The Constitutionality of Mandatory Genetic Screening Statutes

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THE CONSTITUTIONALITY OF MANDATORY GENETIC SCREENING STATUTES

Recent advances made in the genetics field enable the medical profession, through genetic screening devices, to predict for parents whether their child will carry or be afflicted with genetic problems. Accompanying this medical breakthrough are important legal questions concerning the constitutional propriety of legislatively mandated genetic screening programs. In this Note, the author identifies four potential constitutional challenges to mandatory genetic screening laws, analyzing the possible arguments under each approach. The author concludes with proposals for improving existing screening statutes and suggests guidelines within which future screening statutes should be able to withstand constitutional scrutiny.

INTRODUCTION

A BIOMEDICAL revolution is occurring in the field of genetics. Knowledge has been accumulating rapidly in the genetic field since the late 1960's when scientists first were able to decipher the genetic code. More recent developments in the understanding of genetic defects include detection of both carriers of genetic defects and those individuals afflicted with genetic disease by genetic screening and a growing legal acceptance of birth prevention. These medical and legal advances relating to human reproduction “have given parents new options aimed at avoiding the tragedy of bearing genetically defective children.” Medical science increasingly is prepared, through the process of genetic screening, to predict for parents whether their child will carry or be afflicted with

2. Throughout this Note, a distinction will be made between carriers of a genetic disease and those individuals suffering from the disease. This distinction is made because most of the genetic diseases discussed in this Note are autosomal recessive. This characteristic means that the carrier of the defective gene does not manifest the disease and cannot pass the disease onto his or her offspring unless the other parent is also a carrier or has the disease. When two carriers reproduce a child, that child has a 25% chance of being genotypically normal (does not inherit the defective gene at all), a 25% chance of being afflicted with the disease (inherits the defective gene from both parents), and a 50% chance of being a carrier (inherits the defective gene from either the mother or father). Genetic diseases which occur when a child inherits the gene from either parent are labeled autosomal dominant. In these cases, a carrier of the genetic disease also manifests the disease. See Annas & Coyne, “Fitness” for Birth and Reproduction: Legal Implications of Genetic Screening, 9 FAM. L.Q. 463, 464-69 (1975).
4. Id. at 333.
genetic problems.\textsuperscript{5}

As with most medical advances, the procedures for genetic screening raise a plethora of questions concerning legal, ethical, social, political, and moral matters.\textsuperscript{6} This Note will discuss the legal problems accompanying genetic screening laws. Initially, the Note will survey the significant advances made in understanding genetic disease and its causes.\textsuperscript{7} This survey will examine the various types of genetic screening devices and the potential problems associated with each device. The Note then will review the historical development of genetic screening laws.\textsuperscript{8} Included in this discussion will be the Maryland model state statute and the Federal Genetic Diseases Act.

The Note then will focus on the four major constitutional challenges to a mandatory genetic screening program: \textsuperscript{9} 1) the fourth amendment challenge that mandatory screening procedures, such as blood tests and amniocentesis, constitute an unreasonable search;\textsuperscript{10} 2) the fourteenth amendment challenge based on the right of privacy in making marriage and procreation decisions\textsuperscript{11} or based on the right of privacy regarding the confidentiality of data collected through screening;\textsuperscript{12} 3) the fourteenth amendment equal protection challenge that only persons testing positive would receive counseling and, therefore, be treated differently than those persons testing negative;\textsuperscript{13} and 4) the first amendment attack based on the notion that since the acceptance or refusal of medical treatment hinges on religious tenets, mandatory genetic screening and its procedures abridge the constitutional guarantee of free-

\begin{itemize}
\item Genetic screening most often involves a blood test or testing of the amniotic fluid. The blood and/or fluid can be tested to ascertain whether its donor is suffering from a genetic disease or is merely a carrier. \textit{See} notes 36, 45, \& 50 \textit{infra} and accompanying text.
\item Methods of genetic screening include prenatal screening, screening of newborns, screening of children when they reach school age, and screening of adults in their childbearing years.
\item Some of these questions are: Whether people want to know if they carry a defective gene; whether those individuals with defective genes will be willing to limit their choice of a mate or forego having children when they discover they carry a defective gene; whether parents should choose abortion or bring a defective child into the world once they are notified that the fetus is afflicted with a genetic disease; and who defines normal.
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\textsuperscript{8} \textit{See} notes 16--61 \textit{infra} and accompanying text.

\textsuperscript{9} \textit{See} notes 83--168 \textit{infra} and accompanying text.

\textsuperscript{10} \textit{See} notes 169--370 \textit{infra} and accompanying text.

\textsuperscript{11} \textit{See} notes 175--225 \textit{infra} and accompanying text.

\textsuperscript{12} \textit{See} notes 241--74 \textit{infra} and accompanying text.

\textsuperscript{13} \textit{See} notes 275--83 \textit{infra} and accompanying text.
dom in exercising religious beliefs.\textsuperscript{14}

The Note will conclude by outlining proposals for improving genetic screening legislation.\textsuperscript{15} Some of these proposals include: careful definition of the groups covered by screening legislation to avoid an equal protection challenge; funding for continuing research; periodic evaluation of screening procedures and follow-up medical surveillance of those persons tested; adequate disclosure to those individuals screened of the capabilities of genetic screening and full explanation of the results; and provision for strict confidentiality of data collected through screening.

I. THE DEVELOPMENT OF THE LEGAL SIGNIFICANCE OF GENETIC SCREENING

Every individual carries between two and eight lethal genes. The average number of defective genes possessed by each person—the genetic load—presently is increasing.\textsuperscript{16} Advancements in medical science which prolong the average life span, and thereby expand the overall number of childbearing years, are causing this increase.\textsuperscript{17} Additionally, medical advances keep carriers and those persons actually afflicted with genetic disease alive, enabling them to reproduce and pass on genetic defects to subsequent generations. Genetic weaknesses and deformities increase as the life span and the number of childbearing years expand.\textsuperscript{18}

The increase in the genetic load previously was offset by death and natural selection, but today those individuals with genetic in-

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  \item \textsuperscript{14} See notes 331-70 infra and accompanying text.
  \item \textsuperscript{15} See notes 371-97 infra and accompanying text.
  \item \textsuperscript{16} Estimates of defective genes vary since not all defective genes are detectable, but the average genetic load is between two and eight. L. CAVALLI-SFORZA & W. BODMER, THE GENETICS OF HUMAN POPULATIONS 364 (1971). Presently, there are more than 2,000 catalogued traits that are positively or tentatively shown to be determined by a single gene, and, on the average, 100 additional traits are added each year. Foreword to V. McKusick, MENDELIAN INHERITANCE IN MAN at vii (5th ed. 1975). See notes 23-25 infra and accompanying text.
  \item \textsuperscript{17} “Our biological mastery of life has certain unwelcome side effects when we fail to guard against them.” J. FLETCHER, THE ETHICS OF GENETIC CONTROL 27 (1974). The average American’s life span in 1900 was 47; in 1930, 54; in 1967, 70.5. For Christian Scientists, a religious group whose members refuse medical treatment, the average life span in 1967 was 69.5. These figures indicate that preventive health systems are adding years to the life span. Ingle, Genetic Basis of Individuality and of Social Problems, 6 ZYGON 183 (1971).
  \item \textsuperscript{18} The number of children afflicted with Down’s syndrome (monogolism), for example, has tripled due to improvements in neonatal surgery and support systems. See Shaw, Doctor, Do We Have a Choice?, N.Y. Times, Jan. 30, 1972, § 6 (Magazine), at 44.
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firmities are "preserved and protected" through medical science.\textsuperscript{19}

Gene mutation also contributes to the genetic load. A gene mutation is a spontaneous change in a gene which is usually dangerous.\textsuperscript{20} Once a gene has been transformed, the change is reproduced whenever the gene is passed on to the next generation.\textsuperscript{21} Radiation (X-ray) and chemical influences are known causes of mutant genes.\textsuperscript{22} As the mutation rate increases, the genetic load also increases.\textsuperscript{23} The combination, therefore, of a longer life span through medical science and mutations cooperate to increase the genetic load. With an average of four to five generations per century, the present genetic load should double within two centuries.\textsuperscript{24} This increased load could lead to an increased demand for medical services, placing a drain on human and monetary resources.\textsuperscript{25} The increasing genetic load, the numerous people affected by genetic disease,\textsuperscript{26} and the monetary and emotional costs involved in treating such disease\textsuperscript{27} explain the interest in eliminat-

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  \item \textsuperscript{19} See J. Fletcher, supra note 17, at 29.
  \item \textsuperscript{20} A gene mutation is a physical change in a gene which causes the gene to specify an altered gene product or fail to function. See Annas & Coyne, supra note 2, at 465.
  \item \textsuperscript{21} Carlson, When Man Seeks to Control Heredity, The Province Sunday Journal, June 5, 1977, § N, at 44, col. 2.
  \item \textsuperscript{22} Crow, Mechanisms and Trends in Human Evolution, 90 Daedalus 416, 430 (1961).
  \item \textsuperscript{23} Id.
  \item \textsuperscript{24} The more often a mutant arises and the less the selection against it, the higher will be its frequency in the populations. To reduce the genetic load one would have to lower the mutation rates and/or increase the elimination rates. What is actually happening in human populations is exactly the reverse—mutation rates tend to increase and selection rates tend to decrease.
  \item T. Dobzhansky, Heredity and the Nature of Man 291 (1964).
  \item \textsuperscript{25} See J. Fletcher, supra note 17, at 29.
  \item \textsuperscript{26} Id.
  \item \textsuperscript{27} "An untold amount of suffering is due to diseases predominantly genetic in origin—at least 20–25% of chronic disease being of this type." Robinson, Genetics and Society, 1971 Utah L. Rev. 487. An estimated 12 million Americans suffer from genetically caused diseases and disabilities. National Institute of General Medical Sciences, National Institutes of Health, What are the Facts About Genetic Disease? 6 (HEW Pub. No. (NIH) 75-370, 1975).
  \item The cost involved in caring for children afflicted with Down’s syndrome (1 in every 600 births) is $1.7 billion per year. A child suffering from Tay-Sachs disease, with a life expectancy of 3-5 years, costs his or her family $20,000–$40,000 per year to receive adequate medical treatment. H.R. Rep. No. 498, 94th Cong., 2d Sess. 19, reprinted in [1976] U.S. Code Cong. & Ad. News 709, 727.
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The emotional injuries to the family and society are similar to those harms connected with communicable disease. Joseph Fletcher, a theologian and moral philosopher with strong opinions on the subject, has stated:

[I]t is always unjust and therefore unethical or . . . immoral, to knowingly and deliberately victimize innocent others. . . . [T]o deliberately and knowingly bring a diseased or defective child into the world injures society. [It] very probably injures the family, and certainly injures the individual who is born in that
ing genetic disease.

A cultural lag exists between the medical-biological advances and the law.28 Physicians have been held liable in wrongful birth actions29 for failure to use screening devices.30 A similar cause of action, wrongful life, is one brought by the diseased child against the physician for allowing his or her birth.31 As the legal community begins to recognize such causes of action, attorneys, judges, and legislators must be aware of genetic programs and their legal implications.32 Furthermore, as more diseases become detectable through genetic screening, and as society learns more about ge-

28. "Where one part of culture changes first through some discovery or invention, and occasions changes in some part of culture dependent upon it, there frequently is a delay. . . . The extent of this lag will vary . . . but may exist for . . . years, during which time there may be said to be a maladjustment." W. Ogburn, Social Change With Respect to Culture and Original Nature 201 (1922).

29. [P]arents of a genetically defective child should have a cause of action when they can show that the doctor knew or, acting within the standard of care of similarly situated practitioners, should have known of the risk of that disorder, that he [or she] should have foreseen that such information would be relevant to a reasonable person, and that had these parents known of this possibility, they would not have had the child. Once these requirements have been met, the parents should be awarded substantial damages for their emotional anguish and economic injury.

Note, Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling, 87 Yale L.J. 1488, 1515 (1978).

30. Physicians have been held liable in wrongful birth actions for failure to detect the risk that parents may produce a genetically defective child and for inadequately or inaccurately warning these parents of such risk. Giving parents the necessary information to make thoughtful decisions about childbirth includes explaining screening techniques, often using a screening device, and interpreting those results accurately. See, e.g., Howard v. Lecher, 42 N.Y.2d 109, 110-13, 366 N.E.2d 64, 64-66, 397 N.Y.S.2d 363, 364-66 (1977) (physician held negligent for failing to detect the parents' risk of producing a child with Tay-Sachs disease and had to pay medical and funeral expenses although the court denied the parents' cause of action for emotional distress); Park v. Chessin, 60 App. Div. 2d 80, 87-88, 400 N.Y.S.2d 110, 114 (1977) (court refused to dismiss child's cause of action for "injuries and conscious pain and suffering" against a physician who gave inaccurate genetic risk information).

31. No courts of last resort have upheld a wrongful life cause of action. Peters & Peters, Wrongful Life: Recognizing the Defective Child's Right to a Cause of Action, 18 Duq. L. Rev. 857, 857-58 (1980). The authors conclude that the wrongful life action should be recognized. Id. at 875-76.

32. This Note specifically concerns problems in the legislation of genetic screening programs and the constitutionality of mandatory programs. For a review of the legal problems concerning other aspects of genetic screening see, Capron, Tort Liability in Genetic Counseling, 79 Colum. L. Rev. 618 (1979); Murray, Problems Behind the Promise:
ngetic disease, larger segments of the public may advocate mandatory screening programs. In the 1960's, a majority of states legislated mandatory screening programs for newborns. Many of these programs are still in effect. As more people become aware of the increasing genetic load, the emotional and monetary costs of genetic disease, and the availability of screening devices, the demand for mandatory screening programs will become more acute. To understand the legal problems caused by genetic screening, an elementary understanding of genetic screening devices and their effects is necessary.

A. Genetic Screening Devices

1. Prenatal Screening

Amniocentesis is an accurate technique by which a fetus can be tested to determine whether it has a genetic disease. At least sixty genetic diseases can be detected through amniocentesis, including Tay-Sachs disease, sickle cell anemia (SCA), and Down's syndrome. Other methods used to screen prenatally in-

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Ethical Issues in Mass Genetic Screening, 2 Hastings Center Rep. No. 2, at 10 (1972); Peters & Peters, supra note 31; Note, supra note 29.

33. “Society must define the goals of genetic screening. If the techniques only increase a woman's autonomy over her decisions, then government concerns diminish. If society sees genetic screening as a tool to decrease the incidence of congenital defects, then the system requires more complex laws.” Feinman, Getting Along With the Genetic Genie, 7 Legal Aspects Med. Prac. 37, 43 (1979).

34. See notes 85–90 infra and accompanying text.

35. Feinman, supra note 33, at 41.

36. Recent studies indicate that amniocentesis is 99.4% accurate. National Institute of Child Health and Human Development National Registry for Amniocentesis Study Group, Midtrimester Amniocentesis for Prenatal Diagnosis, 236 J.A.M.A. 1471, 1475 (1976). Amniocentesis is performed by inserting a needle into the uterus and removing some of the amniotic fluid surrounding the fetus. Amniocentesis must be performed after 16 weeks but prior to the 20th week of pregnancy. It often takes four weeks or longer to get the results. The risks include hemorrhage, abortion, and injury to the fetus, but the risk level is less than one percent. See generally Annas & Coyne, supra note 2, at 470–72; Milunsky, Gregory & Lawrence, Prenatal Genetic Diagnosis, 283 New Eng. J. Med. 1370 (1970); Powledge, Prenatal Diagnosis: New Techniques, New Questions, 9 Hastings Center Rep. No. 3, at 16 (1979); Turnbull, Gregory & Lawrence, Antenatal Diagnosis of Fetal Abnormality with Special Reference to Amniocentesis, 66 Proc. Royal Soc'y Med. 1115 (1973).


38. See notes 27 supra and 40 & 112 infra.


40. See notes 27 supra & 51 infra.

This Note emphasizes four major genetic diseases: phenylketonuria (PKU), sickle cell anemia (SCA), Tay-Sachs disease, and Down's syndrome. These diseases represent a cross section of the various techniques used in screening programs. Three of the diseases (SCA,
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clude fetoscopy, radiography, and ultrasound. Amniocentesis and the other prenatal screening devices give parents the option of aborting an affected fetus. Thus, parents who know they have the chance of producing a child with a genetic disease can conceive, screen the fetus for the disease, and if the results show that the child does not have the disease, deliver a healthy child. The dilemma arises in cases where the fetus is stricken with a genetic disease, and the parents must decide whether to abort the fetus.

Prenatal screening, unfortunately, is not helpful in decreasing the genetic load. Individuals carrying an undesirable trait are born and may pass on that trait. Ironically, amniocentesis may increase the genetic load. Previously, a family with a badly diseased child often opted not to risk having a second child, thus preventing passage of the trait. Presently, parents have the security of attempting to have a healthy child and aborting the diseased fetus. If born, however, the child may pass on the defective genetic trait.

2. Screening Newborns

The most common screening device used on newborns is a

Tay-Sachs, and Down's syndrome), for example, are detectable through amniocentesis. Children are screened routinely for PKU and SCA. The various diseases also are identifiable to a certain group of persons. SCA mainly affects Blacks but also can occur in those individuals of Latin, Asian, Greek, Indian, Puerto Rican, or Mediterranean origins. Tay-Sachs disease is most common among Ashkenazic Jews, while PKU often is associated with the Irish. The incidence of Down's syndrome increases as the mother's age increases and is especially high in births when mothers are over 35. PKU and SCA have generated extensive legislation at both state and federal levels, including mandatory screening in some jurisdictions.

41. Fetoscopy is a risky screening procedure which allows visualization of a fetus through the use of fiber optics. See Emery, Antenatal Diagnosis: Limitations and Future Prospects, in MEDICAL GENETICS TODAY 289, 294 (X Birth Defects Original Articles Series, No. 10, D. Bergsma ed. 1974).

42. Radiography is a method used to make photographs from X-rays and can be used to study the fetus to detect skeletal abnormalities. Id. at 290.

43. Ultrasound is an apparently safe method used to detect regions of altered density within the body. This technique is used to discover the position of the fetus, the presence of twins, and gross structural abnormalities. See Campbell, The Prediction of Fetal Maturity by Ultrasonic Measurement of the Biparietal Diameter, 76 J. OBSTET. GYN. BRIT. COMM. 603 (1969).

44. It must be remembered that amniocentesis occurs between the 16th and 20th weeks of pregnancy and that it often takes four weeks to receive the results. Most mothers are noticeably pregnant by this time (the fifth and sixth months) and may have developed an emotional tie with the fetus. Thus, to abort also must be viewed in light of others knowing of the pregnancy and the parents' own ties with the fetus, as well as the parents' moral attitudes concerning abortion.
blood test of the infant, usually through a heel prick or a blood
test of the umbilical cord.\textsuperscript{45} Most infants in this country are tested
at birth for metabolic disorders, including phenylketonuria
(PKU),\textsuperscript{46} but due to high costs, usually these children are not
screened for chromosomal or other genetic abnormalities.\textsuperscript{47}
PKU testing became enormously popular in the 1960's when it
was publicized that a relatively inexpensive screening procedure
could be used to detect PKU and related metabolic disorders,
which in turn could be treated successfully through a specific
diet.\textsuperscript{48} Screening of newborns also can detect the same genetic
diseases that are detectable in children and adults, such as Tay-
Sachs disease and SCA. Testing for such diseases at birth is ben-
eficial to parents who have not been screened because the discovery
of a child with a genetic disorder will inform the parents that fu-
ture children are in danger of inheriting the same disease. The
necessary steps and precautions then may be taken.

3. Screening Children and Adults

Blood tests given to children and adults can detect numerous
genetic diseases.\textsuperscript{50} In many cases, a genetic disease is obvious
from physical and mental characteristics, but a blood test will ver-
ify the diagnosis.\textsuperscript{51} Commonly, genetic screening tests are admin-
istered upon school entrance\textsuperscript{52} and marriage. Giving adults of
childbearing age a screening test informs them initially of their
genetic background and their chances of bearing genetically dis-

\textsuperscript{45} See Levy, Newborn Screening for Metabolic Disorders, 288 NEW ENG. J. MED.
1299 (1973).
\textsuperscript{46} See notes 83–90 infra and accompanying text.
\textsuperscript{47} See Annas & Coyne, supra note 2, at 473.
\textsuperscript{48} Other diseases similar to PKU include maple-syrup-urine disease, homocys-
tinuria, tryosinosis, and galactosemia. Similar in their metabolic origin, these diseases
manifest an absence or deficiency of an enzyme causing a chemical imbalance that can
result in mental and physical problems, including severe mental retardation. Those indi-
viduals suffering from PKU, for example, have high amounts of phenylalanine in their
blood due to the absence of the enzyme phenylalanine hydroxylase. The treatment for
PKU involves a diet low in phenylalanine. This requirement may mean consuming only
specially prepared flour and milk. By adhering to the low phenylalanine diet, a child with
PKU can develop normally. As a child affected with PKU grows older, the brain becomes
less sensitive to the high amount of phenylalanine in the blood so the diet can become less
strict. \textit{Id.} at 467, 473; PBS Transcript, \textit{supra} note 27, at 3–4.
\textsuperscript{49} For a discussion of PKU screening legislation and its subsequent problems and
changes, see notes 85–102 infra and accompanying text.
\textsuperscript{50} See Annas & Coyne, supra note 2, at 473–74.
\textsuperscript{51} Down's syndrome, for example, usually is easily detectable because it is mani-
ifested by physical characteristics.
\textsuperscript{52} See note 107 infra and accompanying text.
eased children. Problems have arisen, however, with administering screening tests to school-aged children. One problem is that carriers often are stigmatized or treated as if they had the disease.\textsuperscript{53} Also, since children are not able to understand fully the implications of the screening results, the tests may seem unnecessary and perhaps be feared.\textsuperscript{54}

\textbf{B. Advances in the “Treatment” of Genetic Disease}

Very few genetic diseases respond to medical treatment.\textsuperscript{55} Opponents of genetic screening argue that since there is such a limited opportunity for treatment of genetic disease, the sole purpose of screening must be to detect carriers and discourage them from having children.\textsuperscript{56} Advocates of screening answer that all persons should have the information necessary to make intelligent decisions regarding such important matters as choosing a mate and bearing children.\textsuperscript{57} Advances in artificial insemination\textsuperscript{58} and in

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\item \textsuperscript{53} Some children screened for SCA whose results were positive, for example, were precluded from physical education classes even though most of them merely carried SCA and had no need to abstain from physical activities. \textit{See PBS Transcript, supra note 27, at 8–9.}
\item \textsuperscript{54} \textit{Id.} “Children in school particularly had the finger pointed at them as something being wrong, because in medicine, we don’t test for something unless there’s something wrong with you.” \textit{Id.} at 8.
\item \textsuperscript{55} A genetic disease is not curable in the sense that the disease can be eliminated. Once the defective gene has been passed to a person, it is there for life and can be transmitted to the next generation. There are, however, treatments for certain genetic diseases. Cleft palate, for example, is an inherited trait. Through surgery, this defect can be corrected physically, but the individual with the cleft palate still carries the responsible gene. As was discussed in note 48 supra, metabolic disorders can be treated through proper diets. These diets, however, are dangerous and ultimately may cause physical harm and death. \textit{See Parker, Some Legal Aspects of Genetic Counseling, 7 PROGRESS IN MED. GENETICS 217 (1970).}
\item The pain of some genetic diseases, such as SCA, can be treated through medication, but there is risk of addiction and overdose. There are very few genetic diseases, however, that can be treated effectively. Moreover, there is no way, short of not having natural children, that a person with a genetic defect can avoid the risk of passing that defect onto his or her offspring. For a general discussion of treatments and proposed treatments of genetic disease, see Rimoin, \textit{The Medical Genetics Clinic and Community Health}, in \textit{BIRTH DEFECTS 67} (Birth Defects Original Articles Series No. 1, D. Bergsma ed. 1970).
\item \textsuperscript{56} \textit{See P. REILLY, GENETICS, LAW, AND SOCIAL POLICY 67 (1977); Annas & Coyne, supra note 2, at 485 n.90.}
\item \textsuperscript{57} \textit{See P. REILLY, supra note 56, at 147–48; PBS Transcript, supra note 27, at 7.}
\item \textsuperscript{58} Artificial insemination is a technique by which a woman is impregnated with sperm from a donor through mechanical means. The donor could be the woman’s husband, friend, or an unknown male. Where the man carries a genetic disease or trait and the woman does not, artificial insemination with another man’s sperm offers the couple one means to have healthy children. Technologically, artificial insemination is nearing perfection. There even have been normal births of healthy infants from semen that has been frozen for three years. \textit{See Gorney, The New Biology and the Future of Man, 15 U.C.L.A.}
vitro fertilization\textsuperscript{59} offer couples new choices as these individuals determine the genetic risks involved in having their own natural children. Couples also may adopt children if they think that the risk of producing genetically diseased children is too great. Artificial insemination and in vitro fertilization, when used correctly,\textsuperscript{60} not only give prospective parents new options concerning childbearing, but unlike the use of amniocentesis, help to reduce the genetic load. For this reason, these techniques are widely advocated as the appropriate methods for having children if the risk of genetic disease exists.\textsuperscript{61}

\textsuperscript{59} In vitro fertilization (IVF) is the process by which the immature ova are removed from a woman and fertilized. The product of this conception is transplanted into a woman's uterus several days later. See Edwards, Barrister & Steptol, \textit{Early Stages of Fertilization In Vitro of Human Oocytes Matured In Vitro}, 221 NATURE 632 (1969). See also Cohen, \textit{The "Brave New Baby" and the Law: Fashioning Remedies for the Victims of In Vitro Fertilization}, 4 AM. J.L. & MED. 319 (1978).

\textsuperscript{60} Again, the warning is that unless all prospective donors are screened for genetic defects and their donations marked properly with accurate, inclusive genetic data, the risk remains that the donee will choose a donor with the same or another genetic defect.

\textsuperscript{61} Gorney, \textit{supra} note 58, at 293. In the extreme, some individuals advocate sterilization of those persons with genetic disease that should not be passed on, leaving the latter with only the choices of having no children or having children through adoption, artificial
C. Negative and Positive Eugenics

Eugenics is the science of genetic planning and improvement. The concept of eugenics originated in ancient Greece, but was revived at the turn of this century. There are two types of eugenics practiced—negative eugenics and positive eugenics. Negative eugenics involves the prevention of genetically defective conceptions and can be accomplished through persuading those persons with a high probability of passing on a defective gene not to reproduce. Artificial insemination is an example of a negative eugenics practice. Those individuals at high risk of passing on a genetic disease are persuaded not to reproduce naturally but to use artificial insemination by a genetically healthy donor. Sterilization is another example of a negative eugenics procedure which prevents the occurrence of defective conceptions.

Positive eugenics involves selective breeding to reduce the genetic load and increase superior and favorable genetic qualities. A special use of artificial insemination provides an example of a positive eugenics practice. This special use involves the artificial insemination of women with sperm from a specific class of donors, such as Nobel Prize recipients. The donors must be screened for genetic defects and then studied for special qualities one would like to see propagated throughout society. Under a positive eugenics policy, many individuals would be prohibited from bearing children, while others, through artificial insemination and in vitro fertilization would bear several children.


62. Eugenics is the science that concerns those influences upon individuals that better future generations, both physically and morally.

63. "[Eugenics] is not a new concept. Over 2,000 years ago, in his masterpiece The Republic, Plato envisioned a state headed by philosopher rulers who were given the power to decide which married couples could procreate." Feinman, supra note 33, at 37.

64. The beginnings of modern eugenics in this country are found in the early sterilization laws. Those laws typically ordered sterilization for criminals, the chronically poor, and those individuals with mental retardation, mental disorders, and epilepsy. See C. DARWIN, THE ORIGIN OF THE SPECIES 80 (1859); Ferster, Eliminating the Unfit—Is Sterilization the Answer?, 27 OHIO ST. L.J. 591 (1966).

65. Gorney, supra note 58, at 293.

66. See note 58 supra and accompanying text.

67. See notes 61–64 supra and accompanying text.

68. Gorney, supra note 58, at 294.

69. Positive eugenics often is viewed as more threatening than negative eugenics. Gorney, supra note 58, at 293. This viewpoint probably results because both good and bad genetic traits are considered. The problem of who decides whether traits are good or bad becomes even more important. Id. at 293–95.
Some physicians, counselors, and scientists think that the only valid purpose associated with genetic counseling is personal counseling of the family. These professionals believe that "a genetic counselor's job should not, in any way, be construed as eugenic in practice."\textsuperscript{70} Counselling based on statistical projections for future generations (e.g., the effect on gene frequency of sickle cell anemia if all [carriers] are counseled to forego having offspring) fails to weigh compassionately the needs of the unborn fetus and [its] parents, just as it fails to meet the likelihood of effective treatment for the disease. Thus, the counselor who acts as an agent of eugenic policy, must in the long run shortchange his [or her] patients—fail in his [or her] role as physician.\textsuperscript{71}

A contrary view proposes that genetic counseling should go beyond the best interests of the individual family under counsel and instead strive to reduce the genetic load, thus benefitting the entire population.\textsuperscript{72} Those individuals taking an intermediate position may subscribe to a eugenics policy but think that they should not influence their clients' decisions in favor of such a policy.\textsuperscript{73} Although many of these counselors strive for objectivity, their personal views may nevertheless be influential.\textsuperscript{74} As the severity of the genetic disease increases, the goal of objectivity becomes more difficult to maintain.\textsuperscript{75} In counseling a client, for example, who is pregnant with a fetus with Tay-Sachs disease, a genetic counselor's opinion about the severity and hopelessness of the disease\textsuperscript{76} might lead him or her to counsel aborting the fetus. "It would be unrealistic to expect genetic counselors to suppress completely such strongly held views."\textsuperscript{77} Although genetic counselors do have the opportunity to advise clients consistent with a eugenics policy, clients do not always heed such advice.\textsuperscript{78} It is difficult, therefore, to ascertain the influence genetic counselors

\textsuperscript{70} Lappé, The Genetic Counselor: Responsible to Whom?, 1 Hastings Center Rep. No. 2, at 6 (1971). "The genetic counselor's obligation . . . never should extend beyond the family within his [or her] purview. If we are a society interested in 'genetic improvement of the stock,' this is a job for some other professional or governmental body—it is not to be the [genetic counselor's] stock and trade!" \textit{Id.}

\textsuperscript{71} \textit{Id.} at 8.

\textsuperscript{72} See J. Fletcher, supra note 17, at 48-50; P. Reilly, supra note 56, at 152-63.

\textsuperscript{73} See Lappé, supra note 70.

\textsuperscript{74} \textit{Id.}

\textsuperscript{75} See P. Reilly, supra note 56, at 156-57.

\textsuperscript{76} See note 112 infra.

\textsuperscript{77} P. Reilly, supra note 56, at 157.

\textsuperscript{78} Research findings indicate that two out of every six couples decide to continue the pregnancy after learning of the diseased fetus. See J. Fletcher, supra note 17, at 49.
have over their clients.  

Other individuals argue that eugenic goals are wrong and immoral because these goals cause unnatural behavior. In reply, it has been argued:

Man is very much a part of nature. He has always used his genius to preserve and enhance the quality of life. To this end, man has developed medical science and a vast variety of technical tools and luxuries. But medical science has upset natural selection. Technical developments . . . have increased the mutation rate in man. Accordingly, man's genetic load is increasing. Thus, man has already "intervened in nature" and acted "unnaturally." The decision now is in what direction shall man continue to direct his evolution.

The key legal issue in eugenics is who will decide which traits are desirable. Political, moral, and ethical problems must be considered in the resolution of this issue. Legislative enactments and judicial decisions have illustrated the law's ability to draw lines in controversial areas. The question of who will decide ultimately the desirability of a given trait is not ripe for decision, since it has not been established that any type of eugenics program would be permissible in this country. The current issue, consequently, is whether genetic screening should be mandated by law. Such a mandatory screening program is only one step in the implementation of any eugenics program.

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79. For a good review of legal problems involving genetic counselors, their standards of care, and potential liabilities, see Capron, supra note 32; Note, supra note 29.

80. Crow, supra note 22, at 430.

81. Dobzhansky advocates evaluating each genetic condition on its own merits. If a person carries a genetic trait that has been considered and ruled to be one that should not be passed on, then that person should be sterilized. The author also thinks that all terribly deformed, uncorrectable fetuses should be aborted. Dobzhansky, supra note 61. Those individuals opposed to Dobzhansky's view believe such a consideration of each genetic defect and ultimate sterilization will lead to abuse and misuse. It may be decided, for example, that microcephalics are fetuses that should be aborted. The next step might be aborting fetuses with cleft palates. Joseph Fletcher's retort to this "slippery slope" argument is that surgeons often amputate legs with gangrene, yet they have not decided to amputate legs with poison ivy. See J. Fletcher, supra note 17, at 33. Fletcher thinks it is inhuman to have the knowledge necessary to increase the quality of life for human offspring and not to use that knowledge. "Surely, when [a society has] the necessary knowledge to prevent the birth of a seriously diseased person [society has] the responsibility to do so, out of loving concern for human beings." PBS Transcript, supra note 27, at 18 (remarks of Joseph Fletcher).

82. See, e.g., Roe v. Wade, 410 U.S. 113 (1973) (Court weighed the state's, fetus', and mother's interests in abortion and drew lines based on these competing interests); Furman v. Georgia, 408 U.S. 238 (1972) (invalidation of a death penalty statute).
II. PRESENT GENETIC SCREENING LEGISLATION AND ITS BACKGROUND

Screening statutes of some type currently are in effect in a majority of the states and at the federal level. To create a genetic screening statute which will survive future constitutional scrutiny, it is necessary to understand the present screening laws and their background.

A. PKU Screening Laws

During the mid-1960’s, popular science writers reported a breakthrough in the treatment of PKU, a relatively rare genetic disorder which accounts for less than one percent of institutionalized retarded children. The literature unfortunately gave the lay reader the impression that medical science fully understood PKU and was capable of PKU’s accurate diagnosis and effective treatment. Readers were excited by the prospect of a cure for mental retardation caused by PKU. Apparently, a simple, inexpensive blood test at birth could indicate whether a child had the disease, and if the results were positive, a special diet could be implemented to affect a cure. State legislatures throughout the country passed laws requiring or recommending a blood test at birth for the purpose of screening newborns. Between 1963 and 1967, forty-one states passed PKU screening laws, with most of these states requiring mandatory screening.

In retrospect, the PKU legislation was premature. The PKU laws have epitomized how not to legislate in the genetic field.

83. See note 90 infra and accompanying text.
84. See notes 145-68 infra and accompanying text.
85. See note 48 supra. A child’s chance of inheriting PKU is 1 in 15,000. See P. REILLY, supra note 56, at 59.
86. See Annas & Coyne, supra note 2, at 481.
87. See Swazey, Phenylketonurix: A Case Study in Biomedical Legislation, 48 J. URB. L. 883 (1971). In fact, the treatment for PKU was controversial and sometimes dangerous. Id. at 900-01.
88. Id. at 908.
89. See Annas & Coyne, supra note 2, at 481.
90. By 1977, 42 states had adopted PKU screening laws. 36 of the 42 states required mandatory screening. 27 of the states had a policy of exempting infants from testing if the infant’s parents objected to screening on religious grounds, and three states exempted testing of infants merely for parental objection. Five states left the discretionary power in the Department of Health to institute mandatory screening, and one state had a voluntary program. In five states, failure to comply with the screening law constituted a misdemeanor. Only nine states had treatment provisions. See id. at 908-14; Grant, Genetic Control and the Law, 1978 MED. TRIAL TECH. Q. 306, 319.
91. See Swazey, supra note 87, at 920.
Both the screening device and the treatment are not the panaceas that the public and the legislators anticipated.\(^\text{92}\) When the federal legislature attempted to develop a national PKU screening program in 1967, the proposed bill died in committee.\(^\text{93}\) A major reason for the bill's failure was the criticism it received from the American Academy of Pediatrics' Subcommittee on Legislation. This subcommittee stated that the bill was a "poor piece of legislation ... with noble aims, but based upon unwarranted medical assumptions."\(^\text{94}\) The subcommittee requested that the funds expended on such legislation be spent on further research in the field.\(^\text{95}\)

There were several problems with the initial PKU laws, most of which remain uncorrected. Two main problems were the use of a rudimentary diagnostic test\(^\text{96}\) and a treatment administered before its effects were known.\(^\text{97}\) The majority of the PKU statutes also lacked provisions for data collection, storage of data, and confidentiality of results,\(^\text{98}\) and most statutes contained no provisions for counseling\(^\text{99}\) or treatment.\(^\text{100}\) Other problems included the lack of provisions for education concerning genetic disease,\(^\text{101}\) both privately and professionally, and the failure of most state statutes to provide for quality control in the screening procedure.\(^\text{102}\)

### B. Sickle Cell Anemia Statutes

The predominantly mandatory PKU screening laws of the 1960's seemed to lead to a "screening mentality" in the state legislatures.\(^\text{103}\) As a result, in the early 1970's, twenty states passed genetic screening statutes for another genetic disease, sickle cell

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92. "In regard to the laws on PKU, the public and the legislatures have been led to believe that a higher degree of certainty exists in our medical understanding than now appears to be the case." Bessman, *Legislation and Advances in Medical Knowledge—Acceleration or Inhibition?*, 69 J. PEDIATRICS 334, 337 (1966).

93. See Swazey, supra note 87, at 914.


95. Id.

96. See Swazey, supra note 87, at 891–99.

97. Id. at 899–908.

98. See notes 387–90 infra and accompanying text.

99. See notes 381–86 infra and accompanying text.

100. See notes 391–92 infra and accompanying text.

101. See notes 393–94 infra and accompanying text.


103. PBS Transcript, supra note 27, at 4.
anemia (SCA). Some of these statutes made testing mandatory for certain classifications of people. There was a basic difference, however, between the screening test used for PKU and that used for SCA. The PKU screening device informed those individuals tested whether they had the disease. The SCA test could not differentiate between those persons afflicted with sickle cell disease and those individuals merely carrying the sickle cell trait. This ambiguity led to confusion for school children who tested positive because they were treated as though they had the disease, while most often they had only the sickle cell trait. These children were given special diets, detained from physical education classes, and generally treated as if something were wrong with them. Adult carriers of SCA were barred from certain jobs, and various insurance companies raised the cost of insurance for sickle cell carriers. The black community, consequently, suggested that the sickle cell screening program was a method used by the Whites in America to reduce and ultimately eliminate the black population. By 1972, black leaders sought to repeal the very SCA statutes they previously had requested.

Part of the SCA screening problem can be explained by examining the characteristics of SCA and the screening tests formerly available. The only way to eliminate a genetic disease with the characteristics of SCA is to halt the reproduction of children with SCA. During the early 1970's, SCA, unlike a disease such as Tay-Sachs, could not be detected through amniocentesis. Thus, expectant parents at risk of producing a child with the sickle cell trait or disease did not have the benefit of amniocentesis and had to wait for newborn screening to determine whether their child was affected with the disease. Moreover, very few of those indi-

104. Part of the reason SCA became the focus of attention at this time was because black leaders were insisting that physicians and politicians deal with SCA. Id. at 4–5. See Scott, Health Care Priority and Sickle Cell Anemia, 214 J.A.M.A. 731 (1970).
105. See Waltz & Thigpen, supra note 1, at 704–06.
106. Those individuals with sickle cell trait rarely experience any symptoms of sickle cell disease. These people can lead quite normal lives but must remember the possibility of passing on the sickle cell trait or disease to their offspring should their mate also have the sickle cell trait or disease.
107. PBS Transcript, supra note 27, at 6–8.
108. Id. at 8.
109. Id. at 9.
110. See P. Reilly, supra note 56, at 67; Annas & Coyne, supra note 2, at 485 n.90.
111. See notes 40 supra & 112 infra.
112. Recently, an amniocentesis screening device to detect SCA in utero has been developed. This device is not as accurate as the other tests but has been used successfully. This new procedure will give those individuals with SCA the opportunity to use prenatal
individuals screened and counseled for SCA understood the information given to them, and many of them thought that it was another form of stigmatization by Whites. These problems with the SCA screening laws were alleviated significantly by a federal SCA screening statute.

In May, 1972, Congress enacted the National Sickle Cell Anemia Control Act. The Act's purpose was to "establish a national program for diagnosis, prevention, and treatment of sickle cell anemia together with screening and counseling programs and informational programs." The federal law made screening voluntary and also funded voluntary state screening programs. The Act gave the Secretary of Health, Education and Welfare (currently the Secretary of Health and Human Services) the authority to enter "into contracts with public and private entities, for projects" for research, treatment, educational and counseling programs. The Act required confidentiality of screening results. These results, however, could be used in statistical studies and released with proper individual consent. The Act also required that first priority be given for screening and counseling services to persons entering their childbearing years; second priority went to diagnosis and the option of aborting an affected fetus. PBS Transcript, supra note 27, at 11–13. In comparing prenatal screening for SCA with that for Tay-Sachs disease, an important distinction should be remembered—the difference in severity of the diseases. Those individuals with Tay-Sachs disease face inevitable death at the age of three to five years. There is no cure, and the disease is very painful. Those individuals with SCA often live normal lives with few restrictions. Some individuals with SCA have other blood characteristics that keep them virtually free of SCA's debilitating effects. Others, however, do suffer greatly and lead less than normal lives. Despite these hardships, those persons affected with SCA do not face a disease of the same severity as Tay-Sachs disease.

113. P. REILLY, supra note 56.

James Bowman of the University of Chicago School of Medicine, began to argue that compulsory [SCA] screening laws, ostensibly designed to help blacks, could boomerang into a novel source of discrimination. . . . Inevitably, as black citizens realized that sickle cell disease could only be reduced by influencing reproductive behavior, there were cries of genocide. Id. at 67. See also PBS Transcript, supra note 27, at 7–10.


116. "The participation by any individual in any program or portion thereof under this [title] shall be wholly voluntary and shall not be a prerequisite to eligibility for or receipt of any other service or assistance from, or to participation in, any other program." National Sickle Cell Anemia Control Act, Pub. L. No. 92–294, § 1103, 86 Stat. 136 (1972) (repealed 1976).

117. Id. § 1102.

118. Id. § 1101(a)(1).

119. Id. § 1104(a)(2).
children under age seven.\textsuperscript{120}

Although this federal statute was more thoughtfully constructed than most state laws,\textsuperscript{121} problems remained. The congressional declaration of purpose, for example, provided that “sickle cell anemia is a debilitating, inheritable disease that afflicts approximately two million American citizens and has been largely neglected.”\textsuperscript{122} It is true that while two million American citizens have the sickle cell gene, most of these persons are merely SCA carriers and fewer than 50,000 actually suffer from the disease.\textsuperscript{123} Thus, the differentiation between sickle cell carriers and those individuals afflicted with sickle cell disease was not recognized by the federal legislators.\textsuperscript{124} As with the PKU statutes, SCA statutes were promulgated when the SCA test was not perfected\textsuperscript{125}—a fact which added to the criticism of the statutes.\textsuperscript{126}

C. Statutory Refinement of the Initial PKU and SCA Screening Laws

Both state and federal lawmakers responded to criticism of earlier screening laws by enacting new genetic screening statutes. The model state statute is Maryland’s.\textsuperscript{127} Unlike past genetic screening legislation, this statute exhibits thoughtful planning and drafting. At the federal level, Congress responded to the previous problems of genetic screening legislation by repealing the 1972 National Sickle Cell Anemia Control Act and replacing it with a

\textsuperscript{120} Id. § 1104(a)(4).

\textsuperscript{121} Many state laws demonstrated that their creators were unknowledgeable about SCA. The Georgia legislature created a bill entitled “Education-Immunization for Sickle Cell Anemia Required for Admission to Public Schools” (emphasis added). The title, however, was not placed in the code. The Louisiana legislature provided for the special dietary needs of children with SCA. These legislators apparently were assuming that since PKU could be treated through a diet so could SCA. See P. Reilly, supra note 56, at 68. Another problem involved the placement of SCA legislation. Some states attached the SCA sections to those dealing with communicable diseases such as syphilis. This attachment only enhanced the potential stigma attached to SCA. Id. at 69. For other examples of SCA screening statutes and their problems, see id. at 65–72; Waltz & Thigpen, supra note 1, at 704–06.


\textsuperscript{123} P. Reilly, supra note 56, at 68.

\textsuperscript{124} See notes 106–10 supra and accompanying text for a discussion of the problems associated with the failure to differentiate between sickle cell carriers and those individuals with sickle cell disease.

\textsuperscript{125} See text accompanying note 106 supra.

\textsuperscript{126} P. Reilly, supra note 56, at 72–73.

\textsuperscript{127} Id. at 100. See Md. Ann. Code art. 43, §§ 814–821 (1957).
broader and better planned screening statute.\textsuperscript{128}

The Maryland statute is more general than most statutes because it does not mention specific diseases but treats many genetic diseases. As such, the statute applies to more varied screening programs.\textsuperscript{129} The statute begins with a section listing legislative findings and declarations.\textsuperscript{130} This section indicates the problems associated with past screening laws according to the Maryland legislature. One provision, for example, states that carriers of genetic disorders should not be stigmatized or discriminated against\textsuperscript{131} and that the screening should be voluntary and strictly confidential.\textsuperscript{132} This statement indicates the Maryland legislators' concern with these issues which were handled inappropriately by other genetic screening statutes.

A novel aspect of the Maryland law is the creation of a commission to oversee the administration of the genetic screening statute.\textsuperscript{133} The commission's powers include: the establishment of regulations for the detection and management of hereditary disorders; the control of information about genetic disorders; the authority to investigate charges of discrimination against a person with a hereditary disorder; and continuous reevaluation of the screening statute.\textsuperscript{134} The commission, however, cannot establish rules or principles contrary to those rules listed by the legislature in section 818.\textsuperscript{135} These legislative restrictions dictate the following: a screening program cannot require "mandatory participation, restriction of childbearing, or be a prerequisite to eligibility for, or receipt of any other service or assistance from or to participation in any other program;"\textsuperscript{136} informative and nondirective

\begin{itemize}
\item \textsuperscript{129} See Powledge, New Trends in Genetic Legislation, 3 Hastings Center Rep. No. 6, at 6 (1973).
\item \textsuperscript{130} Md. Ann. Code art. 43, § 814 (1957). Included is a finding that genetic screening for some hereditary disorders can lead to the alleviation of the problems associated with the disorder and can help in the future understanding of hereditary disorders and their eventual alleviation or cure. \textit{id.} § 814(c).
\item \textsuperscript{131} \textit{id.} § 814(f). The legislature's concern with the stigma carried by those individuals with the SCA trait accounts for the failure to proscribe discrimination against persons afflicted with SCA. P. Reilly, supra note 56, at 99.
\item \textsuperscript{132} Md. Ann. Code art. 43, § 814(j) (1957).
\item \textsuperscript{133} \textit{id.} § 814(k).
\item \textsuperscript{134} \textit{id.} § 817.
\item \textsuperscript{135} \textit{id.} § 818.
\item \textsuperscript{136} \textit{id.} § 818(f).
\end{itemize}
counseling must be available to all individuals;\textsuperscript{137} pretesting counseling must be available to explain the risks, costs, and possible results of the test(s);\textsuperscript{138} and test results are to be confidential, with provision for statistical analysis and informed consent for release of the data.\textsuperscript{139}

The Maryland law, though approved as a model statute,\textsuperscript{140} has not been adopted in other states. The Washington legislature introduced a statute virtually identical to the Maryland law, but due to funding considerations, the proposal did not become law.\textsuperscript{141} Lack of financial resources may explain why a carefully written statute such as Maryland’s has not been widely adopted. A statute requiring only a simple blood test at birth is certainly less expensive to implement than a comprehensive program such as Maryland’s\textsuperscript{142} which furnishes treatment, counseling, and other services, but the cheaper program is also inadequate compared to the Maryland system.\textsuperscript{143} There also have been recent changes made by some states contrary to the Maryland model provisions. Arizona, for example, passed a law requiring mandatory prenatal screening to detect metabolic disorders.\textsuperscript{144}

Congress responded to the inadequacies of the 1972 SCA statute by enacting the National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and Genetic Diseases Act (Genetic Diseases Act).\textsuperscript{145} Genetic diseases other than sickle cell anemia were included in the Act’s provisions, enabling more Americans to share in the nation’s health resources.\textsuperscript{146} Dissatisfaction with the ad-

\textsuperscript{137} Id. § 818(g).
\textsuperscript{138} Id. § 818(h).
\textsuperscript{139} Id. § 818(i)–(j).
\textsuperscript{140} See Powledge, note 129 supra, at 7.
\textsuperscript{141} P. REILLY, supra note 56, at 101. The present law is found at WASH. REV. CODE ANN. §§ 70.83.010–.83.050 (West Supp. 1980).
\textsuperscript{142} The New York statute, for example, requires that tests be administered to detect PKU, SCA, and other diseases, but exemptions are allowed for parental religious objections. N.Y. PUB. HEALTH LAW § 2500-a (McKinney 1977). In 1977, this program cost New York approximately $250,000. P. REILLY, supra note 56, at 97.
\textsuperscript{143} Funding also became an issue in the administration of the federal law concerning genetic screening. See notes 147–48 infra and accompanying text.
\textsuperscript{144} ARIZ. REV. STAT. ANN. § 36–694(B) (West Supp. 1980).
\textsuperscript{146} H.R. REP. No. 498, supra note 27, at 20–21, reprinted in [1976] U.S. CODE CONG. & AD. NEWS 709, at 728–29. Congress stated the purpose of the Act as follows: In order to preserve and protect the health and welfare of all citizens, it is the purpose of this title . . . to establish a national program to provide for basic and applied research, research training, testing, counseling, and information and education programs with respect to genetic disease, and genetic conditions, such as
ministration of this Act of 1976, however, compelled Congress to amend the Act in 1978. The program was to be administered by the Health Services Administration (HSA), but Congress was "deeply concerned" about HSA's approach. Congress, consequently, reinterpreted the Act to ensure that its future management reflected congressional intent.

Moreover, Congress designed the 1978 Genetic Diseases Act to be flexible. The Act was designed to incorporate new scientific and medical advances that are made in the genetic field by providing genetic services. These services include: "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." The first three years of the 1976 Act exhibited limited progress due to the lack of planning provisions for "research, training, counseling, and the detection, prevention and treatment of genetic disease . . ." The amended Genetic Diseases Act provides for planning and program evaluation.

The federal statute is similar to Maryland's screening law as

Sickle Cell anemia, Cooley's anemia, Tay-Sachs disease, cystic fibrosis, dysautonomia, hemophilia, retinitis pigmentosa, Huntington's chorea, muscular dystrophy, and genetic conditions leading to mental retardation . . . or genetically caused mental disorders.


148. Id. at 33, reprinted in [1978] U.S. CODE CONG. & AD. NEWS 9134, at 9166. Congress was concerned deeply about the approach the HSA was taking in its implementation of the Genetic Diseases Act. The HSA was "locking itself into a definition of genetic diseases to be covered" by the Act. This definition meant that only a few genetic diseases were dealt with under the 1976 Act.

149. "The committee's bill stresses noncategorical initiatives in comprehensive genetic services based on effective planning, evaluation, and needs assessment. The bill further broadens the scope of its coverage to include 'genetic conditions leading to mental retardation or mental illness, and conditions requiring genetic services.'" Id., reprinted in [1978] U.S. CODE CONG. & AD. NEWS 9134, at 9166.


153. Id. § 300b-3(d). "[T]he Secretary shall . . . [develop] a procedure under which persons from among members of the general public and from among leading medical or scientific authorities . . . will have the opportunity on a regular basis to make recommendations to the Secretary." Id.

154. See notes 127–39 supra and accompanying text.
it provides for education of the public and professionals regarding
genetic disease and services.\textsuperscript{155} Participation in such a program is
voluntary and is not a prerequisite to eligibility for other
programs.\textsuperscript{156} Screening results are strictly confidential unless waived
through informed consent or for statistical purposes.\textsuperscript{157} The Act
provides for counseling concerning genetic disease\textsuperscript{158} and the
development of special programs to train genetic counselors.\textsuperscript{159} Ad-
ditionally, there are provisions for treatment\textsuperscript{160} and research\textsuperscript{161} of
genetic disease. Finally, funding is available to private and public
groups for research, screening programs, counseling services, and
dissemination of educational materials.\textsuperscript{162} Eligibility for fund-
ing requires that programs be voluntary\textsuperscript{163} and results be
confidential.\textsuperscript{164}

Congress realized that the 1978 Genetic Diseases Act was a
"significant new initiative which [would] require new staff posi-
tions to insure the intelligent expenditures of funds and careful
implementation of programs."	extsuperscript{165} Congress, therefore, urged the
Secretary of Health and Human Services to create new positions
and authorized \$45 million annually for fiscal years 1979, 1980,
and 1981.\textsuperscript{166} Congress also authorized the National Commission
for the Protection of Human Subjects of Biomedical and Behav-
ioral Research to do a study on the "ethical, social, and legal im-
lications of voluntary testing, counseling, and information and
education programs with respect to genetic diseases."\textsuperscript{167} Congress
hoped the study would clarify the implications of mandatory ver-
sus voluntary screening, which indicates that Congress has not yet
rejected the idea of mandatory genetic screening programs.\textsuperscript{168}

\textsuperscript{156} Id. § 300b–2.
\textsuperscript{157} Id. § 300b–3(a)(2).
\textsuperscript{158} Id. §§ 300b(a)(1), 300b–1(4), –4, –6.
\textsuperscript{159} Id. § 300b–1(2).
\textsuperscript{160} Id. §§ 300b–1(4), –4, –6.
\textsuperscript{161} Id. § 300b–1.
\textsuperscript{162} Id. § 300b.
\textsuperscript{163} Id. § 300b–2.
\textsuperscript{164} Id. § 300b–3(a)(2).
\textsuperscript{165} S. REP. No. 860, supra note 37, at 35, reprinted in [1978] U.S. CODE CONG. & AD.
News 9134, at 9168.
III. THE CONSTITUTIONALITY OF A MANDATORY GENETIC SCREENING PROGRAM

Mandatory genetic screening may be attacked under four major constitutional doctrines: the fourth amendment's protection against unreasonable searches; the fourteenth amendment's guarantee of due process of law and equal protection of the laws; and the first amendment's assurance that the freedom to exercise religion will not be abridged. To understand the focus of attack under each doctrine, it is necessary to view genetic screening in two distinct ways. In some instances, the act of screening itself—the drawing of blood or amniotic fluid—is under attack. In other instances, the effects of screening are under attack. An individual testing positive, for example, might next undergo counseling. Although counseling is designed to be objective, it ultimately may have the effect of causing an individual to make critical decisions concerning marriage and childbearing. Because positive screening results may impact on these fundamental decisions, the constitutionality of the counseling and the actual blood test must be scrutinized.

A. The Fourth Amendment—Protection From Unreasonable Searches and Seizures

The fourth amendment attack would be brought against the actual screening procedures—the blood test and amniocentesis. Although fourth amendment arguments involving illegal searches

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169. See notes 175–225 infra and accompanying text.
170. See notes 226–83 infra and accompanying text.
171. See notes 284–330 infra and accompanying text.
172. See notes 331–70 infra and accompanying text.
173. Some physicians, counselors, and scientists believe that genetic counseling should be tailored to meet the needs of the particular family under counsel. See Lappé, supra note 70.
174. Although many counselors strive for objectivity, their personal views nevertheless may be influential. See notes 70–71 supra and accompanying text.
175. The fourth amendment reads:

[T]he right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probable cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized.

U.S. CONST. amend. IV.

The fourth amendment is enforceable against the states through the due process clause of the fourteenth amendment. Mapp v. Ohio, 367 U.S. 643, 655 (1961).
and seizures usually concern physical property, for nearly a century, the right to be free from such searches has involved more than the unlawful search of property.\textsuperscript{176} The right to be free from unreasonable searches and seizures includes protection from unreasonable bodily intrusions such as mandatory blood tests.\textsuperscript{177} Compelled blood tests, however, have survived constitutional scrutiny in some cases.\textsuperscript{178} In \textit{Schmerber v. California},\textsuperscript{179} Justice Brennan upheld a compelled blood test but warned:

> The integrity of an individual’s person is a cherished value of our society. That we today hold that the Constitution does not forbid the States minor intrusions into an individual’s body under stringently limited conditions in no way indicates that it permits more substantial intrusions, or intrusions under other conditions.\textsuperscript{180}

In determining the constitutionality of a mandatory blood test or amniocentesis for genetic screening, the requirements of a legal search must be examined. The Constitution guarantees to all persons that their private lives will be protected from unwarranted governmental intrusion.\textsuperscript{181} “[W]hat [a person] seeks to preserve as private, even in an area accessible to the public, may be constitutionally protected.”\textsuperscript{182} The fourth amendment provides that searches are unlawful unless a warrant has been obtained\textsuperscript{183} and that probable cause must be shown to obtain a warrant.\textsuperscript{184}

\textsuperscript{176} “The principles laid down in this opinion affect the very essence of constitutional liberty and security. . . . It is not the breaking of his doors . . . but it is the invasion of his indefeasible right of personal security, personal liberty and private property . . . .” Boyd v. United States, 116 U.S. 616, 630 (1886).

\textsuperscript{177} The compelled puncture of skin and the extraction of blood are considered searches under the fourth amendment. Schmerber v. California, 384 U.S. 757, 767 (1966) (search was held to be reasonable since probable cause was shown). See note 178 infra. See also People v. Duroncelay, 146 Cal. App. 96, 303 P.2d 617 (1956); Block v. People, 125 Colo. 36, 240 P.2d 512 (1951).

\textsuperscript{178} The involuntary drawing of blood has been upheld in both criminal and civil cases. See Schmerber v. California, 384 U.S. 757 (1966) (blood test upheld when used to determine if defendant was intoxicated after he had been involved in an automobile accident and appeared drunk); Jordan v. Davis, 143 Me. 185, 57 A.2d 209 (1948) (involuntary blood test upheld in bastardy proceeding); Cortese v. Cortese, 10 N.J. Super. 152, 76 A.2d 717 (Super. Ct. App. Div. 1950) (involuntary drawing of blood upheld in paternity proceeding).


\textsuperscript{180} 384 U.S. at 772.


\textsuperscript{182} \textit{Id.} “Wherever a man may be, he is entitled to know that he will remain free from unreasonable searches and seizures.” \textit{Id.} at 359.

\textsuperscript{183} U.S. CONST. amend. IV. See Agnello v. United States, 269 U.S. 20, 33 (1925).

"[S]earches conducted outside the judicial process, without prior approval by judge or magistrate, are per se unreasonable under the Fourth Amendment . . . ." If these constitutional principles concluded the inquiry, screening procedures, to be held constitutionally valid, would have to require a warrant to screen each individual. In some situations, however, warrants are easily obtainable or unnecessary.

In *Camara v. Municipal Court*, the Supreme Court held that persons inspecting for safety, fire, health, and related violations could not demand to enter private homes and other premises without a search warrant. The *Camara* Court was concerned with arbitrary governmental invasion. The government asserted that warrantless administrative searches were necessary to protect the public health and safety of urban populations. The Court held that "the burden of obtaining a warrant . . . [was not] likely to frustrate the governmental purpose behind the search." Thus, the Court required a warrant, overruling past cases which had permitted such searches without a warrant. Nevertheless, the holding was not as strict as it seemed, since the Court held that the various inspectors did not have to show probable cause of a specific violation to obtain the warrant. "If a valid public interest justifies the intrusion contemplated, then there is probable cause to issue a suitably restricted search warrant."

The government may avoid fourth amendment problems with genetic screening by seeking a *Camara*-type warrant. Authorities

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185. 389 U.S. at 357. Exceptions to the general rule can be found in *Warden v. Hayden*, 387 U.S. 294 (1967) (warrantless search permitted if justified on "hot pursuit" grounds); *Zap v. United States*, 387 U.S. 294 (1967) (no warrant is needed if person searched has consented); *Agnello v. United States*, 269 U.S. 20 (1925) (warrantless search permitted if incident to a lawful arrest).

186. See notes 188–96 infra and accompanying text.

187. See notes 200–214 infra and accompanying text.

188. 387 U.S. 523 (1967).

189. *Id.* at 540. The holding was limited to nonemergency situations in which immediate access is not required.

190. *Id.* at 528.

191. *Id.* at 533.

192. *Id.*

193. *Id.* at 533–34.


195. 387 U.S. at 536–37. In determining not to require the showing of probable cause, the Court balanced society's interests in making the inspection against the individual's interest in being safe from intrusion.

196. *Id.* at 539.
could show a public interest, such as the protection of public health and welfare, and attempt to obtain a warrant to screen large groups of persons. The reviewing judge or magistrate, following Camara, would use reasonableness as the ultimate standard.

Such an approach neither endangers time-honored doctrines applicable to criminal investigations nor makes a nullity of the probable cause requirement in this area. It merely gives full recognition to the competing public and private interests... at stake and, in so doing, best fulfills the historic purpose behind the constitutional right to be free from unreasonable government invasions of privacy.

While the public interest in genetic screening is strong enough to permit the issuance of a Camara-type warrant, it is still an inconvenience for the government to seek such warrants. Camara did recognize exceptions to the warrant rule: "[N]otthing we say today is intended to foreclose prompt inspections, even without a warrant, that the law has traditionally upheld in emergency situations." In the past, such emergency searches and seizures have been upheld in the following situations: the seizure of tainted food; compulsory smallpox vaccinations; quarantines for health purposes; and the killing of cattle with tuberculosis. The health purposes behind genetic screening are comparable to these types of cases. Although the need to detect genetic disease presently may not connote the dangers of contagious disease, arguably when genetic disease becomes more prevalent and its costs increase, genetic screening will be viewed similarly to smallpox vaccinations. The emergency situation then may permit genetic screening absent a search warrant.

The Court also has allowed warrantless searches in other areas. The Court held, for example, in Wyman v. James, that

197. Id. at 538-39. Individual warrants for each premise and dwelling unit were not required. Id.
198. See id. at 539.
199. Id. (citing Eaton v. Price, 364 U.S. 263, 273-74 (1960)).
200. See notes 24-35 supra and accompanying text.
201. 387 U.S. at 539.
206. See notes 16-19 supra and accompanying text.
207. See notes 25-27 supra and accompanying text.
208. See, e.g., United States v. Biswell, 406 U.S. 311 (1972), where the Supreme Court held that a warrantless inspection of a weapons dealer by a federal agent was legal, reason-
home visits to recipients of Aid to Families With Dependent Children funds did not require a search warrant. While the Court said such visits were not searches in the traditional criminal law context, it analyzed the visits as searches. The factors examined by the Court included: 1) the purpose of the visit which was to aid the government in benefitting the child receiving the funds and not to attain criminal information; 2) the effectiveness of the means used to accomplish this purpose and the availability of alternative means; and 3) the severity of the intrusion. The Court relied heavily on the fact that these visits, even if searches, were not criminal in nature.

Screening procedures may be viewed similarly to the Wyman visits. The Wyman Court emphasized the importance of the public interest being protected—the child's needs—and commented that this purpose was unlike the purposes behind criminal

ing that the dealer entered into a business subject to heavy federal licensing requirements that lent itself to unannounced searches for effective inspection and enforcement. Id. at 316–17.

In Almeida-Sanchez v. United States, 413 U.S. 266 (1973), the Court held that immigration officials could conduct legal warrantless searches at borders. Id. at 272–73. In Almeida-Sanchez, however, the search of defendant's car 25 miles from the Mexican border was held unconstitutional because there was no reason for the arresting officer to believe the defendant had crossed the border. Id. at 273.

When the situation entails the search of body cavities and requires the subject to undress, customs inspectors must make a strong showing of probable cause for the search. Henderson v. United States, 390 F.2d 805 (9th Cir. 1967).


210. Id. at 317–18.
211. Id.
212. Id. at 318.
214. 400 U.S. at 317–18, 323, 325. The distinction between civil and criminal searches has been made in another context. In discussing the constitutionality of a mandatory mass screening program to detect those persons disposed to criminal behavior, one commentator concluded such a search would be criminal and ultimately would be held unconstitutional, but not necessarily on fourth amendment grounds. The author also contended that if the screening program were classified as civil rather than criminal, it would withstand constitutional scrutiny. Note, Guilt by Physiology: The Constitutionality of Tests to Determine Pre-disposition to Violent Behavior, 48 S. CAL. L. REV. 489, 507, 527 (1974).
215. 400 U.S. at 318.
searches. The purposes behind genetic screening are also non-
criminal and are offered to protect the public's health and wel-
fare. Genetic screening procedures resemble the Wyman
welfare visits more than the Schmerber blood test or the
Camara inspection since in the latter cases the searches were
conducted to discover criminal activity. The Wyman Court
also emphasized the mildness of the intrusion posed by a welfare
visit. Similarly, a blood test is not overly burdensome. Justice
Brennan stated that a compelled blood test was a minor intru-
sion even though it was taken in a criminal context. Thus, a
compelled blood test in a civil context may present a lesser
intrusion.

Since genetic screening procedures fall in the civil context and
have as their purpose the protection of the public welfare, a court
may view the procedures similarly to the welfare visits in Wyman.
As such, warrantless screening would not constitute a violation of
the fourth amendment. Courts also could compare the screening
procedures to emergency situations, such as smallpox vaccina-
tions, thus allowing screening without a warrant. If a court re-
quired a warrant, a Camara-type warrant could be obtained.
The fourth amendment prohibition against illegal searches and
seizures, therefore, will not render mandatory genetic screening
tests unconstitutional.

B. The Fourteenth Amendment—Substantive Due Process

The due process clause of the fourteenth amendment pro-

216. See note 214 supra.

217. It is within a state's police power to establish reasonable regulations to protect the
health and safety of its citizenry. Lawton v. Steele, 152 U.S. 133 (1894); New Orleans Gas
Co. v. Louisiana Light Co., 115 U.S. 650, 661 (1885); Railroad Co. v. Husen, 95 U.S. 465,
470-71 (1877).

218. See notes 177-80 supra and accompanying text.

219. See notes 188-99 supra and accompanying text.

220. The criminal activity in Schmerber was driving while intoxicated. The illegal ac-
tivity in Camara was the violation of a housing code regulation. See 400 U.S. at 324-25.

221. Id. at 320-22.

222. Some people may have religious beliefs that make the intrusion seem more severe.
See notes 343-49 infra and accompanying text.

223. 384 U.S. at 772. For Justice Brennan's quote, see text accompanying note 180
infra.

224. See notes 201-07 infra and accompanying text.

225. See notes 197-199 infra and accompanying text.

226. "No State shall . . . deprive any person of life, liberty, or property, without due
hibits state governmental deprivation of life, liberty, and property, unless proper legal procedures are observed. When focusing on the substantive content of life, liberty, or property, the Court engaged in a substantive due process analysis at the beginning of this century to strike down any economic regulation that was not a fair and reasonable exercise of the states' police power. Although the Court no longer engages in such analysis to scrutinize economic regulation, it still uses substantive due process to protect certain noneconomic rights, such as the right of privacy. The cases in which the right of privacy has been upheld are typically within the "sex-marriage-childbearing-childrearing" areas. Although the standard of judicial review

227. The fifth amendment protects persons from federal governmental interference. U.S. CONST. amend. V.

228. See Developments in the Law-The Constitution and the Family, 93 HARV. L. REV. 1157 (1980) [hereinafter cited as Developments]. "The doctrine that governmental deprivations of life, liberty, or property are subject to limitations regardless of the adequacy of the procedures employed has come to be known as substantive due process." Id. at 1166. See also Brown, Due Process of Law, Police Power and the Supreme Court, 40 HARV. L. REV. 943 (1927); Corwin, The Basic Doctrine of American Constitutional Law, 12 MICH. L. REV. 247 (1914).

229. This time in history often was called the Lochner era. See Lochner v. New York, 198 U.S. 45 (1905); Developments, supra note 228, at 1166-67.

230. See, e.g., Williams v. Standard Oil Co., 278 U.S. 235 (1929) (state price controls on gasoline struck down as a deprivation of property without due process); Adkins v. Children's Hosp., 261 U.S. 525 (1923) (law prescribing minimum wages for women struck down as unconstitutional abridgement of freedom to contract); Adams v. Tanner, 244 U.S. 590 (1917) (law prohibiting employment agencies from collecting fees from workers constituted deprivation of property without due process).

231. See Developments, supra note 228, at 1167-68.

232. Id. During the Lochner era, the Court began "finding certain liberty guarantees of the Bill of Rights applicable to the states by force of the due process clause of the fourteenth amendment." Id. See, e.g., Wolf v. Colorado, 338 U.S. 25, 27-28 (1949); Palko v. Connecticut, 302 U.S. 319, 324-25 (1937).

This process of incorporation (making the right applicable to the state through the fourteenth amendment) has continued, and presently, some rights not explicitly contained in the Bill of Rights are being incorporated. See, e.g., Roe v. Wade, 410 U.S. 113 (1973); Griswold v. Connecticut, 381 U.S. 479 (1965). Once a right is incorporated, heightened judicial scrutiny is applied. See United States v. Carolene Prods. Co., 304 U.S. 144 (1938). For a discussion of the problems of incorporating fundamental values not contained in the Bill of Rights, see Developments, supra note 228, at 1168-77.


234. See Ely, Forward: On Discovering Fundamental Values, 92 HARV. L. REV. 5, 11 (1978). Professor Ely notes, however, that what makes this composite a unitary area is unclear. The diversity in the area is manifested by the cases. See, e.g., Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (Court referred to the "private realm of family life" in upholding a restriction on maximum work hours for children); Skinner v. Oklahoma, 316 U.S. 535, 541 (1942) (marriage and reproduction fundamental to existence of race and basic civil rights of all individuals); Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925)
varies, the Court always balances the state's interest in establishing a law against the impact of such law upon the constitutional rights of those individuals challenging the law.

As an intrusion becomes more destructive of a right, it may be outweighed only by increasingly substantial state interests, and the degree of fit demanded between means and ends will increase as well.

Even given a balancing approach, the Court's use of strict scrutiny language in substantive due process cases might not be wholly inappropriate. That family rights, when their infringement is at its apex, be outweighed only by compelling state interests is consistent with the level of protection afforded other substantive constitutional values protected under the due process clause of the fourteenth amendment.

Since mandatory genetic screening and counseling may influence decisions of marriage and childbearing, the right of privacy becomes involved. Two attacks on genetic screening are possible based on the right of privacy. First, counseling those individuals with positive results affects their decisions regarding the protected areas of marriage and procreation. Second, the screening procedure involves data collection and storage, the confidentiality of which is protected by the right of privacy.

1. The Right of Privacy and Its Impact on Mandatory Counseling of Those Individuals with Positive Screening Results

The right of privacy has been recognized implicitly for nearly one hundred years. The Court and its individual justices have

(Oregon law requiring children to attend only public schools invalidated); Meyer v. Nebraska, 262 U.S. 390, 399 (1923) (liberty includes the right to marry and to have and rear children).

235. See Developments, supra note 228, at 1195 (quoting Professor Ely: "In due process analysis no threshold marks the passage from the most minimal to the most exacting scrutiny.").

236. Id. at 1194–95.

237. Id. at 1195–96. In this Note, the most lenient judicial scrutiny will be referred to as the "rational basis test." The most stringent scrutiny will be referred to as "strict scrutiny."

238. See notes 70–79 supra and accompanying text.

239. Developments, supra note 228, at 1195–96. Since the right of privacy is most relevant to the right to exercise personal autonomy in the areas of marriage and procreation, the terms right to marry and right to reproduce or have children sometimes will be used.

240. Id.

found the basis for the right of privacy in the first,\textsuperscript{242} fourth, fifth,\textsuperscript{243} ninth,\textsuperscript{244} and fourteenth\textsuperscript{245} amendments as well as in the penumbras of the Bill of Rights.\textsuperscript{246} Since the right of privacy involves the right to marry and procreate, counseling carriers or those persons afflicted with genetic disease against having children may impinge on their right of privacy.\textsuperscript{247} The counseling foreseen in this Note, however, would provide only genetic information to facilitate intelligent decisionmaking concerning marriage and reproduction.\textsuperscript{248}

While the additional information made available by genetic counseling will enhance an individual's ability to make informed decisions, there is concern that government-compelled screening and counseling may lead to government-compelled abortion and restrictions on childbearing.\textsuperscript{249} These concerns, in addition to the questionable objectivity of genetic counseling,\textsuperscript{250} warrant a detailed analysis of the possible infringements on an individual's right of privacy.

The right to marry is not absolute. In 1914, for example, the Wisconsin premarital blood test law requiring males about to be married to undergo screening for venereal disease was challenged.\textsuperscript{251} The challengers argued that the law restricted marriage.\textsuperscript{252} The Wisconsin Supreme Court noted that it was

\begin{itemize}
\item \textsuperscript{242} See Stanley v. Georgia, 394 U.S. 557, 564 (1969).
\item \textsuperscript{243} See Terry v. Ohio, 392 U.S. 1, 8–9 (1968); Katz v. United States, 389 U.S. 347, 350 (1967).
\item \textsuperscript{244} See Griswold v. Connecticut, 381 U.S. 479, 486 (1965) (Goldberg, J., concurring).
\item \textsuperscript{245} See Meyer v. Nebraska, 262 U.S. 390, 399 (1923).
\item \textsuperscript{246} See Griswold v. Connecticut, 381 U.S. 479, 484–85 (1965).
\item \textsuperscript{247} See note 234 supra and accompanying text.
\item \textsuperscript{248} See notes 70–79 supra and accompanying text. See also Capron, supra note 32; Note, supra note 29.
\item \textsuperscript{249} In fact, both of these alternatives are being recommended presently. See note 81 supra and accompanying text. Some individuals recommend the immediate adoption of eugenics programs, even when there is only limited knowledge available. See Vukovich, \textit{The Dawning of the Brave New World—Legal, Ethical and Social Issues of Eugenics}, 1971 U. ILL. L.F. 189, 197. Other individuals recommend that coercive methods should be used to insist that carriers of a disease ascertainable through amniocentesis not have affected children. Murray, supra note 32.
\item An alternative, suggested by Nobel laureate Linus Pauling, is to screen everyone at birth or during early childhood to detect their genetic defects. A small tattoo then should be placed on the child identifying the genetic defects carried. When dating begins, young people would be able to detect immediately whether or not their dating partner is compatible genetically with them. Pauling, \textit{Reflections on the New Biology: Forward}, 15 U.C.L.A. L. Rev. 267, 269 (1968).
\item \textsuperscript{250} See notes 70–79 supra and accompanying text.
\item \textsuperscript{251} Peterson v. Widule, 157 Wis. 641, 147 N.W. 966 (1914).
\item \textsuperscript{252} The plaintiffs also challenged the cost of the test most often used and questioned
undeniably within the state's police power to control and regulate marriage through reasonable laws. Since this statute was reasonable, it did not violate due process. Most states currently require premarital testing for venereal disease, and, in most of these states, positive results prevent issuance of a marriage license. Other restrictions on marriage include age limits, consanguinity laws, and statutes forbidding drunkards and imbeciles from marrying. These limits placed on marriage and procreation have withstood constitutional challenge.

Not all restrictions on marriage and procreation have been upheld. In Griswold v. Connecticut, for example, the Court struck down a statute forbidding the use of contraceptives and forbidding any person from aiding, counseling, or causing someone to use contraceptives. The majority in Griswold recognized that various constitutional guarantees gave rise to a zone of privacy and that the use of contraceptives by married persons fell within that zone. The Court did not classify the right of privacy as fundamental but indicated that the right should be reviewed by utilizing a standard stricter than the rational basis test.

whether the legislature intended that only one test be used. Id. at 641, 651-55, 147 N.W. at 966, 969-71.

253. Id. at 656-57, 147 N.W. at 971. The challengers also argued that the law violated equal protection by singling out men about to marry and not women. While recognizing the validity of this argument, the court nevertheless rejected it because women were not contracting venereal disease and giving it to men. The court noted that both common knowledge and statistics showed that a great number of women who married were pure and in no need of a premarital blood test. Id. at 648-49, 147 N.W. at 968.

254. See P. Reilly, supra note 56, at 135-36. In New York, there is a statute requiring that an SCA test be given to marriage license applicants who are not Caucasian, Indian, or Oriental. The results are to be given to the applicant and "no application for a marriage license shall be denied solely on the ground that the test proves positive nor shall the absence of such test invalidate a marriage." N.Y. Dom. Rel. Law § 13-aa (McKinney 1977).

255. An Ohio statute provides, for example, that "no marriage license shall be granted when either of the applicants is a habitual drunkard, imbecile, or insane person, is under the influence of an intoxicating liquor or controlled substance, or is infected with syphilis in a form that is communicable or likely to become communicable." Ohio Rev. Code Ann. § 3101.06 (Page 1980).

256. 381 U.S. 479 (1965).

257. Id. at 485.

258. Id.

259. Id.


In Griswold, Justice Goldberg's concurring opinion indicated that a compelling state interest (strict scrutiny) test was being used. 381 U.S. at 497-98.
In *Eisenstadt v. Baird*, the Court restated its *Griswold* holding as follows:

It is true that in *Griswold* the right of privacy in question inhereed in the marital relationship. Yet the marital couple is not an independent entity with a mind and heart of its own, but an association of two individuals each with a separate intellectual and emotional makeup. If the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.

This reading of *Griswold*, though dicta, has become the accepted interpretation.

After *Griswold*, the Supreme Court came "naturally" to the next question involving the right to choose to bear or beget a child—whether such a right also included the right to abort. In *Roe v. Wade*, the Court held that although the right to abort was not absolute, the right to bear a child did include the right to abort. At a certain point, the state’s interest in the health of the mother and fetus attains sufficient importance to override the woman’s choice to abort. The *Roe* Court spoke in terms of compelling state interests and fundamental rights, indicating that for at least three months, the right of privacy included the right to abort.

Such substantive due process decisions indicate that right of privacy challenges will receive heightened judicial scrutiny. This level of scrutiny does not mean, however, that statutes restricting the right of privacy automatically will be struck down as unconstitutional. In each case, the Court will employ a balancing

262. *Id.* at 453 (emphasis in original).
264. *Developments, supra* note 228, at 1185.
265. 410 U.S. 113 (1973). "This right of privacy... is broad enough to encompass a woman’s decision whether or not to terminate her pregnancy." *Id.* at 153.
266. *Id.* at 154. The Court acknowledged that it was not clear whether the right of privacy explicated in *Roe* included the rights of personal autonomy—"an unlimited right to do with one’s body as one pleases." *Id.*
267. *Id.* at 154, 162–63.
268. *Id.* The Court thought that the state’s interest in the health of the mother became compelling after the first three months of pregnancy. *Id.* at 163.
269. "Whatever the truth of the maxim that strict scrutiny is strict in theory but fatal in
The purpose behind genetic screening statutes and their requirements for counseling those individuals with positive results will be weighed against the infringement on the right of privacy. If the counseling is objective and only given for informational value, the governmental interests in screening outweigh the invasion of the right of privacy, just as the governmental interests in the health of the expectant mother and her fetus outweigh the mother's right to terminate a pregnancy once it has advanced to a certain point.

If genetic counseling becomes slanted toward urging persons to abort, not to reproduce, or not to reproduce with a certain partner, then the invasion of privacy would be more severe. If, however, there are no forced abortions, sterilizations, or other restrictions on childbearing, the state interest in protecting the public from genetic disease and its future implications is strong enough to allow such pointed counseling. Those persons challenging mandatory genetic counseling statutes must show that the right to make procreative decisions is so fundamental that no compelling interest of the state could justify the counseling.

Testing alone will not achieve the purposes behind genetic screening—reducing the genetic load and reducing costs of genetic disease. Genetic screening and counseling of those individuals with positive results, however, will provide those people with added knowledge to aid in the decision whether to have children. To reduce the genetic load and costs, many adults will have to forego having children or terminate some pregnancies. The ultimate decision, however, remains with the individual. The choices to forego having children or to seek an abortion may be personal decisions, but these choices should be made with the knowledge of one's genetic makeup. If courts view genetic screening as a method of enhancing informed decisionmaking, screening legislation should survive the challenge that it deprives a person of free

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270. See text accompanying note 237 supra.
271. See note 267 supra and accompanying text.
272. The Court has upheld laws which arguably infringed on a personal autonomy right—the right to do with one's body as one chooses. It is arguable that a person's right to choose what to do with his or her body should have been sufficient to invalidate such laws. See Doe v. Commonwealth's Attorney, 403 F. Supp. 1199 (E.D. Va. 1975), aff'd mem., 425 U.S. 901 (1976), rehearing denied, 425 U.S. 985 (1976) (law against homosexuality between consenting adults upheld).
273. See notes 26-27 supra and accompanying text.
choice in the areas of marriage and childbearing. The Supreme Court has stated that "freedom of personal choice in matters of marriage and family life is one of the liberties protected by the due process clause of the fourteenth amendment."274 A mechanism to assist a person in making a more intelligent, thoughtful, and informed choice certainly should not be held unconstitutional.

2. The Right of Privacy and Its Impact on the Collection and Storage of Screening Test Results

An additional challenge based on the right of privacy is that information obtained through genetic screening, and subsequently stored, invades a constitutionally protected zone of privacy.275 In Whalen v. Roe,276 the Court confronted a case involving government storage of personal information.277 Justice Stevens, in his majority opinion, recognized two types of privacy: "One is the individual interest in avoiding disclosure of personal matters, and another is the interest in independence and in making certain kinds of important decisions."278 Justice Stevens found no violation of either type of privacy.279 Safeguards against improvident disclosure accompanied the gathering of personal information,280 and the statute did not infringe on an individual's right to make

275. In half of the states, the screening statutes mandate that health authorities gather data on persons with positive screening results. In some states, that data is gathered indirectly. In North Carolina, for example, hemophiliacs receive a special tax deduction. See Riskin & Reilly, Remedies for Improper Disclosure of Genetic Data, 8 RUT.-CAM. L.J. 480, 483-86 (1977).
277. In Whalen, names and addresses of all patients who had obtained prescriptions for certain dangerous but legal drugs and the names of the prescribing physician and dispensing pharmacy were stored in computers. Physicians and their patients sued, alleging that the statute authorizing this information storage infringed their rights of privacy. The Supreme Court reversed the lower court's finding that the statute infringed the plaintiffs' rights of privacy. Id.
278. Id. at 599-600.
279. Id. at 600.
280. The Court noted the following safeguards: the computer tapes were destroyed after five years; the receiving room for reporting forms was surrounded by a locked wire fence and alarm systems; the computer tapes were kept in locked cabinets; and the computer was run on an exclusive access to all other terminals when the tapes were being run. Id. at 593-94. In a concurring opinion, Justice Brennan voiced concern that "[t]he central storage and easy accessibility of computerized data vastly increase the potential for abuse of that information, and I am not prepared to say that future developments will not demonstrate the necessity of some curb on such technology." Id. at 607.
his or her own decisions.\textsuperscript{281} The evidence in the case showed no violation of the disclosure requirements, and the Court noted that the remote chance of negligent disclosure was not enough to invalidate the statute.\textsuperscript{282} Thus, under Whalen, an attack based on the confidentiality strand of the right of privacy should fail if the screening statute contains provisions for the careful storage of test results.\textsuperscript{283}

C. The Fourteenth Amendment Guarantee of Equal Protection of the Laws

Although the equal protection clause of the fourteenth amendment guarantees persons equal protection of the laws,\textsuperscript{284} the clause does not prohibit the government from drawing distinctions between individuals.\textsuperscript{285} Indeed, government must make differentiations.\textsuperscript{286} In recognition of the daily needs of governance, the Court scrutinizes most laws making such distinctions under the rational basis test and generally upholds the law, since all that must be shown is a rational relationship between the classification and the legitimate interest of the state in having such a law.\textsuperscript{287} Not all governmental classifications, however, receive the benefit of the rational basis test. To protect "discrete and insular minorities,"\textsuperscript{288} that have been "saddled with disabilities or subjected to such a history of purposeful unequal treatment, or relegated to such a position of political powerlessness as to command extraordinary protection from the majoritarian political process,"\textsuperscript{289} the courts use a strict scrutiny standard of review.\textsuperscript{290} Thus far, the only categories labelled as "suspect classifications" are race\textsuperscript{291} and national origin.\textsuperscript{292}

\textsuperscript{281} Id. at 600-04.
\textsuperscript{282} Id. at 600-01.
\textsuperscript{283} See notes 387-90 infra and accompanying text.
\textsuperscript{284} "No state shall... deny to any person within its jurisdiction the equal protection of the laws." U.S. Const. amend. XIV, § 1. "The federal government is subject to a similar imperative under the due process clause of the fifth amendment." Developments, supra note 228, at 1187. See Bolling v. Sharpe, 347 U.S. 497 (1954).
\textsuperscript{285} See Developments, supra note 228, at 1187-88.
\textsuperscript{286} Government, for example, must decide who to draft, who is to receive welfare, and how old a person must be to drive, vote, drink, or marry.
\textsuperscript{287} See Developments, supra note 228, at 1188.
\textsuperscript{290} See Developments, supra note 228, at 1189.
\textsuperscript{291} McLaughlin v. Florida, 379 U.S. 184, 192 (1964).
\textsuperscript{292} Korematsu v. United States, 323 U.S. 214 (1944). In Korematsu, the Court sub-
The strict scrutiny standard of review also is used if the government classification infringes on a fundamental right.293 "[T]he fundamental rights branch of equal protection will be available only to protect rights that are otherwise substantively protected by the Constitution, including newly recognized substantive due process rights."294

An equal protection challenge to a mandatory genetic screening statute would focus on the mandatory counseling of those individuals with positive test results. Although all persons would be screened mandatorily, only those individuals with positive screening results would receive counseling.295 Thus, screening laws may be attacked for treating persons with positive results differently than those persons with negative results.

1. Equal Protection—The Suspect Class Strand

A successful suspect class challenge requires either a showing that persons testing positive would constitute a suspect class296 or that there is no rational relationship between the classification of those individuals with positive results and the purposes behind genetic screening laws.297 If those individuals with positive results could show that they are a suspect class, they would receive the benefit of a strict scrutiny standard of review.298 Since those individuals with positive results, however, are not a race or a nationality,299 they would not fall within the present definition of a suspect class.

footnotes:

294. Developments, supra note 228, at 1193. See 434 U.S. at 383-87. For a more detailed discussion of Zablocki, see notes 314-22 infra and accompanying text.
295. See notes 384-86 infra and accompanying text. Under the model statute, everyone is educated about genetics and reproduction and counseled before the screening. The positive group, therefore, is not the only group to undergo genetic counseling. Those individuals with positive results, however, may need more counseling to help them make informed decisions. One way to avoid the equal protection attack altogether is to have only prescreening counseling. This remedy would be less effective since the particular genetic defect would be unknown. Under this approach, everyone, regardless of defect, would receive general information on genetics instead of individual counseling on their particular genetic problem.
296. See notes 288-92 supra and accompanying text.
297. See note 287 supra and accompanying text.
298. See notes 288-92 supra and accompanying text.
299. See notes 291-92 supra and accompanying text.
Recently the Court has shown a tendency to depart from its rigid two tier system of analysis in the equal protection area. 300 For example, a gender-based classification, although not a suspect class, has been subjected to scrutiny more strict than the rational basis test and less rigid than a strict scrutiny analysis. 301 If those individuals with positive screening results could convince the courts that they deserve heightened scrutiny, their equal protection challenge would have a greater chance of success. If their challenge were relegated to the rational basis standard, those individuals with positive results would have difficulty showing that no rational connection exists between positive screening results and future counseling to help interpret those results, particularly if the purpose of such counseling is merely to inform those individuals with positive results of their particular defect and its effects. 302 Since everyone eventually is apprised of genetic information and education, 303 those individuals with positive results cannot argue that they alone receive genetic counseling. Moreover, the government may argue that there is a rational relationship between post-test counseling and the classification of those individuals with positive results, since the purpose of counseling is to protect the health and welfare of those persons with positive results by informing them of the severity and effects of their genetic disease. For those with negative results, the prescreening counseling is sufficient protection.

The best counter argument which can be made to gain a heightened standard of review is that those individuals of a certain race are found more frequently among the positive group. This argument would be excellent if only persons of certain races with positive results received counseling. When everyone with positive results receives counseling, however, it is difficult to argue that the classification is based on the suspect class of race. 304 Those individuals against screening could argue that an unusually large

300. The two tier system under an equal protection analysis refers to the Court's use of a rational basis test or a strict scrutiny test with no intermediate standard of review. See notes 287–94 supra and accompanying text.


302. Under the rational basis test, prenatal screening probably would withstand constitutional scrutiny. A woman with positive screening results for Tay-Sachs, for example, will probably require future counseling to aid in her decision of whether to abort.

303. See notes 384–86 infra and accompanying text.

304. Persons with positive test results would be counseled as a class. The class would consist of all races and both sexes since there are screening devices to detect genetic disease in all persons.
number of Blacks, Orientals, or some other race typically discriminated against were present in the positive results group. This argument might lead to heightened scrutiny of the purposes behind counseling and classification of those persons with positive results. If the available genetic disease testing procedures detected a disproportionate number of diseases in one race, heightened scrutiny might be appropriate.\textsuperscript{305} Available screening tests, however, probably will not demonstrate such disproportionate results.

It is difficult to argue that classification is based on race when all persons with positive results receive counseling. Genetic disease occurs in everyone regardless of race.\textsuperscript{306} Screening devices discover the defective gene even when it is not manifested. Good health, diet, medical care, and education may prevent a genetic disease from having serious effects in some individuals, while poor health, diet, medical care, and education may lead to more grave consequences in the manifestation of genetic disease.\textsuperscript{307} Genetic screening, however, pierces such social and economic factors. In this manner, genetic screening procedures are not discriminatory. Hence, if the available genetic screening procedures do not detect a disproportionate number of diseases in one race, heightened scrutiny will not be available, and the screening laws will survive constitutional attack under the rational basis test.

2. \textit{Equal Protection—The Fundamental Rights Strand}

A successful challenge against genetic screening statutes on the basis that the classification of those individuals with positive results infringes on a fundamental right, requires a showing that the rights to marry and reproduce are fundamental, thus mandating the strict scrutiny test. In support of this argument, the challengers could cite \textit{Skinner v. Oklahoma},\textsuperscript{308} in which the Court, using a strict scrutiny standard of review,\textsuperscript{309} invalidated Oklahoma’s Habitual Criminal Sterilization Act which provided for the steriliza-
tion of certain criminals. The Court viewed the rights of "[m]arriage and procreation . . . fundamental to the very existence and survival of the race." To deprive persons of these rights was tantamount to the deprivation of the "basic civil rights of men." The Court concluded that the importance of these rights was sufficient to override the great deference afforded a state in the exercise of its police power.

In Zablocki v. Redhail, the Supreme Court struck down a Wisconsin law prohibiting certain Wisconsin residents from marrying without court permission. The class of residents included any "Wisconsin resident having minor issue not in his custody and which he is under obligation to support by any court order or judgment." Court approval was available upon a showing that the applicant was meeting his support obligations and that "the children covered by the support order [were] not then and [were] not likely thereafter to become public charges." Justice Marshall, in the majority opinion, described the standard of review: "Since our past decisions make clear that the right to marry is of fundamental importance, and since the classification at issue here significantly interferes with the exercise of that right, we believe that 'critical examination' of the state interests advanced in support of the classification is required."

Although Justice Marshall appeared to regard marriage as a fundamental right, he later clarified his position:

> By reaffirming the fundamental character of the right to marry, we do not mean to suggest that every state regulation which

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310. *Id.* at 541–42. The Act was invalidated on equal protection grounds because it made exceptions for certain types of criminals. An embezzler convicted three times, for instance, was not sterilized while those persons convicted three times of grand larceny were sterilized. *Id.* at 541. In fact, Skinner's three offenses consisted of one conviction for stealing chickens and two convictions for armed robbery. *Id.* at 537. The Court also spoke of fundamental and basic liberties, language and ideas typical of a substantive due process case. *Id.* at 541.

311. *Id.* at 541.

312. *Id.*

313. *Id.*


315. *Id.* at 375.

316. *Id.*

317. *Id.* at 383. The state asserted two purposes for the statute: To give the state the opportunity to counsel the applicant regarding his duty to support the children, and to protect the welfare of children receiving support benefits. The Court accepted the two interests as valid, but "since the means selected by the State for achieving these interests unnecessarily impinge[d] on the right to marry, the statute [could not] be sustained." *Id.* at 388.
relates in any way to the incidents or prerequisites for marriage must be subjected to rigorous scrutiny. To the contrary, reasonable regulations that do not significantly interfere with decisions to enter into the marital relationship may legitimately be imposed.\textsuperscript{318}

In \textit{Zablocki}, the Court spoke in terms of equal protection,\textsuperscript{319} but the Justices differed on the appropriate level of scrutiny to be applied—a common characteristic of substantive due process cases utilizing a balancing approach instead of the typical two tier analysis of equal protection review.\textsuperscript{320} Justice Stewart, for example, advocated a case-by-case approach which would move from the two tier approach toward a balancing approach.\textsuperscript{321} Justice Marshall also recommended a move toward balancing.\textsuperscript{322}

When a right is held to be fundamental, strict scrutiny will be applied under the two tier system, and it will be difficult to uphold the challenged law.\textsuperscript{323}

Since the meaning of most rights is not unequivocal and “right” is a general term encompassing a broad range of protected interests, there is a danger that holding a right to be fundamental will overvalue some interests. If this happens, legislatures may be proscribed from acting where they would ordinarily be found justified to act.\textsuperscript{324}

Marriage and procreation are both fundamental rights; however, this declaration does not mean that all restrictions which are placed upon them will be subjected automatically to strict


\textsuperscript{319} \textit{See} Developments, \textit{supra} note 228, at 1197.

\textsuperscript{320} In practice, the “flexible balancing” thought appropriate in substantive due process cases will most likely occur both in decisions explicitly cast in substantive due process terms and in those formulated under the rubric of equal protection. The concurrences in \textit{Redhail} suggest that the protection of an individual liberty may be more complicated than the protection of the more general right not to be classified on the basis of certain characteristics.

\textit{Id.}

\textsuperscript{321} 434 U.S. at 396. Justice Stewart said the proper concerns in an equal protection inquiry include:

the nature of the individual interest affected, the extent to which it is affected, the rationality of the connection between legislative means and purpose, the existence of alternative means for effectuating the purpose, and the degree of confidence we may have that the statute reflects the legislative concern for the purpose that would legitimately support the means chosen.


\textsuperscript{322} \textit{See text accompanying note 318 supra.}


\textsuperscript{324} \textit{Id.}
Those individuals attacking screening laws under the fundamental rights strand must show that counseling of those persons with positive results does restrict marriage or reproduction. If the counseling is purely informative, the only restrictions are those which individuals choose to place on themselves. This "freedom of personal choice in matters of marriage and family life is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment." 325

If counseling is directed toward abortion, sterilization, or discouraging certain people from having children, the argument may arise that such directive counseling is a restriction on marriage and procreation. The challenge then could be made that those fundamental rights were infringed by the screening laws. The government could support the validity of the law and its counseling provisions for those individuals with positive results by asserting that the counseling sessions were "reasonable regulations that [did] not significantly interfere with decisions to enter into the marital relationship." 326

Arguably, counseling sessions do not impose significant restrictions on marriage or reproduction. People are not prohibited from marriage or procreation. In fact, marriage is not the issue since genetic disease is not spread through marriage. Only reproduction increases the genetic load and genetic disease. Counseling, even if directive due to a counselor's personal feelings, 327 does not restrict reproduction. Perhaps counseling will initiate careful consideration of natural reproduction and its alternatives, but to date, counseling does not produce forced abortion or sterilization. Those individuals testing positive merely receive counseling concerning the implications of such results. Even if a counselor suggests abortion or sterilization, the ultimate decision remains with the individual.

If screening statutes require objective counseling, the statute should withstand constitutional scrutiny because there has been no infringement of a fundamental right. Conversely, statutes advocating highly directive counseling may violate the fundamental right to freedom of choice. In such a case, the analysis would fo-

328. See notes 72-79 & 173-74 supra and accompanying text.
cus on whether the state had a sufficiently important reason to require the counseling, and whether the counseling was closely tailored to effectuate only the governmental interest.\textsuperscript{329} Even under this analysis, if there are no forced abortions or sterilizations, directive counseling may not pose a sufficient restriction on the right of reproduction to mandate invalidation of the statute. This result will be particularly likely if the Court moves closer to a balancing test in this area.\textsuperscript{330} After balancing the various interests and restrictions, even directive counseling may withstand constitutional scrutiny.

D. Attack Under the First Amendment—The Guarantee of Freedom of Religion

The first amendment guarantees an individual the freedom to exercise religious beliefs.\textsuperscript{331} This guarantee is applicable to the states under the fourteenth amendment.\textsuperscript{332} Traditionally, "religious freedom in [America has occupied] a 'preferred position' as a legal right, but is by no means absolute."\textsuperscript{333} In \textit{Sherbert v. Verauer},\textsuperscript{334} however, the Supreme Court applied a strict scrutiny standard of review, which required a showing of a compelling state interest: \textsuperscript{335} "It is basic that no showing merely of a rational relationship to some colorable state interest would suffice; in this highly sensitive constitutional area, 'only the gravest abuses, endangering paramount interests, give occasion for permissible limitation.'\textsuperscript{336} In addition, the Court recognized that the freedom of religion was not absolute: "[E]ven when [an] action is in accord with one's religious convictions, [it] is not totally free from legisla-
tive restrictions."^{337}

In *Jacobson v. Massachusetts*,^{338} a freedom of religion attack was brought against mandatory smallpox vaccinations. The plaintiff contended that mandatory vaccinations infringed on his fourteenth amendment rights. In response, the Court stated:

"[I]n every well-ordered society charged with the duty of conserving the safety of its members the rights of the individual in respect of his liberty may at times, under the pressure of great dangers, be subjected to such restraint, to be enforced by reasonable regulations, as the safety of the general public may demand."^{346}

The Court viewed the statute as reasonably related to a valid state interest and thus a proper exercise of the state's police power.^{341} Although *Jacobson* did not concern a religious objection to the vaccinations specifically, it did concern the defendant's belief that it is the "inherent right of every freeman to care for his own body and health in such way as to him seems best . . . ."^{342}

In *Sadlock v. Board of Education*,^{343} the Court specifically dealt with the freedom of religion attack. The plaintiff argued that the statute requiring vaccination for school admittance denied schooling to some individuals because of their religious beliefs.^{344} The Court replied that the constitutional guarantee of religious freedom was not intended to be absolute. Such a right was only relative and must be viewed in terms of the public well-being: "The principle is too well-established to require citation that the so-called constitutional liberties are not absolute, but are relative only. They must be considered in the light of the general public welfare. To hold otherwise would be to place the individ-

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337. 374 U.S. at 403 (citing Braunfeld v. Brown, 366 U.S. 599, 603 (1961)).
338. 197 U.S. 11 (1905).
339. Id. at 14.
340. Id. at 29.
341. Id. at 31, 35. The Supreme Court reaffirmed its *Jacobson* holding in Zucht v. King, 260 U.S. 174 (1922). Other courts have followed the Supreme Court's lead. In State v. Drew, 89 N.H. 54, 192 A. 629 (1937), the court stated: "If all men were to take the position that individual opinions are equivalent to rights, law would be replaced by anarchy." Id. at 57, 192 A. at 632.
342. 197 U.S. at 26.
343. 137 N.J.L. 85, 58 A.2d 218 (1948). The statute under attack allowed the board of education to exclude any teacher or pupil who had not received a successful smallpox vaccination, unless they were ruled medically unfit to receive the vaccination.
344. Id. at 86–87, 58 A.2d at 219–20. Religions such as Christian Scientists and Jehovah's Witnesses do not believe in injections, blood transfusions and withdrawals, or medical treatment.
ual above the law."345

Genetic screening statutes could be attacked at the level of the procedure itself since there are religions which do not believe in medical treatment.346 Common screening devices such as blood tests and amniocentesis are medical procedures to which some religions may object.347 For a screening law to survive attack under the freedom of religion doctrine, it must be shown that the government has a substantial public interest sufficient to override the individual's freedom to exercise religious beliefs.348 The present attitude toward genetic disease may not be sufficient to force screening upon those individuals who do not believe in medical treatment and procedures. As information concerning the increase in the genetic load becomes widespread, however, the need to screen everyone, regardless of religious beliefs, will become more apparent. If smallpox again reached epidemic proportions, there is little doubt, in light of past case holdings,349 that the law would require all persons to receive vaccinations. When genetic disease becomes widespread or even when many believe that genetic disease will become widespread, the courts may show an increased propensity toward upholding mandatory genetic screening laws.

The attack on genetic screening under the freedom of religion doctrine is comparable to similar attacks brought against compulsory medical treatment.350 The courts have become more liberal in their use of parens patriae351 to order treatment for both children and adults. In Cude v. State,352 an Arkansas court appointed

345. Id. at 91, 58 A.2d at 222. The Court in Reynolds v. United States, 98 U.S. 145 (1878), held that a statute prohibiting polygamy was constitutional as applied to all persons, regardless of their religious belief.
346. See note 344 supra.
347. Freedom of religion presently is recognized in many state screening statutes through an exemption from the test for religious reasons. See note 90 supra.
348. A religious cult that believed in murder certainly would not be permitted to kill. The overriding governmental interest in the public safety and welfare would be sufficient to uphold the murder laws.
350. See generally Riga, supra note 332.
351. The power of the state to appoint a guardian and to order medical treatment or some other form of aid is known as parens patriae. For a recent summary of the area, see Developments, supra note 228, at 1221–42. See generally Note, Compulsory Medical Treatment: The State's Interest Re-evaluated, 51 MINN. L. REV. 293, 298–301 (1966); Note, The Right to Die—A Comment on the Application of the President and Directors of Georgetown College, 9 UTAH L. REV. 161 (1964).
352. 237 Ark. 927, 377 S.W.2d 816 (1964).
a guardian for three siblings whose ages ranged between seven and fifteen and ordered the guardian to have the children vaccinated against smallpox when the natural parents refused the vaccinations on religious grounds.\textsuperscript{353} The state statute in question required children to have smallpox vaccinations before entering school. Another state law required parents to send their children to school.\textsuperscript{354} By not obeying the vaccination statute, the parents also violated the mandatory school entrance law. The court stated that parents could not deny an education for their children because their religious beliefs did not permit a vaccination. The constitutional grant of religious freedom was not sufficient to allow these parents to behave in a manner inconsistent with the health, safety, and welfare of others. The children, therefore, were vaccinated.\textsuperscript{355}

Recently, some courts have extended the parens patriae doctrine. In \textit{Raleigh Fitkin-Paul Morgan Memorial Hospital v. Anderson},\textsuperscript{356} a pregnant woman, of the Jehovah's Witness religion, refused a blood transfusion on religious grounds. The woman's condition made it likely that without a transfusion she would place both her own life and that of her fetus in grave danger.\textsuperscript{357} The New Jersey court had no difficulty in ordering the transfusion to save the fetus but faced a tougher issue in ordering a transfusion for the mother. The court held, however, that the lives of the mother and fetus were so intertwined that the transfusion was justified.\textsuperscript{358}

Judge Skelley Wright extended the doctrine of parens patriae further in \textit{Application of President and Directors of Georgetown College, Inc.}\textsuperscript{359} Again, a husband and wife, both Jehovah's Witnesses, refused to consent to a lifesaving blood transfusion for the wife.\textsuperscript{360} The couple had a seven month old child. Judge Wright immediately visited the couple in the hospital. Determining both

\textsuperscript{353} The court stated that if the natural parents did not take back the children, the children would be placed for adoption. \textit{Id.} at 930, 377 S.W.2d at 817–18.
\textsuperscript{354} \textit{Id.} at 931, 377 S.W.2d at 818.
\textsuperscript{355} \textit{Id.} at 936, 377 S.W.2d at 818–19.
\textsuperscript{357} \textit{Id.} at 423, 201 A.2d at 538.
\textsuperscript{358} The court ordered the transfusion by remanding the matter to the trial court with instructions to appoint a guardian for the fetus and substitute the guardian for the hospital as plaintiff. Under this arrangement, the guardian could consent to the transfusion, the mother could be directed to have the transfusion, and the woman's husband could be restrained from interfering. \textit{Id.}, 201 A.2d at 538.
\textsuperscript{359} 331 F.2d 1000 (D.C. Cir. 1964).
\textsuperscript{360} The wife had suffered a ruptured ulcer and had lost two-thirds of her blood sup-
that the woman could not decide for herself at the time and that she wanted to live, Judge Wright ordered the transfusion. Judge Wright reasoned that the state had an interest in preserving the mother's life so that she could continue her "community responsibility" of caring for her child.

Courts have appointed guardians to order medical treatment for children needing blood transfusions and for those children suffering from arthritic symptoms, eye disease, and limb deformity. Courts, however, often will refuse to order dangerous or risky medical treatment. The courts' willingness to extend the parens patriae doctrine to adults shows a change in the judicial attitude toward the freedom to exercise religion. Although such decisions are not without their critics, the rulings do show a willingness by some courts to balance the competing interests of the adult's right to refuse medical treatment against the state's desire to treat the adult.

As genetic disease becomes more prevalent, the courts may be willing to use the parens patriae power to demand screening for children whose parents have refused such screening on religious

ply. Id. at 1006. With the transfusion, her chance of survival was over 50%, but without it, she would die. Id. at 1007.

361. Judge Wright ordered the transfusion and requested immediate review so that a precedent would not be set without full court review. Judge Wright said: "To refuse to act, only to find later that the law required action, was a risk I was unwilling to accept. I determined to act on the side of life." Id. at 1010.

362. Id. at 1008. The D.C. Circuit later refused to rehear the case en banc. The mother already had left the hospital, and the order for the transfusion had expired. President and Directors of Georgetown College, Inc., 331 F.2d 1010 (D.C. Cir. 1964).


365. See, e.g., In re Vasco, 238 App. Div. 2d 128, 263 N.Y.S. 552 (1933) (child had eye condition that probably would lead to a malignancy and eventual death, and the surgery for the disorder had a 50% cure rate).

366. See, e.g., In re Rotkowitz, 175 Misc. 948, 25 N.Y.S.2d 624 (Dom. Rel. Ct. 1941) (stigma associated with the deformity was enough to cause the child psychological harm). But see In re Hudson, 13 Wash. 2d 632, 126 P.2d 765 (1942) (guardian not appointed to 12 year old child whose left arm was almost as large as her body even though the large arm was causing both physical and emotional harm).


368. See Note, Compulsory Medical Treatment: The State's Interest Re-evaluated, supra note 351, at 298-301; Note, The Right to Die—A Comment on the Application of the President and Directors of Georgetown College, supra note 351.
grounds.\textsuperscript{369} Again, the courts' reactions to religious objections against screening will depend on the prevalence of genetic disease and the extent to which medical science can demonstrate the future implications of an increasing genetic load.\textsuperscript{370} The greater the understanding of these future implications, the more likely that religious objections will not prevent a mandatory genetic screening program.

IV. PROPOSALS FOR BETTER GENETIC SCREENING LEGISLATION

Although both the Maryland screening statute\textsuperscript{371} and the 1978 Genetic Diseases Act\textsuperscript{372} manifest strides forward in genetic screening legislation, problems still remain with screening statutes. The incidence of genetic screening certainly will continue to increase,\textsuperscript{373} thus mandating careful consideration of screening legislation. This increase requires a "conscious, deliberate formulation of public policy with respect to genetic technology."\textsuperscript{374} It has been suggested that a carefully drafted compulsory premarital screening law, which would apply to all citizens, would survive judicial scrutiny:

As long as the law provided for competent screening services, high quality genetic counseling for persons with positive test results, public education, and confidentiality of test data and did not require any action on the basis of test results, it would be approved. Similarly, preschool testing that made provision for data storage and a subsequent counseling session would be legally acceptable.\textsuperscript{375}

In view of the potential constitutional challenges\textsuperscript{376} to such a statute, it is necessary to define guidelines for developing genetic screening legislation which will leave open fewer avenues of constitutional attack.

\textsuperscript{369} Just as courts have ordered smallpox vaccinations and have used parens patriae to affect such an order, courts may do the same regarding a genetic screening test. See notes 352–55 supra and accompanying text.

\textsuperscript{370} See text accompanying note 349 supra.

\textsuperscript{371} See notes 127–44 supra and accompanying text.

\textsuperscript{372} See notes 145–68 supra and accompanying text.

\textsuperscript{373} See Riskin & Reilly, supra note 275, at 484–86.


\textsuperscript{375} P. Reilly, \textit{supra} note 56, at 147 (emphasis supplied).

\textsuperscript{376} See notes 169–370 supra and accompanying text.
A. Guidelines

A screening program should define carefully the group(s) it seeks to affect. This goal does not require that a statute be written for each particular group to be screened. The statute, however, should be written carefully, assuring inclusion of the necessary groups in a nondiscriminatory way.

Screening legislation should strive to ensure the highest quality of laboratory work. The inaccuracy of the PKU and SCA screening tests caused many problems. To avoid such problems, statutes should require special training for laboratory technicians, establish special laboratories, and allocate funds for further research. Such precautions also would aid in attaining the lowest level of inaccurate results.

The legislation should include provisions for both evaluation of the procedures and medical followup on the persons screened. Since the future effects of screening procedures are unknown, followups would be helpful in ascertaining both the physical and the psychological long term effects of screening.

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377. See Powledge & Fletcher, Guidelines for the Ethical, Social and Legal Issues in Prenatal Diagnosis, 300 NEW ENG. J. MED. 168, 169 (1979). This article exclusively concerns prenatal screening, but many of its ideas for better legislation are relevant to all types of screening.

378. Id.

379. See notes 83-126 supra and accompanying text.

380. Prenatal diagnosis presents special problems concerning false negative and false positive results. A false negative result indicates a negative result when in truth it should be positive. A false negative result indicates an affected fetus is healthy. This result can lead to the birth of an undesired, affected child. Another example is found in adult screening when a carrier of a genetic disease is told that he or she does not carry the disease. This result leads to a false sense of security and may lead to the birth of an affected child.

False positive results indicate a positive result when actually the result is negative. Prenatally, a false positive result indicates that the fetus is affected when, in fact, it is healthy. This result can lead to abortion of a healthy fetus. In adults, a person is told erroneously that he or she is a carrier of a disease. This result can affect an adult's decision to marry and have children. Most screening tests are performed only once. Further test results, therefore, are not available to correct the initial misdiagnosis. These undesirable consequences underscore the need to develop reliable methods for genetic screening. Improvements must be made in obtaining amniotic fluid and assuring an adequate sample, in shipment of the fluid, blood, or urine, and in general laboratory procedures. See generally Annas & Coyne, supra note 2, at 474-75; Franklin, Medical Mass Screening Programs: A Legal Appraisal, 47 CORNELL L.Q. 205 (1962); Friedman, Legal Implications of Amniocentesis, 123 U. PA. L. REV. 92, 103-04 (1974); Powledge & Fletcher, supra note 377, at 169-70.

381. See Powledge & Fletcher, supra note 377, at 170.

382. Amniocentesis and ultrasound both are considered to be relatively safe procedures, yet their future effects are unpredictable. Id. See also notes 36-43 supra and accompanying text.

383. It would be helpful in future counseling of carriers of genetic disease to study the
procedures.

Screening statutes should provide that adequate information be given to persons screened, both before and after the screening. Before screening, information concerning how the test works, what it can detect, possible results, and effects of those results should be discussed. After the test, the results should be explained with an exploration of the available options. To provide such services, a screening statute should include provisions for adequate training of genetic counselors. Not all genetic counselors must be psychologists or doctors, but guidelines should be established and obeyed. Licensing requirements represent one method of attempting to assure competent counseling.

To protect the privacy of those individuals screened, statutes must have provisions for confidentiality of data. The release of genetic information about an individual could be quite harmful, therefore, every effort must be made to protect against this harm. A countervailing consideration is the need to store the data, thereby enabling followups and statistical analyses to improve genetic screening standards. Another problem concerning confidentiality of screening results arises when a physician or genetic counselor feels compelled to notify relatives of a person who has tested positive so that the family can be screened to ascertain if they also carry the same genetic disease. Under a mandatory genetic screening program, this problem would be eliminated since everyone would be screened. Specific legislation

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384. See Powledge & Fletcher, supra note 377, at 170.
385. The early counseling should include the future implications of positive screening results. Such implications may include choosing whether to have children naturally, deciding whether to abort an affected fetus, and determining whether the expense of rearing an affected child is within the family budget.
386. For a discussion of the genetic counselor’s standard of care, see Capron, supra note 32, at 620–25, 668–71.
387. See Riskin & Reilly, supra note 275, at 486–506. It is recommended that immediate legislation be implemented to help data collection agencies in their effort to avoid improper disclosure.
388. Harms include: 1) employers not hiring those individuals with certain genetic defects; 2) increase in insurance rates or cancellation of policies; and 3) personal harms such as a husband discovering his wife is an XY female or discovering that his wife’s child could not be his own.
389. See Riskin & Reilly, supra note 275, at 483–86.
could help in this area, as well as in the area of what results should be disclosed to the person screened.\textsuperscript{390}

Genetic screening statutes should provide for treatment.\textsuperscript{391} Not all communities and states will have the revenue necessary to pay for treatment, but within these practical limits, everything possible should be done to provide treatment for those individuals who cannot afford it and to allocate funds for research.\textsuperscript{392}

Finally, provisions should be made for educating the public about genetic disease and its consequences.\textsuperscript{393} With education comes understanding and less prejudice due to ignorance.\textsuperscript{394} This education should lessen stigmatization of genetic disease carriers and should cause people to seek screening to make informed choices about having a family.

B. Voluntary Versus Mandatory Screening Programs

Legislators must decide whether a screening program should be mandatory or voluntary. Both the federal and the Maryland statutes are voluntary. Congress, however, has addressed the possibility of mandatory genetic screening,\textsuperscript{395} and many state screening statutes are mandatory.\textsuperscript{396} Since it is the mandatory program that will cause the most problems constitutionally,\textsuperscript{397} some states may prefer a voluntary program. The only way to inform every-

\textsuperscript{390} Some individuals advocate telling everything to those persons who have been screened and then counseling them to explain the results and reach a decision. \textit{See} Capron, \textit{supra} note 32, at 645–47. Other individuals think that only some results should be disclosed. Amniocentesis results, for example, indicate the fetus’ sex. There is a concern that some parents might abort a fetus because it is not the sex they prefer. \textit{See} Powledge & Fletcher, \textit{supra} note 377, at 171–72.

\textsuperscript{391} “One of the ultimate goals of prenatal diagnosis should be the treatment and eventual cure of disease in the fetus or infant.” Powledge & Fletcher, \textit{supra} note 377, at 171.

\textsuperscript{392} Few genetic diseases respond to treatment. \textit{See} note 55 \textit{supra} and accompanying text.

\textsuperscript{393} \textit{See} P. Reilly, \textit{supra} note 56, at 147.

\textsuperscript{394} The Tay-Sachs screening program and the SCA programs, for example, were received differently. A founder of Tay-Sachs screening thinks the major difference between the two programs was that:

Many of the people that were screened for sickle cell didn’t really understand what it was they were being tested for. Whereas . . . most of the people—[probably all of them]—that came voluntarily and extended an arm to have a blood sample drawn for a Tay-Sachs [sic] carrier test knew that they weren’t being tested for a disease that they had, knew that this was a test that had to do with their reproduction, and knew that whatever the test results might be that there were some options available to them to deal with the problem.

\textit{PBS Transcript, supra} note 27, at 11.

\textsuperscript{395} \textit{See} note 168 \textit{supra} and accompanying text.

\textsuperscript{396} \textit{See} note 90 \textit{supra} and accompanying text.

\textsuperscript{397} \textit{See} notes 169–370 \textit{supra} and accompanying text.
one of his or her potential for having children with a genetic disease, however, is to screen everyone. If such screening were done, all persons would have the information necessary to make informed decisions in the areas of marriage and reproduction.

V. CONCLUSION

This Note has shown the growing need for genetic screening. This need must be met through competent legislation. The proposals for improved legislation made in this Note are those proposals necessary to create an adequate genetic screening statute. It may be, however, that the perceived need for a statute requiring mandatory screening and costly programs for providing education, counseling, and treatment concerning genetic disease has not yet impacted upon legislators, much less the American population. The proposed screening statute outlined in this Note, however, could effectively help prevent genetic disease without advocating that genetic counseling be aimed toward reduction of the genetic load or advocating mandatory governmental involvement in the personal decision of childbearing.

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398. See notes 16–82 supra and accompanying text.
399. See notes 83–168 supra and accompanying text.
400. See notes 371–97 supra and accompanying text.
401. See note 249 supra and accompanying text.