, more wary of a possible false negative result of the screening. Currently, tests for HIV and AIDS only screen for the antibody produced by the virus and do not identify the presence of the virus itself. Therefore, patients who are infected, but whose immune systems have not yet begun to manufacture the necessary antibodies, will receive a negative test result. Those patients who are voluntarily screened will be more apt to interpret such a test result in light of their personal circumstances. Individuals who are mandated to receive testing may not appreciate such a result, and relying on a premature negative test result, may not take any precautions.

Third, as voluntary testing does not use more funds than will be necessary to meet the demand of those who proactively seek the screening, it is likely to be less expensive than mandatory testing. Alternatively, a mandatory screening procedure would require funds sufficient to encompass a much larger patient base, as well as potentially provide for ancillary components of a testing program such as counseling and medications.

Finally, a voluntary program is less likely to discourage individuals from undergoing screenings for fear of nonconsensual disclosure of screening information. Mandatory testing goals usually rest on the need to gather and then distribute the information regarding positive test results to persons other than those tested, including medical personnel, health officials, and sometimes employers. In addition, a patient, although consenting to the release of information to the aforementioned third parties, may feel insecure if there are no additional confidentiality safeguards designed to protect the further dissemination of sensitive information beyond these parties. Recent surveys indicate that “societal biases” against AIDS victims “are clearly still operating”; consequently, many individuals potentially infected with HIV or AIDS may

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97. See id. at 331.
98. See infra notes 209-14 and accompanying text.
100. See Ronald Bayer, AIDS and the Gay Community: Between the Specter and the Promise of Medicine, 52 Soc. Rev. 581, 600-01 (1985).
101. Eisenstat, supra note 91, at 366.
actively attempt to avoid the testing rather than risk being discriminated against when seeking employment, medical treatment, housing, and life and health insurance. A voluntary testing program, with assurances of confidentiality and a restricted use of information for the limited purpose of helping the patient, would quell some of these fears. A likely result of voluntary patient participation is also patient behavior modification. "It would appear to be somewhat unrealistic to rely upon self-induced behavior change and notification by people who are being tested against their will." Since a successful testing program would rely upon the continued cooperation of its subjects, mandatory testing could turn subjects away, thereby defeating the goals of the program.

ii. Mandatory Screening

There are certain circumstances under which mandatory testing has been deemed constitutional by the courts. The examples below will illustrate that, generally, such circumstances include diminished privacy expectations and conditions where transferability is more likely to occur.

Mandatory HIV testing for military employees seeking foreign assignment was upheld by a District Court for the District of Columbia. In Local 1812, American Federation of Government Employees v. United States Department of State, the plaintiff sought to enjoin the administration of mandatory screening—claiming that such screening was a violation of his Fourth Amendment rights against unreasonable search and seizure and therefore infringed on his personal privacy. The court noted that the intrusion of the patient’s bodily integrity was minimal as the HIV test would be part of an overall health exam during which blood was drawn for other purposes. Under these circumstances, the individual had a diminished expectation of privacy. As such, the court relied upon the rational relationship standard to sustain the regulation, stating that the Department’s purpose of ensuring that military person-

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102. See id. It has been suggested that “AIDS is the modern day equivalent of leprosy.”

103. See Eisenstat, supra note 91, at 341-42.

104. Id.


106. See id. at 53.
nel going overseas were "fit for duty" was rationally related to the HIV testing.107

New York's recent promulgation of a mandatory HIV screening program for newborns108 signals what may be an emerging trend in using screening technologies to prevent the control and spread of diseases. This statute makes New York the first state to implement a mandatory HIV screening program for newborns.109 The new program110 came as a response to proven medical assessments which indicated that "steps before or at birth can reduce substantially the rate of AIDS transmission from mother to infant."111 One study found that "[a] regimen of . . . [AZT] administered to the mother during pregnancy and during labor and delivery, as well as to her infant during the first six weeks of life significantly reduced the risk of maternal infant transmission of HIV from 25.5% to 8.3%."112

In order to pass constitutional challenges, the State of New York must demonstrate that there is a legitimate state interest in the mandatory screening program and that no other less intrusive alternative would achieve the intended goal(s).113 The state goal for implementing the mandatory screening is two-fold: (1) to reduce the spread of HIV and inhibit the onset of AIDS to newborns through identification and early treatment of HIV-positive infants; and (2) to educate HIV-positive

107. See id.
110. Regulations implementing and governing the comprehensive program are authorized under N.Y. PUB. HEALTH LAW § 2500-f. See supra note 108.
111. Congress Addresses Newborn’s HIV Tests, TIMES UNION (Albany), May 1, 1996, at A3. The finding was considered so important that the study conducted on pregnant women, which revealed these results, was ended early so that those women whose babies tested positive could take advantage of treatment options rather than remaining on placebos. See Linda Farber Post, Note, Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?, 16 CARDOZO L. REV. 169, 176 n.50 (1994). Some believe post-natal testing to be somewhat hopeless: the "testing of newborns will not prevent the transmission of HIV to a single baby." Deal Will Fund HIV Tests for Pregnant Women, BUFFALO NEWS, May 1, 1996, at A9 [hereinafter Deal Will Fund HIV Tests] (quoting Sen. Edward M. Kennedy of Massachusetts).
112. Post, supra note 111, at 176 n.50 (quoting NATIONAL INST. OF ALLERGY AND INFECTIOUS DISEASES, CLINICAL ALERT, IMPORTANT THERAPEUTIC INFORMATION ON THE BENEFIT OF ZIDOVUDINE FOR THE PREVENTION OF THE TRANSMISSION OF HIV FROM MOTHER TO INFANT (1994)).
113. See id. at 202.
women both on the modification of high risk behaviors and on the methods of coping with an HIV infant. Specifically, the purpose of the modification to the Public Health Law’s voluntary testing statute was to “ensure that newborns who are exposed to HIV receive prompt and immediate care and treatment and counseling that can enhance, prolong and possibly save their lives.” Proponents of the new law praise its role in saving the lives of newborns who are incapable of taking care of themselves and who need protection in the event that the mother is unaware of her status or chooses not to pursue treatment for herself or for her child. “Given the recent advances made regarding the prevention of HIV transmission from mother to child, it would be a tragedy if out of ignorance, fear, or lack of health care, children are born with a deadly disease that could have been prevented.”

Opponents of the new law maintain that such mandatory testing offends the constitutional rights that shield individuals from unreasonable search and seizure, as well as the right to privacy. Most importantly, opponents feel that the mandatory nature of the testing will result in the opposite effect of its stated purposes because many of the women will be frightened away from prenatal care due to the prospect of being tested without their consent, especially if they are uneducated about the risk of AIDS to themselves or their children. In addition, many women want to avoid unnecessary stigmatization due to being labeled as “diseased.” Despite these concerns, ninety-three percent of the women surveyed by the Health Department stated that they would have voluntarily agreed to be tested and notified of the test results.

114. See id. at 181. When infants test positive for HIV, the statute provides for the following: post-test counseling (with the informed consent of the mother or person authorized by law to give such consent); arrangements for health care, case management, and other related services; the mother will be provided with referrals for health treatment of the mother and the infant; and strict confidentiality of test results. See Comprehensive Newborn HIV Screening Program, 19 N.Y. St. Reg. 11, 12 (1997).


117. Id. (quoting Sen. Edward M. Kennedy of Massachusetts, ranking Democrat on the Senate Labor and Human Resources Committee).

118. See infra Part IV.B.


120. See Young, supra note 108, at A40.

121. See Sontag, supra note 109, at B6.
B. Privacy Interests of the Individual

Any screening program that necessitates the taking of blood or results in the revelation of highly personal, sensitive medical information implicates the privacy interests of the individual being tested. In the context of medical screenings, the privacy of an individual can be implicated in two ways under the law: (1) unreasonable intrusion under the Fourth Amendment and (2) infringement under the Fourteenth Amendment.

1. Fourth Amendment

The Fourth Amendment protects an individual from unreasonable searches and seizures. The Supreme Court in *Schmerber v. California* decided that the constitutional concerns of mandatory testing "plainly involve[] the broadly conceived reach of a search and seizure under the Fourth Amendment." In the following year, the Supreme Court developed a balancing test designed to assess the reasonableness of the state's intrusion on an individual. In *Camara v. Municipal Court*, the Court first enunciated the need for this test stating that "there can be no ready test for determining reasonableness other than by balancing the need to search against the invasion which the search entails." In that case, the Court considered whether probable cause existed for routine periodic inspections of property to ensure the minimum standards under the local housing code when such inspections were not the result of individualized suspicion. After balancing the concerns, the court held that such inspections were a reasonable invasion necessary to ensure those minimum standards, and as such, probable cause for a warrant existed in order to effectuate such searches of private property.

Currently, the Court maintains the use of the balancing test and has adapted it to better analyze varying degrees of privacy under different circumstances. "Fourth Amendment interests are those interests that relate to an individual's expectations of privacy." Diminished expecta-

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122. See U.S. CONST. amend. IV. "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated . . . ." *Id.*


124. *Id.* at 767.


126. *Id.* at 536-37. The Court also considered and applied the balancing test in the criminal context. See *Terry v. Ohio*, 392 U.S. 1, 12 (1968).

127. See *Camara*, 387 U.S. at 538-39.

tions of privacy have been found in circumstances where the state has demonstrated a “special need” to intrude on an individual’s privacy in order to ensure the public health or safety under the police powers.129

a. Public Safety

Mandatory blood and urine testing has been constitutionally upheld, despite the absence of warrants and individualized suspicion, on the grounds that it is reasonably related to furthering the state’s interest in protecting the public safety.130 For example, in Skinner v. Railway Labor Executives’ Ass’n,131 railroad employees claimed that a regulation requiring mandatory drug and alcohol testing was an unreasonable search and seizure under the Fourth Amendment. The Federal Railroad Administration regulations

(i) require[d] drug and alcohol testing of blood and/or urine specimens of employees involved in train accidents resulting in death, injury or property damage in excess of $500,000; (ii) permit[ed] breath or urine tests when a supervisor has a “reasonable suspicion” that an employee contributed to a reportable accident or incident or when an employee has violated certain rules; and (iii) permit[ed] breath tests based upon personal observation giving rise to a “reasonable suspicion” that the employee is under the influence of alcohol.132

The Court balanced the employee’s reasonable expectation of privacy against the safety considerations inherent in the performance of their jobs and held that although the test did constitute a search, it was not unreasonable.133 The Supreme Court upheld the regulations, ruling that the government’s substantial interest in safe rail transportation justified a departure from the ordinary warrant and probable cause requirements and, therefore, particularized suspicions were not necessary.134 As the Court noted, “the expectations of privacy of . . . employees are diminished by reason of their participation in an industry

land v. Buie, 494 U.S. 325, 333 (1990)).

129. Some commentators have characterized these searches as administrative in nature. See id. at 496.


134. See id. at 624.
that is regulated pervasively to ensure safety, a goal dependent, in substantial part, on the health and fitness of . . . employees."

b. National Security

Protecting national security has been another justification for mandating a genetic screening program. The U.S. Customs Service, in National Treasury Employees' Union v. Von Raab, required drug testing of employees applying for or occupying positions involving drug interdiction, the carrying of firearms, or the handling of classified materials. The Court held that the testing program, which did not require reasonable suspicion of drug or alcohol use, was a search under the Fourth Amendment and therefore must meet the Fourth Amendment reasonableness requirement. After examining the interests of the state under strict scrutiny, the Court held that the regulation was constitutional because the state interest in ensuring national security outweighed the employees' diminished expectation of privacy.

c. Public Health

Courts have relied upon the balancing approach outlined in cases such as Skinner and Von Raab when analyzing the validity of intrusions on the individual for the purpose of maintaining the public health. For example, in Dunn v. White, the Court of Appeals for the Tenth Circuit upheld mandatory testing of prisoners for the AIDS virus on the

135. Id. at 627; cf. Capua v. City of Plainfield, 643 F. Supp. 1507, 1516, 1520 (D.N.J. 1986) (holding that the mass screenings of the City's police and fire departments did violate the Fourth Amendment because the City "had no general job-related basis for instituting this mass urinalysis, much less any individual basis").
137. See id. at 660. The court did not consider the reasonableness of testing those who apply for positions where they would handle classified material. See id. at 677.
138. See id. at 665.
139. See id. at 672, 679.

The Government's compelling interests in preventing the promotion of drug users to positions where they might endanger the integrity of our Nation's borders or the life of the citizenry outweigh the privacy interests of those who seek promotion to these positions, who enjoy a diminished expectation of privacy by virtue of the special, and obvious, physical and ethical demands of those positions. Id. at 679.

140. 880 F.2d 1188 (10th Cir. 1989).
grounds that the intrusion on the prisoner’s Fourth Amendment privacy rights was reasonable under the circumstances. There the court held that prisoners have a lowered expectation of privacy, and that the screening program was rationally related to the state’s substantial interest in preventing the spread of AIDS among the prison community. Also, the court noted in dicta that “the state’s interest in public health may even justify a similar intrusion on free world residents.”

In *Karolis v. New Jersey Department of Corrections*, a New Jersey District Court relied, in part, on *White* in upholding a similar regulation requiring that prisoners be screened for TB. In *Karolis*, the plaintiff claimed that the testing violated his Fourth Amendment right against unreasonable search and seizure and his First Amendment right of freedom of religion. As a Christian Scientist, the plaintiff opposed “intrusive medical procedures.”

The court analyzed the prison policy under strict scrutiny because fundamental rights of privacy were implicated. The court found that the plaintiff had a lowered expectation of privacy due to his status as a prisoner, and that the state had a compelling interest in responding to the threat of any contagious disease by testing and treating prisoners. Additionally, it found that the state had an “affirmative duty” to protect inmates from the spread of infectious disease and that to neglect this duty would be a violation of the constitutional rights of other prisoners. The court concluded by holding that the TB test administered by the prison was the least restrictive means of furthering the state’s compelling interest.

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141. See id. at 1196-97.
142. See id. at 1194-96.
143. Id. at 1195.
145. See id. at 524-25.
146. Id. at 525.
147. See id. at 527.
148. See id.; cf. Jolly v. Coughlin, 76 F.3d 468, 482-83 (2d Cir. 1996) (holding invalid a policy of mandatory TB testing because keeping noncompliant prisoners in “medical keeplock” was not shown to be the least restrictive means to further the compelling state interest).
149. See *Karolis*, 935 F. Supp. at 528-29. The court stated that the TB test indicates dormant TB while the next best alternative, a chest x-ray, will only show signs of active TB. See id. at 529. “This distinction is critical. By the time an x-ray shows signs of TB, the infected individual may have been spreading the disease to other inmates, whereas a positive [TB] test would trigger preventative therapy.” Id. (citation omitted).
2. Fourteenth Amendment Right to Privacy

A right to privacy, although not explicitly mentioned in the Constitution, has been generally recognized by the Supreme Court as a fundamental right afforded citizens under the Fourteenth Amendment due process provision. The Supreme Court in *Griswold v. Connecticut* relied on the Federal Constitution to find that specific guarantees in the Bill of Rights form "penumbras" and create certain "zones of privacy." In so holding, the Court determined that a married couple has a privacy right in their marital relations, and that a state law which criminalizes the use of contraceptive devices represents an unconstitutional intrusion upon this right.

This judicially created privacy right developed generally into two forms: 1) the right of selective disclosure and 2) the right of autonomy in personal decision-making.

a. The Right to Selective Disclosure

The Supreme Court presented some of the basic principles supporting the right to selective disclosure in *Whalen v. Roe*. In *Whalen*, a New York statute required that the state be provided with a copy of every prescription for "certain drugs for which there is both a lawful and an unlawful market." The statute was designed to "prevent unscrupulous pharmacists from repeatedly refilling prescriptions, to prevent us-

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151. 381 U.S. 479 (1965).

152. See id. at 484.

153. See id. at 485-86.

154. The right of selective disclosure is an individual's right in not having personal and sensitive information disclosed to others. See Skinner v. Railway Labor Executives' Ass'n, 489 U.S. 602, 617 (1989) (holding that an employer cannot disclose medical information beyond drug abuse); Whalen v. Roe, 429 U.S. 589, 599-600 (1977) (noting individual's right to avoid "disclosure of personal matters").

155. Autonomy is "personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. . . . A person's autonomy is his or her independence, self-reliance, and self-contained ability to decide." TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 56 (1979); see also Jed Rubenfeld, The Right of Privacy, 102 HARV. L. REV. 737, 750-51 (1989) (stating that privacy includes the "right to make choices and decisions").


157. Id. at 591. The drugs at issue in *Whalen* were classified as "Schedule II drugs" and included opium, cocaine, methadone, amphetamines, and methaqualone. See id. at 593 & n.8.
ers from obtaining prescriptions from more than one doctor, or to pre-
vent doctors from overprescribing.” The plaintiffs argued that even if confidentiality was ensured, the State failed to meet a necessity re-
quirement since the information used in the databank was accessed only two times during the first twenty months of the program’s existence. The Court recognized the right of a patient to avoid “disclosure of per-
sonal matters,” but determined that the state’s public health interest in data collection was a reasonable exercise of its broad police power to regulate the public health. The Supreme Court also found that the State’s failure to show a sufficient basis for the statute was insufficient to deem the statute unconstitutional. Importantly, the Court noted the necessity of affording the states broad police power to regulate the public health in order to encourage progress and guard against judicial prejudices. Specifically, the Court recalled Justice Brandeis’s state-
mation:

To stay experimentation in things social and economical is a grave re-
sponsibility . . . . It is one of the happy incidents of the federal system that a single courageous State may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country. This Court has the power to prevent an experiment . . . . But in the exercise of this high power, we must be ever on our guard, lest we erect our prejudices into legal principles. If we would guide by the light of reason, we must let our minds be bold.

More recently, in Doe v. City of New York, the United States Court of Appeals for the Second Circuit held that individuals have a right to privacy regarding their HIV status. In Doe, the City of New York Commission on Human Rights released the plaintiff’s HIV status in a press release detailing the resolution of a complaint that Doe filed against a potential employer alleging discrimination based on his homosexuality and HIV-positive status. Plaintiff Doe claimed that release of such personal information was a violation of his right to privacy.

158. Id. at 592.
159. See id. at 595.
160. Id. at 599.
161. See id. at 598.
162. See id. at 597.
163. Id. (quoting New State Ice Co. v. Liebmann, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting)).
164. 15 F.3d 264 (2d Cir. 1994).
165. See id. at 267.
and would likely lead to further discrimination and ostracism. The Second Circuit, in balancing the interests of Doe and the State, relied on Whalen, and concluded that the Constitution protects an individual’s right to privacy regarding the disclosure of personal information. Compassionately, the Court of Appeals noted:

Clearly, an individual’s choice to inform others that she has contracted what is at this point invariably and sadly a fatal, incurable disease is one that she should normally be allowed to make for herself. This . . . is especially true with regard to those infected with HIV or living with AIDS, considering the unfortunately unfeeling attitude among many in this society toward those coping with the disease.

b. The Right of Autonomy in Personal Decision-Making

The Supreme Court recognizes an individual’s right to make decisions free from undue governmental interference. Beginning with Griswold, the Supreme Court delineated a limited spectrum of privacy rights included in the “penumbra” which are constitutionally protected. These decisions generally include matters of contraception, marriage, procreation, and education.

Most relevant to the state’s police power to regulate public health, the Supreme Court began to recognize the importance of individual health decisions free from government interference. For example, in Roe v. Wade, a woman was found to have a limited right to choose abortion free from government interference. In Cruzan v. Director, Missouri Department of Health, it was held that an individual has a right to refuse medical treatment. The Court premised its decisions on the notion that “the Constitution embodies a promise that a certain private sphere of individual liberty will be kept largely beyond the reach of government.”

166. See id. The court noted that this right is more accurately “characterized as a right to ‘confidentiality’” regarding the status of one’s health. Id.
167. Id.
169. See Loving v. Virginia, 388 U.S. 1, 2 (1967).
172. See Roe, 410 U.S. at 117-18.
173. See 497 U.S. 261, 270 (1990). However, the Court held that a state can require “clear and convincing evidence of the patient’s” desire to refuse medical treatment. Id. at 286-87. Such evidence was not available in Cruzan. See id.
health and particularly death, "the ... challenging task of crafting appropri-ate procedures for safeguarding ... liberty interests is entrusted to the 'laboratory' of the States." The right to autonomous decision-making, however, is limited by concern for the public as a whole, and may be vulnerable to a compelling state interest—particularly in preserving human life.

Although previous cases such as Cruzan have established a patient's right to refuse medical treatment, the Supreme Court has distin-guished acts such as physician-assisted suicide. In Washington v. Glucksberg and Vacco v. Quill, the Supreme Court refused to find a constitutional privacy right to physician-assisted suicide. The Court rec-ognized the difficulty of determining whether a patient's privacy right outweighed the state's interest in guarding against an involuntary hastening of death. After weighing the competing interests, the Court held that the New York and Washington statutes banning physician-assisted suicide were rationally related to a variety of government interests. Those interests include protecting those individuals who are not truly competent or those who are facing imminent death from making involuntary decisions to hasten death, as well as protecting the medical profession's integrity, and those vulnerable to abuse, neglect, mistake, or social indifference.

The right of autonomy in personal decision-making appears to be unsettled, but Justice O'Connor, in a concurring opinion, enunciated the following description of the right: "Whatever the outer limits of the [substantive sphere of liberty] may be, it definitely includes protection for matters 'central to personal dignity and autonomy.'" This right, according to O'Connor, also includes those decisions that will affect an individual's, or his family's, destiny.

\[\text{\textsuperscript{179}}\]
Competing individual and state interests must be examined in order to determine whether the state should implement a genetic screening program, as well as to establish the bounds of such a program. Although genetic screenings have been used in the past, the completion of the Human Genome Project together with a growing understanding of genetic disease is likely to result in the implementation of genetic knowledge in our everyday lives. Genetic tests developed from this advancing technology is one way through which the benefits of genetic discovery are reaching the public. "It is no exaggeration to aver that genetic testing will, over the course of the next two decades, revolutionize medicine." Genetic screenings will facilitate early detection of disease so that steps can be taken to prevent the onset of the disease, or to reduce the amount of suffering associated with a disease for which there is no current treatment. In addition, scientists will be able to use the genome relational maps to build on existing technologies such as gene therapy and to create new surgeries which will dissipate the effects of genetic diseases. This new information and corresponding developments in treatment technologies would arguably enable a state to find support for implementing a mandatory genetic screening program under its police power. The question then becomes at what point, if any, does the state’s interest in promoting the public health rise to the level of compelling such that individuals must submit to genetic screening for particular diseases.

Generally, the state must demonstrate a compelling interest in protecting public health, safety, or morals when such protection will infringe on the fundamental rights afforded under the Constitution. Genetic testing would implicate fundamental privacy rights of selective disclosure and autonomous decision-making, as well as the Fourth

181. See supra Part III.A.
182. See Fletcher & Wertz, supra note 20, at 758. The authors predict that not only will "[g]enetic information ... transform the practice of medicine ... by every physician," but "children will be raised with the intuition" that genetic information is essential to a healthy existence. Id. (emphasis added).
183. Reilly, supra note 57, at 1333.
184. See infra Part IV.B.2.
185. See supra text accompanying notes 110-12 (discussing how the State of New York used new medical assessments regarding the beneficial effects of early administration of AZT to newborns to support a compelling interest in mandating HIV testing of pregnant mothers).
187. See supra Part III.B.2.
Amendment right against unreasonable search and seizure. Specifically, the government would need to show a compelling interest in the goals of genetic screenings and that such screening statutes were narrowly drawn so as to be the least intrusive method of achieving the state goals before such screening could be mandated.

A. Compelling State Interest in Genetic Screening

In order to successfully implement a mandatory genetic screening program, the state must demonstrate a compelling state interest in the goals of the program. Such interest may rise to the level of compelling if the state can support its rationale for the program with newly released medical discoveries surrounding gene function and the location of genetic diseases on genes. The state’s interest in mandating screening would gain further support with the emergence and development of corresponding technologies which would enable physicians to reduce or even eliminate genetic disease.

The following examples survey some of the more common state rationales for instituting screening programs. These illustrate that in most cases the state’s interest does rise to the level of compelling; however, Professor Eisenstat’s four-prong test, as applied to each scenario, will illustrate that mandatory genetic testing may not be the least restrictive means of achieving the government’s purpose.

1. Preventative Medicine

“The most likely objective of selective genetic screening is improvement in the quality of life by identifying carriers and victims of genetic disease.” This objective can be achieved in a variety of ways, most prominently in prevention efforts. The Human Genome Project’s

188. See supra Part III.B.1.
189. See supra Part III.A.3. for a discussion of compelling state interest in regulation of public health. See also Regents of Univ. of Cal. v. Bakke, 438 U.S. 265, 320 (1978) (holding that a system which reserved positions for disadvantaged minority students was not the least intrusive means of achieving the intended goals).

In reviewing a legislative provision that infringes on constitutional rights, judicial scrutiny will focus not only on “the ends the state seeks to further but also, on ... the necessity of the means which the state has used to achieve its ends.” LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW § 6-13, at 438 (2d ed. 1988).

190. See supra Part III.A.3.
191. Privacy interests of the individual will be addressed below. See infra Part IV.B.
192. Smith & Burns, supra note 4, at 38.
maps will allow scientists to determine more precisely when an individual has or is predisposed to a disease before becoming symptomatic. "Foreknowledge of risk [of disease] presents the opportunity for close monitoring, early diagnosis, and curative interventions." Thus, physicians can concentrate their talents on preventing the actual onset of disease, mitigating the severity of symptoms or preparing patients physically for the inevitable occurrence of disease.

For example, since the early 1960s, medical researchers have designed and implemented screening of newborns thought to be at high risk for phenylketonuria ("PKU"), a genetic disease which, if untreated, can lead to severe retardation. Once the newborns were identified as having this disease, a simple dietary change was all that was necessary for the infants to "mature into perfectly normal, healthy adults." In addition, genetic testing can also be used to screen for incurable or deadly diseases, enabling one who is predisposed to a particular disease to ascertain the probability of its onset. This information is relevant in family planning as well as personal well-being. To illustrate, if an individual has PKU, a simple dietary change can be implemented to prevent severe retardation.

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194. See Iles, supra note 36, at 30. "Once this integrated map is available, locations can be established for ... disorders or predispositions for genetic disease." Id. Genetic tests can then be developed from this information in order "to detect biological changes very early and allow anticipation of problems that may not be visibly expressed in overt symptoms for years." Dorothy Nelson & Laurence Tancredi, Classify and Control: Genetic Information in the Schools, 17 Am. J.L. & Med. 51, 57-58 (1991).

195. Reilly, supra note 57, at 1333.


197. For an historical overview of early state mandated PKU testing from 1963 to 1969 and a survey and citations of the state legislation where such testing was required, see Reilly, supra note 36, at 43-61.


199. Levine & Suzuki, supra note 9, at 232. PKU is a single gene defect; as such, the results of genetic screening are highly determinative, producing results that can be analyzed quickly with relatively less room for error. See id.

Currently genetic tests are available for a variety of other more complex conditions. See Gordon Slovut, Genetics and Medicine; Genetic Testing Makes an Ounce of Prediction Worth a Pound of Fear; Patients, Insurers, Doctors Question Who Should Be Told, Star T(Arg., Oct. 25, 1995, at 1A. Genetic screening exists for some forms of leukemia, cancer, ataxia (inability to coordinate muscle activity), cystic fibrosis, fragile X (mental retardation), myotonic dystrophy (progressive muscle weakness), hemophilia, Huntington's Disease, sickle cell anemia, and Tay-Sachs. See id.

Scientists remain hopeful that they can develop screenings for the more common diseases such as heart disease, colon cancer, lung cancer, and Alzheimer's. See generally Gina Kolata, If Tests Hint Alzheimer's, Should a Patient Be Told?, N.Y. Times, Oct. 24, 1995, at A1 (discussing genetic testing that reveals susceptibility to both heart disease and Alzheimer's).
individual is diagnosed with an incurable disease before the onset of debilitating symptoms, early detection through genetic screening gives patients the opportunity to prepare mentally, physically, and financially for future suffering. 200

Finally, various fiscal goals of the health care industry can be furthered by using genetic screening for preventative purposes. For example, managed care organizations may rely on genetic screenings to keep overall costs down. 201 By screening members for genetic disease or the predisposition for disease, managed care can begin to administer preventive care earlier to avoid the higher costs of treating advanced sickness and disease. 202

The state interest in preventative medicine seems to satisfy the compelling component of the balancing inquiry; however, application of Professor Eisenstat’s four-prong test will illustrate that there may be some shortcomings inherent in such an interest. First, the goal of the testing programs—early diagnosis of the onset or predisposition of genetic disease in order to engage in preventative care—will be met by genetic screening only if the program also includes treatments for such ailments. Diagnosing a genetic disorder which has no cure can frustrate this purpose as people may react self-destructively.

Second, a successful testing program also assumes that the tests are accurate in administration and results. Without accuracy, adverse consequences could easily occur because people will rely on false test results. For example, there is currently no evidence that screenings for ovarian cancer are effective in reducing the number of deaths caused by

200. For example, after Louisa May Alcott was tested and found out that she had a high risk of contracting Huntington’s disease, she commented, “It was now a fact of my life that I had Huntington’s. How I choose to live from this point on is my choice . . . . I can readjust my wants and priorities.” Kimberly A. Quaid, A Few Words from a “Wise” Woman, in GENES AND HUMAN SELF-KNOWLEDGE: HISTORICAL AND PHILOSOPHICAL REFLECTIONS ON MODERN GENETICS 3-17 (Robert F. Weir et al. eds., 1994).


202. Lowering the costs of health care and allocating scarce medical interests are incentives for the state to take action in implementing genetic screening. However, economic burden on the state, while recognized as a legitimate state interest, does not, by itself raise the state’s interest to the level of compelling. See, e.g., M.L.B. v. S.L.J., 117 S. Ct. 555, 567 (1996) (noting the state’s legitimate interest in offsetting the costs associated with indigent litigants); McKesson Corp. v. Division of Alcoholic Beverages and Tobacco, 496 U.S. 18, 50 (1990) (recognizing state’s legitimate interest in sound fiscal planning).

It is important to note that although genetic screening may prove effective in managing health care costs, the information gained through such screening can be misused by insurance underwriters to discriminate against certain genetically predisposed people. See infra Part IV.B.2.a.i.
the disease. Women subjected to the test who receive unconfirmed positive test results have often agreed to surgery exposing them to disabilities, infections, and other adverse health consequences. Of these women, only a “tiny fraction” of those undergoing the surgery are found to actually have the disease. The NIH concluded that these tests currently are ineffective as they lead to ambiguous results, and that the best indicator of a woman’s predisposition or presence of genetic ovarian cancer is tracing family history and applying the appropriate probabilities.

Suppose, however, that technology existed at a relatively low cost which would reduce the onset of ovarian cancer or completely prevent its occurrence. The state, in these circumstances, may have an interest in mandating testing under its police powers for the purpose of protecting the women at risk of developing this particular type of cancer. Yet this argument is likely to be defeated by legislative and judicial precedent as evidenced, for example, by the overturn of the mandatory SCA statutes, mandatory HIV screening en masse, and the judicial recognition of the right to refuse medical treatment.

Third, presuming that the testing program furthers public health goals, the next question is whether mandatory testing for preventative medical purposes utilizes resources that could be more efficiently used in another manner. This question assumes the accuracy of test results and availability of treatments. A mandatory screening program provides the opportunity for all patients at risk to acquire important information about their own and perhaps their family’s health. However beneficial this purpose is, mandatory testing also carries with it a potential responsibility on the state to make available further resources to ancillary components of testing such as treatments and counseling. Without these services, those who cannot afford follow-up treatment after a positive test result would be in the same position as those who test positive for a disease for which there is no cure.

The state may also have to set aside funds to defend itself against

204. See id.
205. See id.
206. Although the SCA testing was once compelled, the Supreme Court held that the intrusion on fundamental rights outweighed the state’s interest; the legislature responded by enacting a voluntary SCA screening statute for adults. See supra Part III.A.1.
207. See supra Part III.A.3.b.
208. The Supreme Court has expressly recognized the right of a competent individual to refuse medical treatment. See Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261, 270 (1990).
foresight lawsuits arising from negligent testing or handling of results or, in some cases, failure to test altogether. For example, in Blair v. Hutzel Hospital, a woman who gave birth to a child with Down’s Syndrome sued the hospital for negligently failing to administer a prenatal exam that may have revealed the presence of the fetal congenital disease. The plaintiff claimed that without this test and information, she was denied the right to make an informed decision regarding her pregnancy; specifically, the plaintiff claimed that she was not given sufficient information to evaluate and exercise her options under Roe. The Michigan Court of Appeals allowed her claim on the grounds that Michigan recognizes wrongful birth, as well as recognizes abortion as a viable option. Blair illustrates judicial recognition of issues such as accurate testing, disclosure of results, and liability of physicians. Although this case involved private parties, it is probable that the same types of parameters will be used to form an action against a state in similar circumstances. A strong dissent noted that state policy favors life over abortion.

Finally, seemingly neutral genetic profiles may also be used to justify siphoning costly medical resources to particular social groups. For instance, if a particular racial or ethnic group is considered to respond better to certain treatments, efforts might be made by the government and private companies such as health maintenance organizations to encourage legislative enactments making screening available only to those likely to benefit from it and to discourage or make unavailable the same treatment to others.

209. 552 N.W.2d 507 (Mich. Ct. App. 1996), rev’d on other grounds, 569 N.W.2d 167 (Mich. 1997). While the course of action was held to be valid, the Michigan Supreme Court reversed and reinstated the trial court’s summary judgment on the issue of causation. See Blair, 569 N.W.2d at 167.

210. See Blair, 552 N.W.2d at 511.

211. See id. at 514 (O’Connell, J., dissenting). The “right to privacy ‘implies no limitation on the authority of a State to make a value judgment favoring childbirth over abortion.’ ... [E]ven the Roe Court acknowledged that the state has an ‘important and legitimate interest ... in protecting the potentiality of human life.’” Id. at 515 (citations omitted).

212. See id., supra note 36, at 47.

213. See id. at 47-48. Economic factors can also affect genetic testing; indeed, “[t]he ability of people to obtain genetic tests and therapies is often influenced by their affluence and social power.” Id. at 48. As a result, testing may be developed according to consumer demand and ability to pay, thereby disadvantaging racial or ethnic groups which cannot lobby for or afford such treatment. See id. at 48.

Allocation of resources is just one example of how genetic information can perpetuate and exaggerate the social, ethnic, and racial discrimination which is plaguing our society. Widespread use and comparison of the genetic characteristics of the population can be manipulated by those in power so that society’s concept of a “desirable” set of traits reflects those of the empowered
In summary, the resources that a state would need to commit to a mandatory testing program based on preventative care would expand far beyond the actual testing to other facets such as treatment, counseling and legal defense funds. If a state, through mandatory screening, forces people to face the difficult issues surrounding sickness or eventual death, the state must also provide ancillary services in order to ensure that the purpose of the testing is, in fact, achieved. As illustrated below, a voluntary testing program would yield a more efficient use of resources.214

2. Inheritable Diseases

A state may also use genetic screening to lower the transfer rate of inheritable diseases by identifying carriers of a disease.215 This technology is of vital importance to potential parents who may be carriers. Specifically, these people are most concerned with the probability of their children inheriting or being born carrying the disease trait. Genetic test results can therefore be extremely informative in the family planning process;216 if a couple discovers that their offspring has a high probability of inheriting the disease, the couple can take alternative paths such as adoption, selective abortion, and contraception.217

Another alternative for carriers that will enable them to produce

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214. See infra Part VI.

215. Genetic carriers are those persons that possess a gene for a particular disease but do not manifest the physical traits of the disease. See Robert Wachbroit, Making the Grade: Testing for Human Genetic Disorders, 16 HOFSTRA L. REV. 583, 587 (1988).

216. Screenings for Huntington's Disease exemplify the benefits of genetic testing by revealing early on whether or not this debilitating, and most often deadly, disease is present in the genome. See Nancy Wexler, Clairvoyance and Caution: Repercussions from the Human Genome Project, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT, supra note 5, at 211, 235-36. The HD test is highly accurate in identifying who has the disease and the probability of contracting the disease in the future. One woman commented that before being tested she felt "damaged" and "emotional turmoil" about the possibility of not being a "fully intact" human being. Quaid, supra note 200, at 13. After finding out that she had only a three percent risk factor, she said, "[M]y vision of what my life held in store changed for me . . . . Now I feel that I can get and have anything I want . . . . [including children]." Id. at 13-14. "I fought to find out what my genetic material had to say and I am grateful." Id. at 14.

healthy children is to remove the diseased trait, if possible, from the fetus or child or to eradicate the disease trait completely though the use of germ-line gene therapy before the child is even conceived. This technology allows scientists to manipulate the disease-causing strands of DNA which cause disease either by removing the genetic material that causes the condition or by selecting for the cells that are healthy. Gene therapy can also be applied to correct genetic defects in the lungs of

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218. Gene therapy is a process by which defective or disease-causing genes are repaired or eradicated. See LEVINE & SUZUKI, supra note 9, at 192-93. The two most common types of gene therapy being researched and developed are somatic cell therapy and germ-line therapy. See id. at 217. Somatic cell therapy is a process that targets tissue cells affected by a genetic disorder; the therapy is “transient” in that it only affects the tissue during the lifetime of the person on whom the therapy was performed. See id.

A second, and more controversial type of therapy is now being explored for use in germ-line procedures (germ-line cells produce sperm or egg). During this type of procedure, a genetic defect is isolated and removed or modified much in the same manner as somatic cell therapy, but the repair is not confined to the lifetime of the individual on which therapy was performed. See id. at 217-18. Rather, the new change becomes part of the permanent genetic composition of the person and will be passed on to all future generations. As one might imagine, there are a host of ethical problems surrounding this type of therapy in any organism, not just that of humans. See id. at 218; see also W. French Anderson, Human Gene Therapy: Scientific and Ethical Considerations, in ETHICS, REPRODUCTION AND GENETIC CONTROL 147, 157-59 (Ruth F. Chadwick ed., rev. ed. 1992) (1987) (considering the ethical issue of engaging in germ-line therapy despite the potential for perpetuating a “mistake” or “unanticipated result” in future generations).

This issue is especially poignant with knowledge that certain traits, once considered defective or undesirable, now are found to have a specific beneficial purposes. See infra Part IV.A.3. Scientists declare that the goal of this type of embryonic alteration is both “humanitarian and economically sensible” because it “enable[s] ... couples to conceive children while avoiding the trauma and financial burden of lethal hereditary ailments.” LEVINE & SUZUKI, supra note 9, at 198. Not all scientists agree. Jeremy Rifkin, benefactor of the Foundation for Economic Trends, noted the grave importance of taking the time to consider the long-term ramifications of such actions: “Every decision by a scientist to edit millions of years of evolution is a eugenics decision .... Perhaps none of us are wise enough, have the clairvoyance, the wisdom, to dictate basic changes in millions of years of genetic evolution. I don’t think any of us should have that power.” Id. at 218-19.

The number of approved procedures for gene therapy is increasing. See Robin Herman, Gene Therapy Is No Longer a Rarity, WASH. POST, Jan. 21, 1992, (Health Magazine), at 7. Over 100 clinical gene-insertion protocols have been initiated as of 1997. See Transfusion Cellular Gene Therapy Has Made Steady, Impressive Progress, GENE THERAPY WEEKLY, July 28, 1997, available in 1997 WL 7483471. The extent to which we should use this technology is a question that this generation will have to consider. Many controversies are likely to arise as more is learned about the human genome and the functioning of DNA, but one thing is certain: with the increased understanding of the human molecular structure as a result of the Human Genome Project, gene therapy is likely to become an integral part of saving and improving lives, especially as the public becomes more aware of this option.

children suffering from cystic fibrosis, modify "an embryo's genome to 'enhance' normal characteristics, [or] to engineer[] wholesale changes in the gene pool of the human race." The present goal of gene therapy, however, is restricted to removing genetic disease from fetuses and reducing the suffering of those children who are born with genetic deficiencies.

The information produced by the Human Genome Project, combined with the use of genetic testing, will dramatically increase the efficacy of gene therapy. A state would clearly have an interest in using this information to reduce, if not eradicate, certain inheritable diseases, thus promoting the health (and economic contribution) of its citizens. This would also serve to facilitate a more efficient allocation of the resources previously dedicated to the diagnosis and treatment of such diseases. However, unlike a genetic disease which can be treated with medication, the state's interest in reducing inheritable diseases, even if compelling, would probably not survive strict scrutiny because it directly intrudes upon personal family decisions; such decisions include whether or not to procreate, or alternatively, to modify or abort a fetus. In addition, this testing program suffers from the same problems as those affecting a mandatory preventative care genetic screening program.

3. Genetic Diversity

Despite the attractiveness of eradicating inheritable disease through gene therapy, some states may develop an interest in securing genetic diversity. In human biological systems, "[t]he presence of mutant [genes] in the population of a species forms the basis for Darwin's theory of natural selection." The presence of mutation, whether it causes a positive or negative effect on its carrier, is essential for survival because it enables organisms to adapt to changing environmental conditions. This necessity may directly be at odds with gene therapy in that scientists have yet to gain a full understanding of the importance of each gene and the relationship of gene functions to one another in the human

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220. Levine & Suzuki, supra note 9, at 193.
221. See infra Part V.C. for a more thorough discussion of this issue.
222. See supra Part IV.A.1.
223. Norton, supra note 29, at 1591. "Many genes exist in alternative forms, or alleles, which contain slightly different genetic information, or DNA sequences." Id. at 1590. In humans, the simplest of inheritance patterns are genes with only two alleles; the dominant allele, which manifests itself when only one copy is present, and the recessive allele, which is exhibited only when it present in two copies in an individual. See id. at 1590-91.
224. See id.
Scientists are now discovering that some genes, once believed to produce only negative effects, also contain positive traits without which survival for some humans may have been made more difficult or even impossible.

For example, SCA, which is found largely among the African-American population, was thought to be a debilitating and undesirable genetic defect. When the sickle cell gene was discovered, although the technology existed to screen for carriers of the disease, science did not have the technology to manipulate the gene. Now, almost sixty years later, scientists have found information revealing that the same gene which causes SCA also allows those individuals who possess the trait to be immune to malaria.

Contrary to the state interest in mandating genetic screening so that the occurrence of genetic disease can be reduced, the state may have a compelling interest in preserving our human genetic diversity based not only on scientific and evolutionary necessity, but social policy as well. The state must consider whether current mutations are desirable enough to be protected, or whether genetic tests should be used to screen for and remove diseases to the extent that technology allows. This decision will be based on societal values. It has been commented:

“Quality of life should be sought by the cautious improvement of our cultural and environmental resource pools, and not by an impulsive over-emphasis upon manipulations of a gene pool whose dynamics and long-term mechanisms still allude us. We should improve the environment of our handicapped brethren, ... [and] seek means to cure

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225. As described earlier, this is the very goal of the Human Genome Project. See supra Part II.B. It is important to emphasize that even though the gene maps may be complete by 2005, these maps are only one of the initial steps in understanding the full complement of gene relationships to one another and their aggregate effect on the human body. A deeper and full understanding of genetics, despite recent advances, is still in a nascent stage. The Human Genome Project is the key that scientists hope will unlock the door to new discovery and progress.

226. See LEVINE & SUZUKI, supra note 9, at 38; Norton, supra note 29, at 1591-92.

227. See REILLY, supra note 56, at 67-72.

228. See id. at 67. For a discussion of SCA testing, see supra Part III.A.1.

229. See LEVINE & SUZUKI, supra note 9, at 40. It is important to note that “[i]n the case of sickle cell anemia, a change in environmental conditions has made the positive effects of [the mutant gene] less beneficial. . . . The benefits and drawbacks of genetic ‘defects’ must therefore be analyzed in the context of specific environmental conditions.” See Norton, supra note 29, at 1592.


231. This proposition begs the question of whether the state should evaluate the quality of an individual’s life, when that person’s life is burdened by disease, sickness or handicap, or long- or short-lived.
phenotypic anomalies instead of alleviating their owners."

This interest would best be implemented through a voluntary program whereby potential parents may, if they choose, receive genetic screening that would enable them to make informed decisions regarding procreation. In this way, the state would free itself from obligatory treatments attendant to mandatory screening which may have dramatic effects on the future life of the fetus.

4. State Interest in Potential Life

If the state has the resources and the technology available to screen for and cure particular genetic diseases at a reasonable or low cost, the state may claim that it has a compelling interest to mandate the genetic screening of potential parents, fetuses, or newborns in order to preserve or assure their health. With increased medical knowledge, the state may try to secure protection for potential life at its earliest stages; the applicability of the standard of viability would then be at issue. The state would justify its need to interfere at these early stages so that effective cell manipulation could occur, thereby eradicating the disease in question.

In such a scenario the state would likely claim that it was protecting potential life. In Roe v. Wade, the Supreme Court explained the historical significance of prior statutes prohibiting abortion and recognized that as long as potential life is involved, the state may assert interests beyond those of the pregnant woman. The Court went on to say that "the State does have an important and legitimate interest in preserving and protecting the health of the pregnant woman, ... and that it has still another important and legitimate interest in protecting the possibility of human life." The Court then set up a trimester framework as a continuum on which the state's interest is deemed to become compelling at the stage of viability, which occurs in the third trimester.

The Supreme Court in Planned Parenthood v. Casey rejected the
trimester approach developed in Roe v. Wade because, among other shortcomings, this approach "in practice . . . undervalues the State's interest in potential life." Evaluating the Pennsylvania statute at issue under the undue burden test, the Court reaffirmed a recognition of the State's legitimate interest in the life of the fetus. The Court stated that the undue burden test was more appropriate in order to balance "the State's profound interest in potential life" against the privacy rights of the pregnant woman.

B. Implications of Genetic Screening on Privacy Interests

1. Potential Intrusions on Fourth Amendment Privacy Interests

As previously discussed, intrusions on an individual's privacy right for the purpose of medical screening has been allowed in limited circumstances characterized as special need or administrative searches. Under these circumstances, individuals have a lowered expectation of privacy.

In the context of genetic screening of the public, there is generally no lowered expectation of privacy. In addition, unlike TB or AIDS, a genetic disorder is not highly contagious and can only be communicated through reproduction. Finally, unless the state is prepared to formally declare that a genetic disease renders an individual unfit for certain public employment tasks related to the public safety or welfare, there is no special need to conduct the testing. For example, unlike the railroad employees in Skinner v. Railway Labor Executives' Ass'n, a predisposition for genetic disease generally does not incapacitate an individual to the extent that the public safety would be jeopardized. But note, as some genetic diseases are being held akin to disabilities, this argument may gain strength.

237. Id. at 878. In this context, the statute was held invalid because it worked a substantial burden on the ability of a woman to seek an abortion before viability. See id.
238. See supra Part III.B.1.
239. For ease of discussion, "public" will refer to those segments of the population who are deemed to be at an above average risk for the particular genetic disease being discussed (for example, ovarian cancer).
240. See infra Part IV.B.2.b. for a discussion about intrusions by the state on reproductive decision-making.
241. See supra Part III.B.1.a.
2. Fundamental Privacy Right Under the Fourteenth Amendment in the Context of Genetic Screening

a. Selective Disclosure and Discriminatory Effects of Genetic Information

Regarding genetic screening, privacy includes "the right of persons to make an informed, independent judgment about whether they wish to be tested and then whether they wish to know the details of the outcome of the testing." Much like the homosexual HIV-positive plaintiff in Doe v. City of New York, an individual being tested for a genetic disorder would have an interest in not having such personal information disseminated without consent, particularly because of a fear of discrimination.

Already there is marked concern about potential employment and insurance discrimination against individuals who have undergone genetic screening and who have tested positive for a predisposition to or actual presence of genetic disease. Such potential discrimination could discourage individuals who would otherwise voluntarily seek testing. As Professor Eisenstat has illustrated, this reaction could frustrate the purpose of an otherwise valid screening program.

i. Insurance Discrimination

There has already been much debate about potential discrimination against those individuals deemed genetically deficient, especially with regard to the availability of affordable health insurance. Agencies will


244. See supra Part III.B.2.

245. Genetic discrimination is defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual." Marvin R. Natowicz et al., Genetic Discrimination and the Law, 50 AM. J. HUM. GENETICS 465, 466 (1992).

People at risk for genetic discrimination are (1) those ... who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease, (2) individuals who are heterozygotes (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic, (3) individuals who have one or more genetic polymorphisms that are not known to cause any medical condition, and (4) immediate relatives of individuals with known or presumed genetic conditions.

Id. at 466.

246. See supra notes 91-95 and accompanying text.

contribute to the creation of an underclass of genetically unfavorable individuals by seeking out member populations made up of only the "genetically superior" individuals. Those with weak genetic makeups or profiles exhibiting undesirable traits will be denied insurance coverage or be forced to pay higher premiums. For example, one health insurance company has already attempted to deny coverage of a child born retarded when prenatal testing revealed a very high probability of a "defective" fetus and the mother refused to abort.

Breast cancer screening provides an example of the public concern regarding confidentiality of genetic information and the potential for discriminatory abuse. General population screenings are currently available for a particular type of genetic defect which causes breast cancer. Many women, however, feel uneasy about having positive results recorded in their medical records due to fears of insurance or workplace discrimination. As a result, awkward and somewhat burdensome measures have been taken to ensure the confidentiality of test results. Thus, some tests are performed under the aegis of research programs that allow doctors to keep the information confidential by encoding results; some doctors advise their patients not to disclose the information to their private practitioner if that doctor has a policy of recording all medical information in the records; and some women have used aliases when testing at sites which do not have the secrecy protections of the research program privilege.

"If we ever needed proof that the system is broken, this is it. . . . The system forces people to take drastic steps to protect themselves. It is putting a terrible burden on patients."
ii. Employment Discrimination

In the workplace, discrimination will take the form of deprivation of equal employment opportunities if employers are allowed to adopt genetic testing as part of the employment application process. From an employer’s point of view... a person [with a disease or even a carrying the gene] could conceivably pose a financial risk in training, work-

§ 12102(2)(A)-(C) (1994); Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Test by Employers and Insurers, 17 AM. J.L. & MED. 109, 122-23 (1991); Judith Richter, Taking the Worker as You Find Him, 8 MD. J. CONTEMPO. LEGAL ISSUES 189, 223-31 (1997); Joseph S. Alper, Does the ADA Provide Protection Against Discrimination on the Basis of Genotype?, 23 J.L. & ETHICS 167, 168-71 (1995); Richard A. Epstein, The Legal Regulation of Genetic Discrimination: Old Responses to New Technology, 74 B.U. L. REV. 1, 13 (1994). In addition, the Act provides protection for those who carry a disease as identified through a genetic screening. These individuals may not be discriminated against simply because they may not be qualified for the job position at a future date, nor can they be discriminated against because their children have a high risk of incurring expensive medical costs for the employer. With regard to insurance, many fear that genetic testing will result in higher premiums or loss of insurance coverage due to tests results which reveal a propensity for illness of the individual or the individual’s child. See Bornstein, supra note 247, at 551-53.


Employment discrimination includes unfavorable treatment in hiring, promotion, assignment of duties, discharge, compensation, and other terms, conditions, and privileges of employment.” Natowicz et al., supra note 245, at 467. Indeed, “genetic tests ultimately will be developed to identify workers with the predisposition toward . . . diseases.” Dreyfuss & Nelkin, supra note 43, at 334 n.124 (citing U.S. CONGRESS, OFFICE OF TECH ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 10-12 (1990)); see also Katherine Brokaw, Note, Genetic Screening in the Workplace and Employer’s Liability, 23 COLUM. J.L. & SOC. PROBS. 317, 326 (1990) (discussing the potential use of genetic screening tests to limit job opportunities for workers and the attendant liability of employers).
men's compensation and insurance premiums, and so forth.\textsuperscript{255} Thus, subsequent to genetic screening, an individual, although asymptomatic for sickness, may be passed over in favor of another individual whose genome results reveal that he or she is free from certain genetic diseases or has a lower probability of developing other types of illnesses. Institutions will then effectively be able to create a genetic norm by which individuals will be measured.\textsuperscript{256} It is probable that unless some protection is afforded genetic information, one's scientifically based genetic profile will be more persuasive in an interview than the individual's outward appearances, personality, or even job qualifications.

b. Autonomous Decision-Making Based on Genetic Information

As Supreme Court precedent illustrates, an individual has a limited right to make important health decisions free from undue governmental interference.\textsuperscript{257} This type of privacy in the context of genetic testing and screening refers to the "right of the individual to control his or her destiny, with or without reliance on genetic information, and to avoid interference by others with important life decisions."\textsuperscript{258} Mandatory genetic testing would strip this choice away from the individual regardless of whether the testing was for the purpose of preventative care or reducing the occurrence of inheritable diseases.\textsuperscript{259}

In summary, if the state considers mandating genetic testing, thereby depriving an individual of selecting the persons to whom their genetic information will be revealed, there must be sufficient confidentiality protections attached to the results of the testing, so that those who test positive do not suffer from discrimination in the workplace or in procuring and maintaining health insurance.\textsuperscript{260}

\textsuperscript{255} Smith, \textit{supra} note 11, at 887.

\textsuperscript{256} As some commentators note, "In our society, we call upon nature by using biological tests to assure that individuals conform to institutional values. The power to define what is normal can impose standards of conformity, while the ability to measure individual deviations can justify classifications and hierarchy." Nelkin \& Tancredi, \textit{supra} note 194, at 58.

\textsuperscript{257} \textit{See supra} text accompanying notes 168-80.

\textsuperscript{258} \textit{INSTITUTE OF MEDICINE, supra} note 243, at 248.

\textsuperscript{259} Reasons why an individual may choose not to be exposed to a genetic screening include "[the lack of effective treatment] and "anxiety over the testing itself," as well as an "inability to undo the knowledge." Bornstein, \textit{supra} note 247, at 573. "Asked whether they would take a genetic test that could tell them what diseases they were likely to suffer in life, nearly as many people said they would prefer to remain ignorant (49%) as said they would like to know (50%)." Philip Elmer-Dewitt, \textit{The Genetic Revolution}, \textit{Time}, Jan. 17, 1994, at 46, 48.

\textsuperscript{260} \textit{See supra} Part IV.B.2.
i. Early Diagnosis of Treatable Genetic Diseases

As discussed earlier, the purpose of preventative care would be frustrated if, after a person underwent screening, no cure or treatment was available. Genetic diseases are generally immutable, and once a disease marker is found on a gene, the release of the results to an individual may imply that there is a treatment or a cure available. Genetic screening which reveals the presence of genetic markers for disease and behavioral disorders does not facilitate simultaneous discovery of the cures and treatments necessary to ease or remove the suffering associated with these conditions. Releasing such information to those who cannot be cured may cause physiological harm such as depression or have a stigmatizing effect on individuals within their communities. Thus, removing the freedom of a person to decide whether to submit to such testing and to be informed of the results of the testing unduly infringes on an individual's right to make autonomous decisions regarding his own or his family's destiny.

ii. Inheritable Diseases

The state's interest in reducing the occurrence of inheritable diseases unduly intrudes on an individual's autonomous decision-making because this interest directly affects family planning. As stated earlier, inheritable genetic diseases are transmitted only through reproduction and in this way are distinguished from highly communicable diseases such as HIV and AIDS.

The Supreme Court has repeatedly afforded the state broad police power when legislation was aimed at controlling the spread of deadly or debilitating diseases. The Court's sentiment that "a community has the right to protect itself against an epidemic of disease which threatens the

261. See supra Part IV.A.1.
262. An immutable gene is not susceptible to change. If the technology does not exist to remove the disease-causing piece of the gene or if scientists have not mapped the location of the disease, screening will merely inform the afflicted individual of the presence of the disease trait, leading the individual to face the knowledge that he or she will inevitably suffer and perhaps die from the presence of the gene.
263. See Smith, supra note 2, at 127.
264. See Brock, supra note 28, at 20.
265. See Bornstein, supra note 247, at 575 n.94 (discussing how some individuals experience suicidal thoughts or actually commit suicide after genetic screening results indicated the presence of a disease trait). Even carriers, those that simply carry the disease in their genetic makeup but do not suffer from it, "often experience confusion, alienation and depression after being tested." Id. at 575.
266. See supra Part III.A.2.
safety of its members still pervades modern legal thought as part of the underlying rationale for instituting medical screening such as HIV tests. However, genetic diseases are distinguishable from communicable diseases that the Supreme Court has dealt with in the past because the transmission of such diseases occurs through reproductive methods and, therefore, do not classify as highly communicable. This factor would tend to diminish the substantiality of the state’s interest; yet, the state may claim that it does have the authority to mandate testing in circumstances where an accurate testing device is available to detect genetic diseases or disorders for which there are accessible treatments or cures.

For example, breast cancer tests currently screen for gene mutations in BRCA1 and BRCA2 genes. Early detection allows women to seek treatment before symptoms appear and before mutations show on a mammogram test. Although some women will be able to prevent the onset of cancer through available treatments, some will not. Currently, there is no cure or guaranteed prevention.

iii. Fetal Genetics

If there is no cure or treatment for the individual being tested, then the state’s interest will focus on preventing inheritability of disease by addressing the health of the fetus. The focus of the analysis would then shift to the question of whether the direct risk to fetuses would raise the state interest to the level of compelling such that the state could mandate genetic testing on pregnant women.

Similar to HIV screening, before a state may intrude on the

268. See supra Part III.A.3.b.
269. Reproduction includes various methods of conception including coital reproduction, in vitro fertilization, and artificial insemination.
270. Cost would be an important factor in order to assure that all individuals subjected to a mandatory screening program would have access to the benefits of testing. If an individual is tested and cannot afford the cure, what is the legislative purpose in collecting the results of genetic testing and forcing those tested to know of their genetic status? In this scenario, the state interest would seem to fall short of compelling.
271. In addition to the lack of available guaranteed cure, some medical commentators have suggested that widespread use of this genetic test is inadvisable because the results are still ambiguous. “Many women with a negative test will still develop breast cancer, and some with a positive test will not... BRAC 1 screening test should thus not be recommended as a population screening test... at this time.” Heather Bryant, Genetic Screening for Breast Cancer in Ashkenazi Women, LANCET, June 15, 1996, at 1638, 1638.
272. The Supreme Court has cautioned that privacy is not to be taken as an unlimited right to do with one’s body as one wishes. See Roe v. Wade, 410 U.S. 113, 154 (1973).
autonomous decisions regarding procreation, a state needs to couch its interest in medical evidence showing that, once genetic disease is detected in the pregnant woman and fetus, treatment would significantly reduce the suffering associated with the disease or prevent the occurrence of the disease in the genome of the fetus. In the case of the New York HIV statute, the state’s interests in reducing the spread of HIV to newborns and to render efficient and effective treatment thereby reducing the occurrence of AIDS in newborns justifies the intrusion into the privacy rights of the mother.273

Finally, it is probable that whether the mother, the fetus, or the newborn is tested for genetic disorders, the same concerns arise with regard to confidentiality and discrimination.274 Such fears could potentially dissuade those patients in need of care from undergoing necessary screening, especially if the patient already suffers from discrimination.

In considering whether genetic screenings should be mandatory or voluntary, the state’s interest in potential life must be balanced against the right to privacy and the freedom to make reproductive decisions free from unreasonable state interference. The Supreme Court first alluded to this decision-making right in Eisenstadt v. Baird,275 where Justice Brennan remarked that the individual has a right “to be free from unwarranted governmental intrusion” in making “the decision whether to bear or beget a child.”276 In that case, the Court relied on Griswold v. Connecticut, which was the first time that the Supreme Court recognized a right to privacy in making personal decisions, specifically, the decision to use contraceptives for purposes of family planning.277 The Court in Roe expanded this concept. While recognizing a state interest in potential life, the Court focused on the right of the pregnant woman to decide whether to carry to term or abort the fetus.278 Casey reaffirmed

273. See supra Part III.A.3.b. The mother’s privacy rights are infringed upon directly, as the choice whether to test her baby for HIV has been stripped away from her, as well as indirectly, for in testing the child, the hospital draws blood from the mother, thereby testing her for HIV by proxy. See Post, supra note 111, at 212.
274. See supra Part IV.B.2.a.
276. Id. at 453.
277. 381 U.S. 479, 485-86 (1965) (holding a statute prohibiting the distribution of contraceptives to married persons unconstitutional). But see Richard A. Posner, The Uncertain Protection of Privacy by the Supreme Court, 1979 SUP. CT. REV. 173. Posner believes that Baird addressed merely the distribution, not the use, of contraceptives, and as such the Court’s opinion is “a pure essay in substantive due process. It unMASKS GrISwold as based on the idea of sexual liberty rather than privacy.” Id. at 198.
278. See Roe v. Wade, 410 U.S. 113, 153-54 (1973). The Roe Court stated that the right to privacy includes a limited right to terminate a pregnancy, and that a state may intervene when the
the essential holding in *Roe* by recognizing the right of a woman to choose to have an abortion before viability without undue interference from the state.\(^{279}\)

Whether or not the autonomous nature of personal decision-making will erode due to future advancements in genetic technology remains an open issue. Specifically, as the Human Genome Project reveals more information about genes and spurs new technology which can save or improve the potential life of a fetus, the question is raised whether a pregnant woman who tested positive for a particular disease through a mandatory testing program will be able to assert her privacy rights in order to choose not to accept treatment for herself and/or the potential life inside of her?\(^{280}\) The Court in *Roe* recognized the slippery slope on which the state police powers would rest if states were allowed to interfere in such personal matters. In dicta, *Casey* reiterated this concern by stating:

> If indeed the woman's interest in deciding whether to bear and beget a child had not been recognized as in *Roe*, the State might as readily restrict a woman's right to choose to carry a pregnancy to term as to terminate it, to further asserted state interests in population control, or eugenics, for example.\(^{281}\)

The Court may have relied on the doctrine of informed consent to support this notion.\(^{282}\) This principle includes the right to refuse medical intervention, even if such refusal results in the patient's own death, as

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\(^{279}\) See Planned Parenthood v. *Casey*, 505 U.S. 833, 860 (1992). The Court also summarized the established rights relating to personal decision-making as precedential support for its decision. "Our law affords constitutional protection for personal decisions relating to marriage, procreation, contraception, family relationships, child rearing, and education." *Id.* at 851.

\(^{280}\) For example, a woman may choose to carry a fetus to term despite the knowledge that the child may suffer from a disease or disorder. Personal religious and moral beliefs shape this type of decision and must be considered in a mandatory testing program.

\(^{281}\) *Casey*, 505 U.S. at 859.

\(^{282}\) Informed consent requires that a physician obtain the consent of a patient before administering treatment or performing an operation.

Informed consent refers to legal rules that prescribe behaviors for physicians in their interactions with patients and provide for penalties, under given circumstances, if physicians deviate from those expectations; to an ethical doctrine, rooted in our society's cherished value of autonomy, that insures to patients their right of self-determination when medical decisions need to be made; and to an interpersonal process whereby physicians . . . interact with patients to select an appropriate course of medical care.

discussed in *Cruzan*. There, the Court explained that "[i]t cannot be disputed that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment."

Contrasting the Court's recognition of the privacy implications in refusing medical treatment, the state has an interest in promoting potential life by regulating abortions. The state, therefore, can enact statutes or regulations which, in effect, promote childbirth as long as these provisions do not impose an undue burden on the woman in choosing one alternative over another. "But courts must be careful not to allow a state to disguise what is actually a coercive rule as a rule merely encouraging [women to be] responsible" for knowing the health risks and the psychological and moral implications of her decision.

V. BALANCING STATE INTERESTS AND INDIVIDUAL PRIVACY CONCERNS

Regardless of whether the state has a compelling or substantial interest in genetic testing, mandatory genetic testing necessarily interferes with the fundamental liberty interest in privacy. As discussed, such an intrusion triggers strict scrutiny; as a result, the question remains whether mandatory screening is the least intrusive method of achieving the state's goal of protecting the public health.

A. Cures or Treatments

Although genetic tests can be developed to diagnose several different diseases, a cure or treatment for many of these ailments does not exist. As such, the current rationale for mandatory genetic screening parallels that of the mandatory HIV testing, namely protection of the

284. *Id.* at 281. When addressing the right to refuse medical intervention, courts have considered four countervailing interests: the preservation of life, the prevention of suicide, the protection of innocent third parties, and the maintenance of the integrity of the medical profession. *See* Thor v. Superior Court, 855 P.2d 375, 383 (Cal. 1993) (in bank); *see also Cruzan*, 497 U.S. at 278-80 (noting the need to balance countervailing interests of individuals and the state).
286. *See id.; see also* Casey, 505 U.S. at 896.
288. *See supra* Part IV.
289. *See supra* Part IV.B.2.b.i.
290. *See Brock, supra* note 28, at 20; *see also* Part IV.B.2.b.i. (discussing treatability of various genetic disorders).
fetus or infant. Genetic tests are used to detect carriers of genetic disorders and provide prenatal diagnosis to determine the presence of an inheritable disease. However, just as New York could not mandate HIV newborn screenings without a medical assessment of the effectiveness of early medical treatment, mandatory genetic testing cannot be implemented for any disease without medical assessment of potential cures.

The absence of available cures and treatments clearly frustrates the purpose of genetic screening. Thus, the purported goals of the program—the protection of public health through preventative care, reducing the occurrence of inheritable diseases, or as in the case of potential life, isolating the presence of genetic disease or predisposition—are insufficient, in themselves, to justify the state’s intrusion on an individual’s right to privacy.

B. Identifiable Patients

Similar to the examples of screenings presented above, medical screening generally requires that those being tested are part of an identifiable group likely to be carrying or infected with a particular disease. Exceptions to this requirement are individuals who are part of a group with a lower expectation of privacy, such as inmates or people involved in certain types of employment. Efforts at mandatory screenings en masse have failed in the past. The rationale behind the prohibition of such testing rests on the premise that the state’s goal of promoting the public health cannot be achieved by testing healthy people. The various state interests listed above embody the same concern. For example, in promoting preventative care through the early detection and treatment of genetic disease, the state would have no need to intrude on a healthy individual’s privacy interests, as this individual is not threatened by genetic disorder.

Mandatory testing is not the least restrictive method of achieving

291. Opponents of genetic screening claim that because treatment opportunities are limited, the sole purpose of genetic screening is to detect carriers of disease, which may result in pressure on future parents to avoid having children so that they do not pass on the diseased gene to their children. See Adelman, supra note 56, at 905.
292. See Robertson, supra note 217, at 698-705 (discussing cystic fibrosis carrier screening and its importance in family planning decisions).
293. See supra Part III.A.
294. See supra Part III.B.1.c.
295. See supra Part III.B.1.a., b.
296. Mandatory SCA and HIV testing are examples of the failure of screening en masse. See supra Parts III.A.1., 3.b.ii.
state goals and a voluntary screening program is one example of a practical solution to this problem. Through a voluntary screening program, members of the population who fear that they are at risk for a genetic disease, or whose medical histories indicate such a risk will present themselves for testing. The individual who volunteers has thereby consented to such screening and the state has not unduly intruded on the individual’s privacy interest, either in the Fourth Amendment or in the Fourteenth Amendment context.

C. Special Consideration: The Impact of Genetic Screening on Reproductive Decision-Making

1. Viability
Reproductive decision-making has traditionally been left to the would-be parents, especially the pregnant woman, while the state interest generally remains subordinate until the fetus reaches viability and is at risk of developing a debilitating disease or dying. As genetic technology increases, however, and science begins to more definitively delineate the boundaries of our biological existence, fundamental rights of privacy of the pregnant mother may erode because genetic science may challenge the point of viability as the adequate threshold at which the state may intervene. For example, increased genetic knowledge already gives scientists the ability to “fix” a genetic problem before a woman’s germ-line egg cell is even fertilized. May the state intervene at such an early stage to ensure that only genetically healthy fetuses are created or carried to term?

2. Rebirth of Eugenics
In addition to altering the underlying scientific facts regarding procreation, increased genomic knowledge can potentially sway public opinion toward eugenics principles. The development of genetic technologies can facilitate such ambitions. For example, germ-line therapy will provide future parents with medical assurance that their child will be free from a particular disease. But, not all parents will be able to comprehend, accept or afford such technology, especially during the in-

297. See supra text accompanying notes 168-80.
298. See id.
299. See supra notes 108-21 and accompanying text.
300. As a precursor to gene therapy, genetic screening on fetuses may be limited because of risk to the fetus. Only women who are at high risk of having a child with the particular inheritable disease may elect this type of screening. See Robertson, supra note 217, at 710.
troduction of this technology into mainstream society. As a result, not all children will be born free of certain debilitating genetic diseases. One commentator has stated that a consequence of the development of this technology is that "a line must somehow be drawn between children who should be born and those who should not." While this idea may seem unconscionable and even morally reprehensible to some, the undercurrent in public America has expressed general approval for selective abortion when a woman is carrying a fetus with a severe defect. The question then becomes, what is to be the standard of "severe genetic defect?" and "who decides this standard?"

These questions spur further inquiry regarding the potential long-term deterioration and perversion of any such standard of genetic normalcy. As genetic testing becomes available, every parent will want not only a healthy child born free of any disease or predisposition toward debilitating infirmities, but also may want to use gene therapy to manipulate genes affecting intelligence, height, appearance, and even behavior. Parents, in attempting to "design" a child, may feel additional pressure to provide the best "biological setup" in order to better ensure their child's future success.

This kind of reliance on diagnostics could lead to decision-making based on society's perceptions of the standards of healthy and normal. As Jeremy Rifkin, co-founder of the Foundation for Economic Trends, notes, genetic engineering principles center around quality control, efficiency, and predictability of outcome. He ponders: "Do parents continue in the time-honored tradition where children are a gift, . . . [o]r . . .

301. LEVINE & SUZUKI, supra note 9, at 203.
302. See DWORKIN, supra note 287, at 32 (revealing that abortions are sought out not only when genetic defects are found, but also based on the gender of the fetus).
304. The question aptly arises whether it is the parents' responsibility to do this. See id. at 435-36 (discussing the use of germ-line therapy to control a fetal characteristics and the legal, ethical, and moral ramifications surrounding such decision-making); see also Ruth Schwartz Cowan, Genetic Technology and Reproductive Choice: An Ethics for Autonomy, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT, supra note 5, at 244, 245-46. Schwartz notes that until genetic cures are found for diseases such as Tay-Sachs and spina bifida, among others, abortion is the only recourse available for pregnant mothers who want a genetically healthy child. Thus "ethical and social implications of the human genome project are going to be inextricable from the ethical and social implications of abortion." Id. at 246.
305. Genetic testing also would play an important role beyond the womb. See Brock, supra note 28, at 21 ("If we gain the capacity to enhance human functioning in significant respects and on a widespread basis . . . by genetic engineering or therapy . . . the result may be to undermine our confidence in what is normal human function.").
306. See LEVINE & SUZUKI, supra note 9, at 204.
do parents see themselves now as architects, as designers, as programmers, for the next generation?"  

D. Preference for Voluntary Testing

In general, a state should not mandate genetic screening because the individual's privacy interests outweigh the state's interest in public health and the risk of communicability of these diseases is limited to inheritability, individual's should be free to choose whether or not to use genetic screening. Furthermore, in accordance with principles of informed consent, the right of individuals to make informed decisions regarding their health should be preserved.  

Furthermore, in accordance with principles of informed consent, the right of individuals to make informed decisions regarding their health should be preserved. This right includes the right to be free from undue state interference when making personal decisions regarding family planning. Finally, the various intrusions on individual privacy and the lack of empirical evidence supporting the efficiency, accuracy, and efficacy of the testing illustrate that mandatory genetic testing in the context of screening the public is not the least restrictive means of achieving state goals of promoting public health. The next section explores the alternative of voluntary testing and sets forth the necessary elements for implementing an efficient and efficacious program narrowly designed to further state goals of promoting the public health.

VI. COMPONENTS AND COMPLEMENTS OF VOLUNTARY TESTING

A voluntary genetic testing program provides the most practical compromise in balancing the state interest in public health against individual privacy interests. As previously discussed, genetic disease, unlike

307. Id. There is some dispute over the concept of a fetus as a "gift" since prenatal testing and the choice of abortion already allow potential parents to reject certain fetuses. With the increased biological knowledge that genetic screenings and treatments such as gene therapy promote, it is not clear how much control potential parents will be able to maintain over family planning decisions and, against the moral ideals of some, the genetic quality of their future family.

308. See Canterbury v. Spence, 464 F.2d 772, 780 (D.C. Cir. 1972) (holding that a patient has a right to know information that would be material in making a fully informed health decision).

309. There would be circumstances in which a state, under very limited conditions when a third party interest was at stake, would have a compelling interest in mandating genetic testing. The area of the law which continues to generate considerable debate around this issue concerns legislation permitting the state to intrude on a pregnant woman's privacy rights in order to protect a newborn or viable fetus from suffering or death and where early detection of genetic disease could lead to successful treatment without unduly interfering with parental rights of privacy and autonomy. See supra Parts III.A.3.b.ii, IV.A.4. Consider arguments about the "quality of life" of the future child. Does less suffering mean that steps must be taken to ensure maximum health, and does this new genetic health also include beauty, strength, and intelligence?
highly communicable diseases such as HIV and TB, is limited to inheritability. In evaluating the constitutionality of mandatory medical screenings, it should be determined whether state compelled public health measures “are reasonable in light of the nature of the risk and how high the risk has to be to justify the deprivation of significant liberty interests.” The Supreme Court has indicated that legislatures have broad powers to protect the public health and has thus deferred to legislative judgment regarding screening for communicable diseases. The Court, however, has warned that the legislature may not curtail fundamental rights such as the right to privacy and autonomy if the risk to the public health is not sufficiently compelling, or the provision infringes on the formally recognized fundamental right to make personal decisions.

As new genetic knowledge is gained, the potential for improving the quality and duration of life renews the tension surrounding the point at which a state interest becomes compelling. The most recent example is the mandatory HIV testing of newborns in New York—where the state interest became compelling at the point when medical technology significantly increased the chances of a newborn’s survival with the early administration of AZT. This example clearly illustrates the erosion of the mother’s privacy rights. Thus, “[t]he medical decisions of pregnant women have been among the most likely to be determined and shaped by social and political interests lying beyond their own judgments of the best interests of themselves and their families.” Rather than continuing to encroach on the rights of the pregnant woman or any individual through mandatory genetic testing, the state would benefit more from expending its limited available resources on a comprehensive voluntary screening program focusing on education, accessibility of

310. Vincler & Gordon, supra note 83, at 1026; see also School Bd. v. Arline, 480 U.S. 273 (1987). Although Arline considered the rights of a teacher under the Rehabilitation Act to continue in her job despite her susceptibility to TB, this case sets forth a standard which could be applied, albeit in a modified form, to the risks associated with genetic disease. Among the factors to be considered are (1) the method by which the disease is transmitted, (2) the amount of time during which the carrier is infectious, (3) the risk of contagion, and (4) the impact of harm that the disease could potentially cause to another. See id. at 288.

311. See supra Part III.A.2.
312. See supra Part III.A.3.
313. See supra Part III.B.2.
314. See supra Part III.A.3.b.
resources, confidentiality of information, and analysis of genetic test results.

In encouraging a voluntary testing program, the state will be able to satisfy its goals of protecting the public health while respecting the fundamental rights of privacy and autonomy in decision-making. As new genetic discoveries become more frequent, especially as a result of the Human Genome Project, scientists and physicians can impart this knowledge in understandable terms to those who may be at risk for genetic disease, to those who would benefit from using this information in family planning and to those who simply are interested in gaining increased self-biological knowledge. The following components are necessary for the success of a voluntary screening program.

A. Accurate Testing

Any genetic test which enters the market should yield accurate and unambiguous results. The breast and ovarian testing examples cited above illustrate the complexity surrounding the administration of genetic tests and use of the results. Specifically, in order for the state to support its goal of promoting the public health, those individuals seeking testing must be provided with information that will facilitate the commencement or continuance of treatment. An ambiguous test result can lead to psychological as well as physical suffering. For example, a pregnant woman mistakenly assured of the genetic health of her fetus may continue to carry to term and give birth to a child who may, as a result of the genetic condition, not live very long or live a life with increased suffering due to genetic disease.

In Creason v. State Department of Health Services, the plaintiff, a mother, sued the State of California for failing to administer accurate genetic tests which resulted in her newborn suffering from severe injuries. California's Hereditary Disorders Act mandates that the state health department test infants for certain genetic and congenital disorders including hypothyroidism, the disease from which the plaintiff's infant suffered. At the time of the testing, the state statute required only that a positive or negative test result be reported rather than the actual indicator values of thyroxin and thyroid hormone. The plain-

316. See supra note 271 and accompanying text.
317. See supra notes 203-05 and accompanying text.
318. 64 Cal. Rptr. 2d 534 (Ct. App. 1997).
319. See id. at 535, 536.
320. See id. at 537.
tiff’s infant had low values, but one of the values was in “normal range,” thereby creating a negative test result. Based on this information, the infant received no treatment within the first three months of birth, which led to the onset of severe, irreversible injury. The California Court of Appeals held that since the statute required medical screenings to be conducted in accordance with generally accepted medical principles and that clinical testing procedures be accurate and provide maximum information, imposing obligations on the state to conduct accurate tests yielding results that are subject to minimum misinterpretation would best reflect the legislature’s intent. Finally, the court concluded that the parents claims, if proven true, would establish a breach of a mandatory duty on the part of the state.

B. Availability of Cures or Treatments

As discussed above, it is necessary that cures or treatments be available in order to support a legitimate purpose in screening an individual. As in the example of HIV, the development of AZT led to the acceptability and widespread use of HIV testing and, in the case of newborns, even led to compelled testing due to the highly beneficial effects of the drug on the infants.

In some instances, treatment or cures may not be available, but screening will still hold a legitimate purpose. Screening for Huntington's Disease enables individuals to learn the probability of the onset of this deadly disease. Attaining this knowledge before becoming symptomatic allows those who will suffer from the disease to plan for premature severe disability and eventual death. In contrast, those who discover that they do not carry the gene or that there is a low probability of inheritance will be free to enjoy aspects of their life that they may have otherwise forgone, such as having children. In either circumstance, patients must be made aware of the fact that no cure or treatment is available before submitting to testing. A voluntary testing program allows the individual to approach testing when they feel it is necessary and when they understand the importance of such screening.

321. See id.
322. See id.
323. See id.
324. In many cases, early administration of AZT can lead to the eradication of HIV in the infant. See supra text accompanying note 112.
C. Public Education

Primary to the success of any voluntary genetic screening program is public education. The public needs to be aware of the availability of genetic testing and to understand fundamentals of genetic technology and the benefits and risks associated with the particular genetic screening program being implemented. The education program must indicate the accuracy rate of such tests. Also, the genetic disease itself needs to be understood in order to comprehend the importance of the genetic test and the impact of the treatment that is available. For example, as with PKU testing of newborns, once parents understand the nature of the disease, such as its potential to be inherited by their children, its effect on their children and the effects of environmental factors, a simple dietary change and monitoring of the child is generally all that is required to promote relatively normal development. Ideally, the educational materials should be adjusted for each sector within a community so that adults with differing degrees of education will be able to fully comprehend the meaning of the information presented.

D. Informed Consent

As a result of public confidence in the accuracy and potential benefits of genetic testing, the state will, in effect, be fostering individual responsibility for genetic health decisions. This responsibility rests on strong foundations of American acceptance of the informed consent process. This educational need is similar to that for HIV testing. See Post, supra note 111, at 222.

The state should educate the public about transmission, prevention, voluntary testing, available treatment, and support services for adults and children regarding other genetic diseases as well.

325. This educational need is similar to that for HIV testing. See Post, supra note 111, at 222.

326. See supra notes 197-99 and accompanying text.

327. See supra note 199 and accompanying text.

328. Encouraging people to accept responsibility for personal decision-making recognizes that the values the state is attempting to protect through a voluntary screening program are “contestable.” See Dworkin, supra note 287, at 151.

The sanctity of life is a highly controversial, contestable value. It is controversial, for example, whether abortion or childbirth best serves the intrinsic value of life when a fetus is deformed . . . . Does a state protect a contestable value best by encouraging people to accept it as contestable, understanding that they are responsible for deciding for themselves what it means? Or does the state protect a contestable value best by itself deciding, through the political process, which interpretation is the right one, and then forcing everyone to conform?

Id. This Note proposes that a voluntary genetic testing program avoids the potential of conformity through legislation and respects the precedent establishing the right of autonomous decision-making by looking on the majority of individuals as capable of making informed decisions about their personal health and related issues, and by providing education to increase the amount of understanding and awareness among these people.
and, therefore, necessitates the dedication of resources for services such as pre-test counseling.

Pre-test counseling should be provided in order to ensure that individuals being tested and members of the individual's family understand the ramifications of a negative or positive test result. This is especially imperative when a positive test result signifies future imminent death or loss of one's faculties. Pre-test counseling also introduces the patient to the particular administrative forms which need to be completed prior to the screening as well as to the procedures involved in the testing itself; this will enable the patient to have a more thorough understanding of the screening as well as foster trust in the legitimacy of the publicized goals behind the screening.

The availability of resources for continual treatment should also be discussed so that the patient knows where to access the necessary medical and psychological care. Therefore, if a patient tests positive, the administering body would make the appropriate referrals so that the patient may receive adequate treatment, taking special care not to unnecessarily disclose information to specialists.

E. Post-Screening Resources

A concern arises with regard to the accessibility of post-screening resources. If patients are aware of the available resources but cannot afford further care, does the state have a responsibility to provide for some basic follow-up care? A voluntary testing program allows the


330. It is important that counselors do not encourage the patient to toward or against genetic screening. For a discussion about the responsibilities of counselors in ensuring the patient's autonomous decision to undergo screening, see GENETIC COUNSELLING: PRACTICE AND PRINCIPLES 46-49 (Angus Clarke ed., 1994).

331. Opponents of voluntary testing argue that mandatory testing ensures that all individuals will be provided with the necessary information to make informed decisions, and that if left to society, the medical community will fail to responsibly assure that the patients have this information. See Juliet J. McKenna, Where Ignorance Is Not Bliss: A Proposal for Mandatory HIV Testing of Pregnant Women, 7 STAN. L. & POL'Y REV. 133, 136-37 (1996), for a discussion about the availability of syphilis testing and the reluctance of doctors and patients to use it voluntarily because doctors feared offending patients and patients feared stigmatization. "Physicians' ... failure to incorporate syphilis screening into routine practice indicates that legislative mandates may be necessary to overcome physicians' reluctance to test patients for diseases which carry a stigma." Id. at 137.

332. Would the state, for example, be required to fund a limited amount of therapeutic visits or needed injections? While the answer to this question is beyond the scope of this Note, the issue is of absolute importance. One would think that the state does owe some responsibility to these
state to allocate necessary resources according to a legislative determination of need. Alternatively, a mandatory testing program would support the argument that if the state interferes without consent into an individual’s health concerns, and as a consequence, the individual gains knowledge that a genetic disease is present in their genome, the state must then provide the necessary treatments to mitigate the suffering associated with the disease in order to meet its goals of protecting the public health or potential life. Without these treatments the state’s interest would seem to rest on an unsecure foundation.\textsuperscript{333}

\section*{F. Timely Notification of Test Results}

Often, treatment success rates depend upon early intervention; therefore, patients must be provided with timely notification of the test results. Currently, this is a special concern for screenings such as the HIV screening of newborns.\textsuperscript{334} In order to maximize the effectiveness of genetic screening, tests should be developed and facilities made available so that results are provided before any potential or further damage to self or child occurs. In order for this to be a practical consideration, funding will be needed\textsuperscript{335} to ensure quick turnaround time from highly capable and efficient laboratories.

\textsuperscript{333} Possible solutions to this question are beyond the scope of this Note. This issue is mentioned to illustrate a potential financially adverse consequence of genetic testing; however, this issue will most likely be addressed by a cost benefit analysis of a voluntary screening program.

\textsuperscript{334} See Post, supra note 111, at 180.

[A] serious drawback to neonatal HIV screening is the delay in obtaining test results. Because ... tests must be performed in specialized laboratories, the turnaround time varies from several days to weeks. ... By that time, most mothers and newborns will have left the hospital without knowing their test results. Of particular concern is that women who intend to breastfeed will have already begun to do so, potentially exposing their infants to HIV.

\textit{Id.} at 180-81.

\textsuperscript{335} Proposals for the method and sources of funding are beyond the scope of this Note. It should be noted, however, that in order to justify its goal in enacting such a screening program, the state may be compelled to produce a certain percentage, if not all, of the funding necessary to ensure high quality and efficient lab work. In addition, there probably will be a strong interest in joint ventures or the privatization of biotech companies who can consistently monitor and improve the genetic testing.
G. Confidentiality of Information

As the public becomes more aware of genetic testing and gains a better understanding of how it can improve their lives, participation in a voluntary program will increase incrementally. One key measure which must be present throughout every stage of the process is the maintenance of confidentiality of patient information. There needs to be a system in place whereby positive test results do not become part of the patient’s medical record in the traditional fashion. Security measures must be implemented so that test administrators, diagnosing physicians and patient care givers can monitor progress without outside physicians, employers and insurance agencies obtaining unauthorized access to the information.\(^{336}\) The state should review the current mechanisms of limiting patient and third party access to medical records so that any existing loopholes can be eliminated according to the legislature’s best judgment.\(^{337}\)

H. Monitoring of the Success of the Program and Continual Implementation of Scientific Findings

The need for accurate medical information and further scientific research is important for improving the integrity and usefulness of genetic screening. As genetic screening becomes more prevalent on a voluntary basis, it is necessary to have an expert administrative body monitor the screening to determine whether it meets the state objectives of promoting public health. In the instance where genetic screening is highly successful at reducing or eradicating a particular disease, this administrative body should decide whether the program should become part of standard medical practice.\(^{338}\) In the event that a voluntary screening program does not effectively achieve state goals, the state should discontinue the effort.

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336. For example, as with mandatory HIV testing, if the newborn tests positive for HIV and this information is placed in the newborn’s medical record, the mother’s HIV status by implication is known to whomever reads her child’s charts.


338. Other programs have supported this idea. See, e.g., N.Y. PUB. HEALTH LAW § 2500-f (McKinney Supp. 1997) (providing for a comprehensive HIV testing program for newborns).
VII. CONCLUSION

[T]he constitutional challenges raised as a direct consequence of the startling advances in bio-science are unique, for they hold every promise of changing some of the most fundamental principles of this country's political order—challenges "that the individual human being is autonomous and exercises free will, that all people are entitled to equal treatment, [and] that individuals enjoy a legitimate expectation of privacy in their dealings with the state . . . ." 340

The completion of the Human Genome Project will mark a major step in the advancement of genetic understanding. The knowledge gained from the continued research on, and completion of, the Human Genome Project can be used by the state to lessen the suffering associated with over 4,000 discovered genetic diseases through the implementation of genetic screening programs. In considering whether or not to mandate such programs for high risk groups, the state's interest in promoting genetic health must be balanced against individual rights to privacy.

It is unquestioned that genetic screening facilitates early detection of genetic disease, thus promoting prevention or reduction of severe suffering. These state interests are legitimate and may even be deemed compelling in the context of a deadly or severely debilitating genetic disease; however, the success of such an analysis depends upon many factors, including the availability of treatment, accuracy of testing results, identification of high risk groups, and confidentiality of genetic information.

Consideration of privacy rights reveals the establishment of an individual's right to freedom from unreasonable searches, selective disclosure of personal information and autonomous personal health care decisions without undue interference from the state. A balancing test concludes that a mandatory screening program is generally not the least restrictive method by which to achieve state goals in promoting the public health.

339. While funding is a vital concern, it is beyond the scope of this Note. It should be noted however, that by utilizing the least restrictive means, government is able to "eschew[ ] gratuitous or unnecessary cost" thereby enabling the state to concentrate its efforts on the efficient allocation of resources, as well as securing the funding needed to promote a successful voluntary screening program. Roy G. Spece, Jr., The Most Effective or Least Restrictive Alternative as the Only Intermediate and Only Means-Focused Review in Due Process and Equal Protection, 33 VILL. L. REV. 111, 113 n.2 (1988).

A voluntary screening program is a viable and cost-efficient solution. It encourages responsibility on the part of the individual to make informed health care decisions, while at the same time fostering the state interests in promoting the public health. The ultimate result is patient cooperation, increased integrity and respect for the medical community, and a more efficient use of genetic screening technology as secured through the guidance and protection—rather than intrusion—of the state under its police powers.

As scientific endeavors continue to exponentially advance, scientific support for genetic screening will buttress the usefulness and viability of such programs. It is not unforeseeable that with future developments it will be possible for individuals to rid themselves and their progeny of genetic disease. The question remains then, will "the individual's right to make certain unusually important decisions that...affect his own, or his family's destiny"\(^3\) be preserved or will future genetic advancement enable the state to steadily increase its intrusion into the privacy of individuals under its police power eventually resulting in the implementation of mandatory genetic screening programs?

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* This Note was inspired by the courageous struggle for life of Baby Alyssa Anne Mushin, a victim of a fatal genetic disease. It is with thoughts of her that I have worked to formulate this Note, and it is with the encouragement and unending support of my family that I have completed it. Special thanks to Professor Alan Lambert for his insight and criticism and to Robert Andrew Weiss who never stopped believing in me.