

NOTE

Not in My Womb: Compelled Prenatal Genetic Testing

By WENDY E. ROOP*

I. Introduction

Fueled by advances in genetic research, medical technology is progressing by leaps and bounds. Genetic information made available by the Human Genome Project has enabled physicians to trace the genetic roots of physical and mental disorders. Genetic testing is now a part of routine prenatal care. Fetal gene therapy is expected to provide even more treatment options in the near future. Moreover, fetal surgery can correct some genetic defects in utero. These extraordinary developments are quickly outpacing corresponding legal precedent. As the availability and level of prenatal care continues to expand, troubling questions arise regarding what constitutes “routine” care. When considered in context with the current imbroglio surrounding abortion and numerous forced caesarean cases, one wonders whether women might ever be compelled to submit to mandatory prenatal genetic testing.

This Note examines various issues raised by the ongoing development of prenatal genetic testing and concludes that states cannot compel women to undergo prenatal genetic testing. Section II lays the groundwork by reviewing key medical and genetic processes essential to understanding the complexity of the issues involved. Section III evaluates the current status of prenatal genetic testing and how such testing is affected by the availability of both genetic treatment and abortion. Section IV questions whether states’ police power is sufficient to impose unwanted treatment on pregnant women. After consideration of several arguments the answer is clear. Mandatory

* J.D., University of California, Hastings College of the Law, 2000. B.A., Florida State University, 1990. Thanks go to my family for their encouragement and support in everything I have done, and to Pat for believing in me from the beginning.

prenatal genetic testing is not an effective way to further states' arguably compelling interest in preventing disease and protecting potential life. Section V discusses women's important fundamental rights that would be violated by state mandated prenatal testing. Finally, Section VI concludes by suggesting a program of voluntary testing. The solution relies on the doctrines of beneficence and autonomy, which together render coercive legislation moot in all but the most unusual circumstances.

II. Understanding the Fundamentals

A. Why Genetics Is Important

The amazing sequence of events that occurs during pregnancy is truly miraculous. A brief overview of the unseen genetic process leads to a keen appreciation of fetal developments often taken for granted. Every cell in the human body, except sperm cells and egg cells, has forty-six chromosomes.¹ Sperm cells and egg cells have only twenty-three.² When a sperm and egg join together, the resulting embryo has forty-six chromosomes.³ In this manner, the embryo acquires half of its genetic material from each parent.⁴

The forty-six chromosomes are arranged in twenty-three numbered pairs.⁵ Twenty-two of the pairs are called autosomes; they mirror each other in size and shape.⁶ The twenty-third pair are the sex chromosomes, X and Y. Unlike autosomes, the sex chromosomes can be different from each other.⁷ An egg cell always carries an X chromosome. A sperm cell carries either an X or a Y chromosome.⁸ Thus, the twenty-third pair consists of either XX (female) or XY (male), depending on whether the sperm contributed an X or Y chromosome.⁹

Chromosomes are made up of as many as 100,000 genes,¹⁰ which in turn are made of spiraling strands of deoxyribonucleic acid

1. See generally ELENA O. NIGHTINGALE, M.D. & MELISSA GOODMAN, BEFORE BIRTH: PRENATAL TESTING FOR GENETIC DISEASE 11-26 (1990) [hereinafter NIGHTINGALE & GOODMAN].

2. See *id.* at 11.

3. See *id.*

4. See *id.*

5. See *id.* at 12.

6. See *id.*

7. See *id.*

8. See *id.*

9. See *id.*

10. See *id.* at 15.

(DNA).¹¹ DNA is sequenced in groups of three which form the code for the body's twenty essential amino acids.¹² Amino acids are the building blocks of protein.¹³ Proteins become enzymes which are necessary for the metabolic processes in the body.¹⁴ If even one enzyme is missing or is defective drastic effects can ensue.¹⁵

B. The Human Genome Project

The Human Genome Project has had a significant impact on the development of prenatal genetic testing. Initiated in October 1990, the genome project is an international research effort with a two pronged goal: discovering the estimated 60,000 to 100,000 human genes, and mapping the genes onto each chromosome.¹⁶ At this time, over 7,000 genes have been traced to specific chromosomes.¹⁷ The Project is intended to provide researchers with the genetic information needed to locate the genes responsible for various genetic disorders.¹⁸ Currently, scientists are using this information to detect and treat genetic disease. Ultimately, the emphasis is anticipated to shift from disease treatment to disease prevention.¹⁹

Research from the Human Genome Project has led to the development of gene testing and, subsequently, to questions as to whether and when such testing is appropriate. Gene testing enables physicians to test for certain genetic disorders by directly examining a patient's DNA microscopically, or testing for the presence of gene products (enzymes or other proteins).²⁰ The tests can be used for newborn screening, prenatal testing, and to determine carrier status for adults.²¹ DNA based tests are currently available for many diseases, including Alzheimer's disease, cystic fibrosis, duchenne muscular dys-

11. *See id.* at 19.

12. *See id.* at 21.

13. *See id.*

14. *See id.* at 15.

15. *See id.* at 16. The single gene disorder called phenylketonuria (PKU) is cited as an example. This disease is characterized by a deficiency in the enzyme phenylalanine hydroxylase which cannot function normally. This causes a build up of the amino acid phenylalanine in the body, and results in brain damage if not quickly detected and treated. *See id.*

16. *See Human Genome Project Information: Frequently Asked Questions* (visited Oct. 22, 1998) <http://www.ornl.gov/TechResources/Human_Genome/faq/faqs1.html>.

17. *See id.*

18. *See id.*

19. *See id.*

20. *See id.*

21. *See id.* Gene testing for adults is often performed when an adult with a family history of genetic disease is considering whether to have a child.

trophy, hemophilia A and B, Huntington disease, phenylketonuria, sickle cell disease and Tay-Sachs disease.²² The availability of these tests raises difficult questions however, due to the limited treatment options for many of these diseases and the uncertainty in interpreting test results.²³

The ethical and societal questions raised by genetic research are an integral component of the Human Genome Project. In recognition of this fact, three to five percent of the Project's budget is allocated to a program dedicated to ethical, legal, and social issues (ELSI).²⁴ ELSI studies such issues as the psychological impact of genetic differences, privacy and confidentiality of genetic information, and when and why testing should be performed.²⁵ Curiously, one of ELSI's enumerated goals is to "[f]oster greater acceptance of human genetic variation."²⁶ This aim appears somewhat incongruous since much of the research developed by the Human Genome Project has been directed towards alleviating undesirable genetic traits.

C. Methods of Prenatal Genetic Testing

Although there are many methods of prenatal genetic testing, no test can detect every genetic defect, and none are one hundred percent accurate. Each test has its own benefits and drawbacks. Not every test will be appropriate for every patient. For these reasons, tests are often used in conjunction with one another to confirm or clarify results. A physician must carefully consider the needs and characteristics of each patient before recommending one test or a series of genetic tests.

1. *Alpha-Fetoprotein Test*

The alpha-fetoprotein (AFP) test is a threshold test designed to indicate the presence of neural tube defects, such as anencephaly or spina bifida.²⁷ The test is performed during the second trimester of pregnancy and measures maternal blood for elevated levels of AFP.²⁸ If the blood test is normal, no further testing is done for neural tube

22. *See id.*

23. *See id.*

24. *See Human Genome Project Information: Ethical, Legal, and Social Issues (ELSI) of the Human Genome Project* (visited Oct. 22, 1998) <http://www.ornl.gov/TechResources/Human_Genome/resource/elsi.html>.

25. *See id.*

26. *Id.*

27. *See NIGHTINGALE & GOODMAN, supra* note 1, at 28-31.

28. *See id.* at 29.

defects.²⁹ If the results are high, then subsequent tests are necessary for two reasons. First it is no simple task to ascertain what levels of AFP are within normal range.³⁰ Second, neural tube defects are not the only causes of elevated AFP levels.³¹ Before proceeding with additional tests, it is important to inform the mother that elevated levels of AFP may be the result of carrying more than one fetus, or an inaccurately calculated date of conception.³²

The AFP test is helpful in diagnosing the presence of neural tube defects, but as noted, the results cannot guarantee the presence or absence of a disorder. According to the California Department of Health Services, AFP testing identifies eighty percent of neural tube defects.³³ As this study indicates, a woman who is deeply concerned about the presence of a neural tube defect will opt for a second test, regardless of the first result, since a positive result must be confirmed, and a negative result has a significant chance of being inaccurate. The potential for confusion and anxiety in interpreting AFP test results has spurred some debate as to whether the test should be a routine component of prenatal care.³⁴

2. *Ultrasound*

An ultrasound test is not a genetic test per se, but it is often utilized to clarify the results of an AFP test.³⁵ Ultrasonography entails passing sound waves through the uterus to create an image. An ultrasound image enables a physician to visualize the fetus, identify detectable deformities, and explain ambiguous test results.³⁶ If more than one fetus is in the womb it will be readily apparent to the examining physician. Also, the physician can determine whether the date of con-

29. *See id.*

30. *See id.*

31. *See id.*

32. *See id.*

33. *See id.* at 30.

34. *See id.* California has mandated that physicians offer AFP testing as a standard component of prenatal care. *See* Nancy Anne Press & Carole H. Browner, *Collective Silences, Collective Fictions: How Prenatal Diagnostic Testing Became Part of Routine Prenatal Care*, in *WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 201, 202 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) [hereinafter *FACING THE CHALLENGES*].

In addition to AFP testing, California has mandated that other tests must also be offered, such as HIV, rubella and fetal blood type. Telephone Interview with Kirk A. Keegan, Jr., M.D., Dean of Continuing Medical Education, Vice-Chair of the Department of Obstetrics & Gynecology, University of California at Irvine (Dec. 1, 1998).

35. *See* NIGHTINGALE & GOODMAN, *supra* note 1, at 31.

36. *See id.*

ception is accurate by assessing the size of the fetus.³⁷ An ultrasound test can be performed at any time, and is the least invasive technique for determining fetal health. Its utility in detecting disorders, however, will vary depending on whether and when the disorder manifests physically.³⁸

3. *Amniocentesis*

Amniocentesis may also be used either in conjunction with an AFP test, or independently to test for other disorders.³⁹ To perform an amniocentesis, a physician withdraws a sample of amniotic fluid via a needle inserted through the mother's abdominal wall and into the womb.⁴⁰ Often, an ultrasound is performed simultaneously to allow the physician to see the needle and to reduce the possibility of puncturing the placenta or injuring the fetus.⁴¹ Analysis of the amniotic fluid can detect abnormalities in several ways. Genetic testing of fetal cells present in amniotic fluid can be performed, the levels of specific substances in the amniotic fluid can be measured, and fetal chromosomes can be karyotyped (a procedure in which chromosomes are stained and examined).⁴²

Amniocentesis generally provides reliable results, however it has notable drawbacks. Most significantly, the procedure cannot be accurately performed in the first stages of pregnancy.⁴³ Results, therefore, are not available until the second or third trimester. At this late stage, genetic information puts a woman in a difficult quandary because her options regarding her pregnancy are limited. Termination of pregnancy in the second and third trimester is not only subject to legal restrictions, but late term abortion is also more psychologically and physically traumatic than a first trimester abortion.⁴⁴ By the second trimester the mother has felt the fetus moving inside her, and she has likely seen the fetal image on an ultrasound.⁴⁵ Additionally, the fetus must actually be delivered to terminate the pregnancy.⁴⁶ Alternatively, if the mother decides to carry the pregnancy to term, she does

37. *See id.*

38. *See id.* at 31-32.

39. *See id.* at 32-35.

40. *See id.* at 32.

41. *See id.*

42. *See id.* at 12-15, 32-34.

43. *See id.* at 34.

44. *See id.*

45. *See id.*

46. *See id.*

so knowing that her child will be affected to an unknown degree by a genetic disorder. Neither of these choices is optimal.

In addition to drawbacks in timing, the procedure itself also presents health risks to both the mother and fetus. Infection or miscarriage can result from insertion of the needle into the amniotic sac.⁴⁷ Although such complications can usually be treated or avoided, the risks should be carefully evaluated.⁴⁸ The potential for serious complications is generally perceived as slim however, and amniocentesis is commonly used in accessing prenatal health.⁴⁹

4. *Chorionic Villus Sampling*

Chorionic villus sampling (CVS) can be performed earlier in the pregnancy than amniocentesis, but again the procedure involves a significant degree of maternal discomfort and invasiveness.⁵⁰ The chorion is the membrane surrounding the fetus that becomes the placenta. The villi of the chorion (finger-like membranes) facilitate the transfer of maternal and fetal blood.⁵¹ The chorion villi cells contain the same genetic information as the fetus.⁵² A sample of the villi is obtained either vaginally or through an incision in the mother's abdomen.⁵³ The timing problem associated with amniocentesis is eliminated because CVS provides results as early as the ninth week of pregnancy.⁵⁴ The risk of infection and miscarriage, however, is similarly significant.⁵⁵

5. *Fetal Cell Sorting*

Fetal cell sorting is the newest prenatal testing procedure.⁵⁶ It is currently experimental and not widely available.⁵⁷ Fetal cell sorting "sorts" a sample of maternal blood by subjecting it to a series of complex procedures that separates traces of fetal blood from maternal

47. *See id.*

48. *See id.*

49. *See id.* at 32-34 (stating that complications affecting the mother or fetus occur in approximately one percent of the procedures).

50. *See id.* at 35-36.

51. *See id.*

52. *See id.* at 35.

53. *See id.*

54. *See id.* at 36.

55. *See id.*

56. *See* Telephone Interview with Kirk A. Keegan, Jr., M.D., *supra* note 34.

57. *See id.*

blood.⁵⁸ The fetal blood is then tested for genetic disorders.⁵⁹ Fetal cell sorting does not present the risks of infection and miscarriage inherent in amniocentesis or chorionic villus sampling, and sorting is significantly less invasive and uncomfortable for the mother.⁶⁰ There is, however, some concern that because of its comparative ease, fetal cell sorting may lend itself to use in less critical situations.⁶¹

D. Availability of Prenatal Genetic Testing

Prenatal genetic testing is not available to all pregnant women on an equal basis. Many factors, most of which are out of her control, affect whether or not a woman has access to testing. These factors include whether a woman has access to and is undergoing regular prenatal care;⁶² whether she receives care from a public or private hospital or clinic; whether she has health insurance; whether her health insurance provides coverage for genetic testing (and how such testing might affect coverage); and her physician's personal convictions towards prenatal genetic testing.

Where a woman lives in the United States also affects the availability of genetic testing.⁶³ Women who live near medical and research facilities that participate in the Human Genome Project, or similar genetic studies, have access to cutting edge genetic technology that is unavailable in technologically isolated areas.⁶⁴ Also, physicians practicing in states that recognize wrongful life and wrongful birth suits are more likely to offer mothers the option of genetic screening.⁶⁵

1. Who Undergoes Prenatal Genetic Testing?

Whether a woman is offered prenatal genetic testing is dependent entirely on her physician's assessment of her pregnancy and her physician's attitude towards testing. Initially, physicians offered prenatal

58. See Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 970 (1996).

59. See *id.* at 970-71.

60. See *id.* at 972.

61. See *id.* at 972.

62. While recognizing that many women receive inadequate or nonexistent prenatal care due to their social or economic status, this Note will nonetheless focus on those women who do receive regular prenatal care.

63. See Michael J. Malinowski, *Coming Into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 HASTINGS L.J. 1435, 1446 (1994).

64. See *id.*

65. See *id.* Malinowski cites New York as an example, stating "the fear of liability has helped to inspire obstetricians to refer virtually all patients who are at any risk to genetic counselors . . . [as a result] twenty-five thousand women in the state of New York are screened for fetal genetic abnormalities each year." *Id.* at 1447.

genetic testing only to women who were considered at risk of delivering babies with genetic disorders.⁶⁶ Factors placing a women in the high risk pregnancy category included being over the age of thirty-five, having a family history of genetic disorders, or having an already born child with a genetic disorder.⁶⁷

The reoccurrence of a genetic disorder in a family's history is a reasonable indication of risk. The selection of age thirty-five as the fulcrum of risk analysis, however, is somewhat arbitrary.⁶⁸ In Canada and the United States, the age at which risk increased was initially set at forty.⁶⁹ In France, a woman is not considered at risk until she reaches the age of thirty-eight.⁷⁰ In reality, a woman's risk of giving birth to a child with a genetic abnormality increases steadily as her age increases.⁷¹ A more accurate way to gauge an individual woman's risk would be to evaluate the risks described above in conjunction with the unique circumstances surrounding her pregnancy.

Today, prenatal genetic testing is offered as a routine component of prenatal care irrespective of a woman's age or family history.⁷² Proponents of genetic testing argue that this approach respects a woman's autonomy, enables her to make informed choices regarding her pregnancy, and in most cases, provides reassurance that her pregnancy is progressing normally.⁷³ This argument of "control, choice, and reassurance" is appealing, however, other commentators have noted several drawbacks.⁷⁴ Some women may not feel the need for medical reassurance.⁷⁵ Others argue that testing for certain disorders devalues those individuals living with the conditions.⁷⁶ Widespread testing in general may be perceived as a blanket treatment that may not be appropriate for all women in every circumstance.⁷⁷

66. See NIGHTINGALE & GOODMAN, *supra* note 1, at 4-5.

67. *See id.*

68. See Abby Lippman, *The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?*, in FACING THE CHALLENGES, *supra* note 34, at 9, 16-17.

69. *See id.* at 17.

70. *See id.*

71. *See id.* at 16.

72. *See* Telephone Interview with Kirk A. Keegan, Jr., M.D., *supra* note 34.

73. *See* Lippman, *supra* note 68, at 14-15.

74. *Id.* at 15.

75. *See id.*

76. *See id.* at 17. *See also* Deborah Kaplan, *Prenatal Screening and Diagnosis: The Impact on People with Disabilities*, in FACING THE CHALLENGES, *supra* note 34, at 49.

77. *See generally* FACING THE CHALLENGES, *supra* note 34.

2. *Why Is Prenatal Genetic Testing Performed?*

Physicians endorse prenatal genetic testing because, in the majority of cases, it reassures the expectant mother that her fetus is healthy and that her pregnancy is progressing normally.⁷⁸ Testing can serve other purposes as well. For example, a woman who decides to carry her fetus to term can use the information provided by a positive test to plan ahead.⁷⁹ Arrangements can be made to give birth in a particular hospital, with specialists and necessary equipment close at hand. Alternatively, a woman may be uncertain as to whether or not she and her family could cope financially, emotionally, or psychologically with a disabled child. Prenatal testing can provide her with answers that ease some uncertainty and enable her to exercise some control over the situation.

III. Prenatal Genetic Testing: Not an End in Itself

Prenatal genetic testing has been accurately described as “offering prospective parents difficult choices regarding the sacrifices they are willing to make to be parents, what mental and physical characteristics their children will have, and what kind of lives they want their children to have at a time when abortion is still an option.”⁸⁰ It is important to recall, however, that genetic tests are available for many more disorders than is treatment for these disorders.⁸¹ As a result, in many instances, a positive test result will not lead to treatment. Rather, upon receiving a positive test result, a woman must decide whether to continue or terminate her pregnancy. The availability of fetal treatment, how such treatment would affect her, the woman’s feelings about abortion, and how she feels she could cope with a disabled child are all issues that she should take into consideration when deciding whether to seek or accept prenatal genetic testing.

A. Prenatal Genetic Testing and the Prevention of Disease

It is imperative to understand what is meant by disease prevention. Genetic testing plays a role in disease prevention only when treatment is available for the disorder in question. Terminating a pregnancy to avoid delivering a child with a genetic disorder is not the same as preventing or treating the disorder. Ruth Faden clearly ar-

78. See Telephone Interview with Kirk A. Keegan, Jr., M.D., *supra* note 34.

79. See *id.*

80. Malinowski, *supra* note 63, at 1478.

81. See *Human Genome Project Information: Frequently Asked Questions*, *supra* note 16.

articulated this point, writing that “[e]liminating an incident of disease or disability by ‘preventing’ the person who would have that disease or disability from being born is not an instance of prevention—not in the sense in which it is ordinarily meant and not as the term ought to be used.”⁸² One must keep this important distinction in mind as prenatal genetic testing is evaluated as a means of disease prevention.

B. Prenatal Genetic Testing and the Treatment of Disease

If a genetic test reveals that a fetus is affected by a genetic disorder, then in an ideal scenario, the condition would be susceptible to in utero treatment. Unfortunately, as noted already, often this is not the case. Despite steady advancement, fetal treatment is in its infancy and remains unavailable for the most commonly tested for conditions such as, Downs syndrome, neural tube defects (such as anencephaly and spina bifida), and cystic fibrosis. Thus, in many cases a positive test result leads to termination of the pregnancy.

1. Available Treatment

Fetal surgery and fetal gene therapy enables physicians to intervene before birth to correct a fetal genetic disorder. Neither procedure is currently routine. Both involve significant risks to the mother and fetus.

Fetal surgery corrects the manifestation rather than the presence genetic disorders. Initially, fetal surgery was relatively simple. First performed in the early 1980s, the procedure involved inserting a needle through the mother’s abdomen and into the fetus to drain the fetal urinary tract.⁸³ Recent advances in medical technology have drastically expanded fetal surgical capabilities. Today, the fetus can be removed from the womb, undergo major surgery, and then be returned to the womb to continue its gestation.⁸⁴ Clearly, this kind of fetal surgery entails major, invasive surgery for the mother. Whether she is willing to take this kind of risk on behalf of her fetus will be addressed below.

Fetal gene therapy is still in experimental stages. Gene therapy attempts to correct the fetal genetic defect before birth by directly

82. Ruth Faden, *Reproductive Genetic Testing, Prevention and the Ethics of Mothering*, in *FACING THE CHALLENGES*, *supra* note 34, at 88, 92.

83. See Scott R. DeBonis, *The Fetal-Maternal Conflict: Judicial Resolution Based Upon Constitutional Rights*, 22 OHIO N.U. L. REV. 479, 482 (1995).

84. See *id.* at 483.

manipulating the associated genes.⁸⁵ A researcher in Southern California has petitioned the National Institute of Health for permission to begin experiments in which he intends to replace defective genes with a copy of a functioning gene, thus preventing, or at least partially correcting, the defect.⁸⁶ One of the risks involved with this kind of direct intervention is that the genetic manipulation could affect the fetus' reproductive genes, thereby affecting future generations.⁸⁷ Although human tests are still some years away, the ethics committee of the National Institute of Health has already begun to evaluate the potential risks and benefits of this kind of direct genetic interference.⁸⁸

In addition to the invasive intervention of fetal surgery and genetic therapy, it is conceivable that some forms of prenatal treatment may cause less inconvenience or discomfort to a pregnant woman. Perhaps as yet undiscovered oral medication, vitamins, or dietary supplements could reverse or minimize the effects of a genetic disorder. When, and if, such simple treatment becomes available, it will create yet another wrinkle in the debate over prenatal genetic testing.

Procedures to intervene and correct fetal genetic defects will surely continue to develop and become more widely available. In all likelihood, they will entail progressively less discomfort to the pregnant woman. Currently however, surgical intervention on behalf of a fetus requires a significant invasion of a woman's bodily integrity, and puts her health at risk. Inevitably, there will be instances when a woman will be reluctant or even unwilling to undergo treatment on behalf of her fetus. This dilemma is the subject of the following discussion.

2. *What Resulting Obligation to Undergo Treatment?*

When a prenatal genetic test is returned with a positive result, and treatment is available to cure or ameliorate the affects, what then? Does the mother have an ensuing obligation to undergo whatever treatment is deemed necessary by her physician? In most instances the expectant mother will do whatever is necessary to assure the health of her fetus.⁸⁹ This behavior is an example of the principle of beneficence, which is concerned with "conferring benefits or seek-

85. See Jennifer Couzin, *RAC Confronts in Utero Gene Therapy Proposals*, SCIENCE, Oct. 2, 1998, at 27.

86. See *id.*

87. See *id.*

88. See *id.*

89. See Telephone Interview with Kirk A. Keegan, Jr., M.D., *supra* note 34.

ing the best interests of others.”⁹⁰ Women generally act with beneficence towards the fetus they carry, and are genuinely interested in doing all they can to successfully carry a healthy baby to term. Unfortunately, this principle does not always prevail, as illustrated by the growing number of infants who are born addicted to drugs or adversely affected by alcohol.⁹¹

But what if a woman chooses not to undergo the prescribed treatment because her religious convictions prevent her from doing so?⁹² What if she is terrified of invasive surgery or seeks to avoid risk?⁹³ What if she fears having to raise a child who is saved by fetal surgery, but is still severely handicapped?⁹⁴ Regardless of her reason, an expectant mother who declines beneficial treatment on behalf of her fetus will, at a minimum, be subjected to intense scrutiny and moral condemnation.⁹⁵ This conflict is known as the fetal-maternal conflict.⁹⁶ Fetal-maternal conflict arises in other situations, namely in the context of forced caesarean cases, which will be discussed below in Section IV.

C. Prenatal Genetic Testing and Abortion

Since there is no treatment for most of the genetic conditions for which tests are conducted, women who undergo prenatal genetic testing have two choices when faced with a positive test result. Either they can carry the pregnancy to term, knowing that their child will be affected by a genetic disorder, or they can terminate their pregnancy. In light of this fact, it is surprising that prenatal genetic testing has been met with such widespread acceptance.⁹⁷ Limited only by the ambiguous “undue burden” standard formulated by the Supreme Court’s 1992 decision, *Planned Parenthood v. Casey*,⁹⁸ states are steadily chipping away at the accessibility of abortion. Many states allow late term abortions only when the mother’s life is in danger, yet often results of

90. Faden, *supra* note 82, at 90.

91. See Telephone Interview with Kirk A. Keegan Jr., M.D., *supra* note 34. Dr. Keegan noted that one in ten infants born in New York is affected by drugs.

92. See Katherine A. Knopoff, *Can a Pregnant Woman Morally Refuse Fetal Surgery?*, 79 CAL. L. REV. 499, 502 (1991).

93. See *id.*

94. See *id.*

95. See DeBonis, *supra* note 83, at 479-80.

96. See *id.*

97. See Telephone Interview with Kirk A. Keegan, Jr., M.D., *supra* note 34. See also Andrews, *supra* note 58, at 1001-02.

98. 505 U.S. 833 (1992).

prenatal genetic tests are not available until the second trimester, when state limitations begin to take effect.

Ironically, many states have laws regulating abortion and genetic testing which are at odds with one another.⁹⁹ For example, soon after Louisiana established regional genetics clinics, legislation was passed that prohibited abortion of fetuses diagnosed with genetic disorders.¹⁰⁰ Tennessee passed a law which forbid the use of public funds for prenatal diagnosis unless there was effective treatment, finding that abortion was against public policy. Four years later, the Tennessee legislature reversed itself, and provided public funds for "abortions of fetuses 'medically determined to have severe physical deformities or abnormalities or severe mental retardation.'"¹⁰¹

Adding to the confusion are health insurance companies, which unfortunately play an unwanted role in women's decision making process. One chilling example involved a woman whose existing child had cystic fibrosis.¹⁰² She was pregnant with a second child and sought prenatal testing for the condition.¹⁰³ After a positive result, she carried the child to term. Her HMO, which had paid for the testing, subsequently notified her that it would not provide health insurance for the baby because it was born with a preexisting condition.¹⁰⁴ Although the HMO eventually capitulated, its initial decision raises the question of whether such a policy might be acceptable in the future.¹⁰⁵

Prenatal genetic testing often leads to abortion when treatment is nonexistent.¹⁰⁶ Unless states assist families with children affected by genetic disorders or provide other alternatives, it is inconsistent for states to simultaneously discourage abortion and encourage prenatal genetic testing. To better serve women and send a consistent message, lawmakers must reconcile abortion law with prenatal testing regulations.

99. See Ellen Wright Clayton, *What the Law Says About Reproductive Genetic Testing and What It Doesn't*, in *FACING THE CHALLENGES*, *supra* note 34, at 131, 147-50. See also Julia Walsh, *Reproductive Rights and the Human Genome Project*, 4 S. CAL. L. REV. & WOMEN'S STUD. 145, 159 (1994).

100. See Clayton, *supra* note 99, at 147-50.

101. *Id.* at 147-48 (citation omitted).

102. See Elena Gates, *Prenatal Genetic Testing: Does It Benefit Pregnant Women?*, in *FACING THE CHALLENGES*, *supra* note 34, at 183, 189.

103. See *id.*

104. See *id.*

105. See *id.*

106. See Andrews, *supra* note 58, at 1002.

IV. Grounds on Which to Advocate Mandatory Prenatal Testing

The advances in genetic technology, the availability of treatment for some detected genetic disorders, and the increased acceptance of prenatal genetic testing, leads one to ask whether a woman could ever be compelled to undergo prenatal genetic testing, or whether a state could mandate prenatal genetic screening for certain conditions. These questions expose a tension between states' interests and the rights of individuals. On one side, the Tenth Amendment of the Constitution grants broad authority to states, stating "[t]he powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people."¹⁰⁷ States' Tenth Amendment police power includes the authority to regulate in the interest of public health and welfare.¹⁰⁸ On the other side, the Constitution guarantees citizens a number of rights and liberties, among them, a right to privacy, freedom from search and seizure, and protection of bodily integrity.¹⁰⁹ After the following evaluation, it is clear that a pregnant woman's rights in this area outweigh those of the state, and that courts would reject compelled prenatal genetic testing.

A. Utilization of State Police Power to Regulate Prenatal Genetic Testing in the Interest of Public Health and Welfare

State authority to regulate public health and welfare under the police power was recognized by the Supreme Court in *Jacobson v. Massachusetts*.¹¹⁰ In *Jacobson*, the Court interpreted state power broadly and upheld a Massachusetts statute which mandated smallpox vaccination.¹¹¹ It stated that the courts' role is not to consider whether the method of regulation is the best method to achieve the

107. U.S. CONST. amend. X.

108. The U.S. Supreme Court described the States' power to regulate the public health as the power to "enact quarantine laws and 'health laws of every description.'" *Jacobson v. Massachusetts*, 197 U.S. 11, 25 (1905) (quoting *Gibbon v. Ogden*, 22 U.S. (9 Wheat.) 1, 203 (1824)).

109. See U.S. CONST. amend. XIV (right to privacy); U.S. CONST. amend IV (freedom from unreasonable searches and seizures); and Christyne L. Neff, *Woman, Womb, and Bodily Integrity*, 3 YALE J.L. & FEMINISM 327, 337 (1991) (finding support for the principle of bodily integrity in common law as well judicial interpretation of the First, Fourth, Fifth, and Fourteenth Amendments of the Constitution).

110. 197 U.S. 11 (1905).

111. See *id.* at 28.

desired means, but solely whether it is reasonably related to the state's objective.¹¹²

In the years following *Jacobson*, states initiated many public health programs.¹¹³ Most of these programs mandated vaccinations and quarantines directed at preventing the spread of communicable diseases.¹¹⁴ Courts usually endorsed mandatory vaccination and quarantine despite the fact that they infringed on individual rights, citing *Jacobson* for the proposition that a state may "enact . . . health laws of every description so long as they are not unreasonable, arbitrary or oppressive."¹¹⁵ In the 1960s and 1970s, however, courts began to recognize limitations on a state's authority.¹¹⁶

In 1975, the Supreme Court held that a state's interest in protecting public health did not outweigh a mental patient's liberty interest, finding that mental illness alone did not justify involuntary confinement.¹¹⁷ More recently, states' response to the increasing prevalence of HIV and AIDS contributed to courts' change in policy.¹¹⁸ More importantly, courts began to recognize the applicability of a strict scrutiny standard of review.¹¹⁹ When a state passes legislation that infringes on individual rights, the strict scrutiny standard requires the state to show that the chosen restriction is the least intrusive means to realize a compelling state interest.¹²⁰ Thus, to justify mandatory prenatal genetic testing, a state must show that testing is the least intrusive means of addressing some compelling state interest. What are the compelling interests that would be served by mandated prenatal genetic testing? The most persuasive are a state's interest in preventing disease and in protecting potential life.

1. *Whether States Have a Compelling Interest in Preventing Disease*

A state might make a persuasive argument that it has a compelling interest in preventing disease.¹²¹ As one commentator has noted, "[f]oreknowledge of risk presents the opportunity for close monitor-

112. *See id.* at 25, 35.

113. *See* Kristin M. Raffone, Note, *The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy*, 26 HOFSTRA L. REV. 503, 520-22 (1997).

114. *See id.*

115. *Id.* at 521 (quoting *Jacobson*, 197 U.S. at 25).

116. *See id.* at 522.

117. *See* O'Connor v. Donaldson, 422 U.S. 563 (1975).

118. *See* Raffone, *supra* note 113, at 524-29.

119. *See id.* at 523.

120. *See id.* at 539.

121. *See id.*

ing, early diagnosis, and curative intervention.”¹²² Early detection enables physicians to offer treatment at an earlier date, with the aim of alleviating or mitigating the symptoms of a genetic disorder. Alternatively, a positive test result for a devastating disorder provides women and their families with information, enabling them to make informed family planning decisions. Many states have already implemented genetic testing of newborns as a preventative measure for certain conditions.¹²³ Neonatal genetic testing could potentially serve as a precedent on which to base prenatal testing if appropriate parallels could be drawn.

California, for example, has mandated neonatal genetic screening for phenylketonuria (PKU).¹²⁴ California Health and Safety Code: Genetic Prevention Service Hereditary Disorders Act section 124980(f) states in part, “[n]o testing, except initial screening for PKU and other diseases that may be added to the newborn screening program, shall require mandatory participation.”¹²⁵ Genetic tests for PKU are highly determinative and reliable because it is a single-gene disorder.¹²⁶ Left untreated, PKU interferes with the development of brain cells and causes mental retardation.¹²⁷ Treatment for the condition consists of strict dietary control for the first ten years of life.¹²⁸

Assuming that a state’s interest in preventing PKU is compelling, one next asks whether genetic testing is the least intrusive method of prevention. In order to test for PKU, the infant’s heel is pricked to obtain a blood sample. A highly reliable blood test is performed and treatment is available for the condition if the test is positive.¹²⁹ PKU is a unique and perfect instance wherein there is both an accurate test and a relatively simple treatment.¹³⁰ The question becomes more complex when one recalls that treatment is nonexistent for the majority of conditions for which genetic tests are available. Additional questions are raised when one considers that genetic tests are available for adult onset diseases, as well as for non-lethal diseases. Is it appropriate to mandate prenatal genetic testing for these disorders?

122. See *id.* at 540 (quoting Philip R. Reilly, *Public Policy and Legal Issues Raised by Advances in Genetic Screening and Testing*, 27 SUFFOLK U. L. REV. 1327, 1333 (1993)).

123. See *id.*; see also NIGHTINGALE & GOODMAN, *supra* note 1, at 91.

124. See Raffone, *supra* note 113, at 540.

125. CAL. HEALTH & SAFETY CODE § 124980(f) (Deering 1999).

126. See Raffone, *supra* note 113, at 540 n. 199.

127. See NIGHTINGALE & GOODMAN, *supra* note 1, at 16.

128. See *id.* at 25.

129. See Raffone, *supra* note 113, at 540; see also NIGHTINGALE & GOODMAN, *supra* note 1, at 91.

130. See *id.*

2. *Whether States Have a Compelling Interest in Protecting Potential Life*

A state might also argue that prenatal genetic testing furthers its compelling interest in protecting the potential life of the fetus. Such a right has been recognized by the Supreme Court.¹³¹ In *Roe v. Wade*, the Court recognized a woman's right to have an abortion.¹³² The Court also found, however, that the state had an "important and legitimate interest in protecting the potentiality of human life."¹³³ In his majority opinion, Justice Blackmun constructed a trimester framework with which to balance a woman's rights against those of the state.¹³⁴ Blackmun's trimester framework was overturned in *Planned Parenthood v. Casey* because it "undervalue[d] the State's interest in potential life."¹³⁵ States have relied on this language in *Casey* to place increasing restrictions on the availability of abortion. In several unsettling cases in which a woman was subjected to court ordered treatment on behalf of her fetus, states have again attempted to further their interest in protecting potential life.¹³⁶

In Re A.C. is a well known case in which a terminally ill woman was forced to undergo a caesarean section, over her objection, to deliver her twenty-six and a half week old fetus.¹³⁷ The baby girl died two and a half hours after the operation was performed.¹³⁸ The mother died two days later.¹³⁹ The court of appeal, in its decision to overturn the order, carefully noted two points.¹⁴⁰ First, the trial judge had been under a tremendous time constraint and had not had the opportunity to deliberate or effectively evaluate the legal issues presented.¹⁴¹ Second, the court stated that although both mother and baby had died after the surgery, the case was not moot because "col-

131. See *Roe v. Wade*, 410 U.S. 113 (1973) and *Planned Parenthood v. Casey*, 505 U.S. 833 (1992).

132. *Roe*, 410 U.S. at 162.

133. *Id.*

134. See *id.* at 163-64.

135. *Casey*, 505 U.S. at 873.

136. See *In Re A.C.*, 533 A.2d 611 (D.C. 1987); *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981) (ordering a caesarean section against the mother's expressed wishes to deliver a thirty nine week old fetus); see also *In Re A.C.*, 573 A.2d 1235, 1243 (D.C. 1990) (citing a survey which found thirteen out of fifteen attempts in the previous five years to acquire court authorization for caesarean interventions succeeded).

137. *In Re A.C.*, 533 A.2d 611 (D.C. 1987).

138. See *id.*

139. See *id.*

140. See *In Re A.C.* 573 A.2d 1235, 1237 (D.C. 1990).

141. See *id.*

lateral consequences will flow from any decision we make in this appeal.”¹⁴²

The court of appeal overturned the court-ordered caesarean based on the theory of informed consent and the concept of bodily integrity.¹⁴³ In determining A.C.’s interest in retaining her constitutionally protected right to bodily integrity, the court considered the decision of a Pennsylvania court in *McFall v. Shimp*.¹⁴⁴ In *McFall*, the court refused to order a man to donate bone marrow essential to save his cousin’s life.¹⁴⁵ The A.C. court approved the following language from *McFall*:

The common law has consistently held to a rule which provides that one human being is under no legal compulsion to give aid or to take action to save another human being or to rescue For our law to *compel* defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limit, and one could not imagine where the line would be drawn.¹⁴⁶

Additionally, the A.C. court acknowledged and rejected the argument that a mother’s duty towards her fetus might be higher than one citizen’s duty towards another, stating that:

It has been suggested that fetal cases are different because a woman who “has chosen to lend her body to bring [a] child into the world” has an enhanced duty to assure the welfare of the fetus, sufficient even to require her to undergo caesarean surgery. Surely, however, a fetus cannot have rights in this respect superior to those of a person who has already been born.¹⁴⁷

After reviewing the *McFall* decision, and other compelled caesarean cases, the A.C. court held that:

[E]very person has the right, under the common law and the Constitution, to accept or refuse medical treatment. This right of bodily integrity belongs equally to persons who are competent and persons who are not To protect that right against intrusion by others—family members, doctors, hospitals, or anyone else, however well-intentioned—we hold that a court must determine the patient’s wishes by any means available, and must

142. *Id.* at 1241.

143. *See id.* at 1243.

144. *See id.* at 1244; *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (1978).

145. *See McFall*, 10 Pa. D. & C.3d at 92.

146. A.C., 573 A.2d at 1243 (quoting *McFall*, 10 Pa. D. & C.3d at 91) (emphasis in original).

147. *Id.* at 1244 (citing John A. Robertson, *Procreative Liberty and the Control of Contraception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 456 (1983) (footnote omitted)).

abide by those wishes unless there are truly extraordinary or compelling reasons to override them.¹⁴⁸

As a general rule, court-ordered caesareans have been overturned on appeal because the courts of appeal “properly based their decisions upon the constitutional issues involved [since] attorneys and courts are not confronted with the time constraints facing the lower court.”¹⁴⁹ As illustrated by the court of appeal’s decision in *In Re A.C.*, a state’s interest in protecting potential life does not presumptively trump women’s rights. A state must show that the mandated action furthers a compelling state interest. Although protecting potential life arguably may be such a compelling interest, prenatal genetic testing does not further that objective. Since treatment is nonexistent for many conditions, a positive test result often leads to termination of the pregnancy. Clearly ending a pregnancy is inapposite to protecting potential life.

B. Policy Arguments Fail to Support Mandated Prenatal Genetic Testing

1. Philosophical Approach

A state may attempt to appeal to public sensibilities to “sell” the idea of prenatal genetic testing. One argument in this vein utilizes a utilitarian approach. This approach advocates the greatest happiness for the greatest number of people.¹⁵⁰ “In a utilitarian analysis, the appropriate method of determining the best outcome involves the balancing of risks against benefits, disadvantages against advantages, pain against pleasure. Utilitarianism requires following the course of action that leads to the best possible outcome, and the ends are permitted to justify the means.”¹⁵¹

A Utilitarian would argue that compelling a woman to undergo unwanted prenatal testing is justified, despite the fact that her rights would be violated, because testing results in a greater good. Prenatal genetic testing provides benefits in two ways. The fetus could be treated, benefiting the fetus who will be unaffected by the abnormal genetic condition, as well as society, which gains a healthy member. Alternatively, some would contend that the fetus could be aborted,

148. *Id.* at 1247 (citing *In Re Osborne*, 294 A.2d 372 (D.C. 1972)). The court then continued its analysis and discussed substituted judgment. It determined that the application of substituted judgment would also have upheld A.C.’s desire not to undergo a caesarean section. *See id.*

149. DeBonis, *supra* note 83, at 493.

150. *See* Knopoff, *supra* note 92, at 505.

151. *Id.*

thereby saving society from the burden of caring for and supporting a potentially dependent child and sparing the fetus from living with a genetic disability.

When the utilitarian approach is extended to other public health issues however, it quickly becomes apparent that it produces unacceptable results. For example, applied to the organ donor program, the utilitarian approach would permit a healthy person to be put to death so that her organs could be donated to save the lives of at least two other people. Although the greater good would be served, no one would choose to live by this rule.¹⁵² A state would have a difficult time persuading the public to embrace utilitarianism. There is, however, an alternative philosophical approach.

Deontology rejects the idea that the ends justifies the means. From the deontological perspective, every action is either inherently right or wrong.¹⁵³ "Deontology requires following the course of action that involves only right acts, never compromising rights or duties for the sake of outcome."¹⁵⁴ Deontology forms the foundation on which the doctrine of informed consent is based.¹⁵⁵ Also, deontology goes hand in hand with the court of appeal's decision in *In Re A.C.* Finally, it is more in sync with society's values and individuals' rights. Deontology does not support state mandated prenatal genetic screening. It does, however, provide a foundation for a voluntary testing alternative.

2. *Legal Liability*

A state could make a legal argument that mandated prenatal genetic testing protects healthcare providers from potential liability. As noted previously, several states, including New York, have recognized wrongful life and wrongful birth claims.¹⁵⁶ The availability of these claims pressures physicians to encourage testing when in fact it may not be indicated.

Again the states' argument fails. A physician need only document that she discussed prenatal testing options with the expectant mother. Once she has done so, the woman can initiate testing if desires. The doctrine of informed consent works in this instance to

152. *See id.* at 505-06.

153. *See id.*

154. *Id.*

155. *See id.* at 507.

156. *See Malinowski, supra* note 63, at 1447.

protect the physician from liability and to encourage the exchange of information between physician and patient.

V. Arguments in Favor of Prenatal Genetic Testing Are Unconvincing Because Women Do Not Give Up Fundamental Rights Upon Becoming Pregnant

As discussed above, the Supreme Court has recognized that states have an interest in protecting potential life and in preventing disease.¹⁵⁷ However, under the strict scrutiny standard, states must also show that prenatal testing is the least intrusive means of furthering those interests.¹⁵⁸ Since there are alternatives which better advance state interests, and because prenatal genetic testing unnecessarily infringes upon several of women's fundamental rights, mandated testing would not be upheld by courts.

A. State Authority to Regulate in the Interest of Public Health and Welfare Does Not Outweigh Women's Constitutional Rights Under the Strict Scrutiny Standard

Several fundamental rights would be infringed upon if a state were to mandate prenatal genetic testing. The right to privacy, protection from unreasonable searches and seizures, protection of bodily integrity, and rights under the equal protection clause would all be violated. A statute creating such a mandate would be subjected to strict scrutiny by the courts. Upon judicial evaluation, the statute would fail.

The right to privacy is a fundamental right guaranteed under the Fourteenth Amendment of the Constitution.¹⁵⁹ This right includes the right to make autonomous personal decisions related to contraception, marriage, and procreation.¹⁶⁰ Justice O'Connor, in her concurring opinion in *Washington v. Glucksberg*,¹⁶¹ stated that "[w]hatever the outer limits of the substantive sphere of liberty may be, it definitely includes protection for matters central to personal dignity and

157. See *Roe v. Wade*, 410 U.S. 113, 63-64 (1973); *Planned Parenthood v. Casey*, 505 U.S. 833, 873 (1992).

158. See Raffone, *supra* note 113, at 539.

159. See *Griswold v. Connecticut*, 381 U.S. 479 (1965) (recognizing a "penumbra" of privacy rights within the Fourteenth Amendment).

160. See Raffone, *supra* note 113, at 536 (citing *Griswold v. Connecticut*, 381 U.S. 479, 480 (1965); *Loving v. Virginia*, 388 U.S. 1, 2 (1967); *Roe v. Wade*, 410 U.S. 113, 117-18 (1973)).

161. 521 U.S. 702 (1997).

autonomy.’”¹⁶² Mandatory prenatal testing provides private information not only to the woman and her family, but also to her physician, and conceivably her health insurance carrier and employer.¹⁶³ Also, mandatory testing fails to recognize that a woman has a right not to know the results of the test.¹⁶⁴ A woman’s right to privacy ensures that she has control over this kind of information. Mandatory testing would strip that control away.

The Fourth Amendment protects citizens from unreasonable searches and seizures.¹⁶⁵ It states that “[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.”¹⁶⁶ As one commentator has noted, “[t]he Fourth Amendment provides an arena for direct confrontation between the government’s interest in law enforcement and the individual’s interest in bodily integrity.”¹⁶⁷ The Supreme Court has held that mandatory testing “plainly involves the broadly conceived reach of a search and seizure under the Fourth Amendment.”¹⁶⁸

A pregnant woman’s interest in protecting her bodily integrity is also threatened by state mandated prenatal genetic testing.¹⁶⁹ This principle has its roots in common law, and has found judicial support in the First, Fourth, Fifth, and Fourteenth Amendments.¹⁷⁰ “No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable power of law.”¹⁷¹ The Court utilizes a balancing test to weigh an individual’s interest in bodily integrity against competing state interests in protecting public health under the police powers.¹⁷² Courts look to the depth of the intrusion, whether the intrusion is routine and reliable, and whether it is “shocking.”¹⁷³

162. *Id.* at 2307 (quoting *Casey*, 505 U.S. at 851).

163. *See Andrews, supra* note 58, at 996; *see also Raffone, supra* note 113, at 550-53.

164. *See Andrews, supra* note 58, at 997.

165. U.S. CONST. amend IV.

166. *Id.*

167. Neff, *supra* note 109, at 344-45.

168. *Schmerber v. California*, 384 U.S. 757, 767 (1966).

169. *See Union Pac. Ry. v. Botsford*, 141 U.S. 250 (1891).

170. *See Neff, supra* note 109, at 338.

171. *Id.* at 337.

172. *See Raffone, supra* note 113, at 530.

173. *See Neff, supra* note 109, at 345.

The Supreme Court has approved urine and blood testing of transportation employees in the interest of protecting public safety.¹⁷⁴ Mandatory HIV testing for prisoners has also been approved by courts.¹⁷⁵ Clearly, these cases are easily distinguishable from mandated prenatal genetic testing. The risks posed by inebriated transportation workers and communicable diseases are in no way similar to the risks addressed by genetic testing.¹⁷⁶

Finally, mandatory prenatal testing singles out pregnant women. It subjects them to intrusive medical testing that no man or non-pregnant woman would ever experience. Thus, a greater burden is placed on women with respect to procreation.¹⁷⁷ This kind of discriminatory treatment is prohibited under the Equal Protection Clause and is subject to an intermediate level of scrutiny.¹⁷⁸ This means that prenatal genetic testing must “serve important government objectives and be substantially related to achievement of those objectives.”¹⁷⁹ Although the state can make a plausible argument that it has an important interests, as noted above, those interests are not furthered by prenatal testing.

B. Policy Arguments Against Mandated Prenatal Genetic Testing

Aside from the Constitutional issues addressed above, there are additional arguments against mandated prenatal genetic testing. First, genetic diversity is threatened by mandatory testing.¹⁸⁰ For example, in the 1970s some states initiated mandatory screening for sickle cell anemia because it was perceived as a “debilitating and undesirable genetic defect.”¹⁸¹ Years later it was determined that the gene that triggers sickle cell anemia also causes immunity to malaria.¹⁸² As this case plainly illustrates, eradicating genetic differences without a complete understanding of their potential benefits can be a dangerous gamble with potentially serious consequences.

174. See *Skinner v. Railway Labor Executives Ass’n*, 489 U.S. 602, 627 (1989); *National Treasury Employees Union v. Von Raab*, 489 U.S. 656 (1989).

175. See *Dunn v. White*, 880 F.2d 1188, 1197 (10th Cir. 1989).

176. See *Glover v. Eastern Neb. Community Office of Retardation*, 867 F.2d 461, 464 (8th Cir. 1989) (enjoining mandatory HIV testing of employees as an unreasonable search and seizure because it violated employee’s privacy interests).

177. See *Walsh*, *supra* note 99, at 164.

178. See *Craig v. Boren*, 429 U.S. 190, 197 (1976).

179. *Id.*

180. See *Raffone*, *supra* note 113, at 546.

181. *Id.* at 547.

182. See *id.*

One should also understand that a woman who wishes to avoid prenatal testing is likely to avoid prenatal care entirely if testing is a mandatory component. Prenatal care is too important to risk alienating pregnant women who, for whatever reasons, do not wish to know genetic information about their fetus or themselves. Also, testing for genetic disorders, particularly those that are non-lethal, may devalue individuals who are living with the conditions. Further, disparities between women with access to prenatal care and those without will become even greater. Women with access to care will likely have fewer children with genetic disorders, making it all the more likely that genetic disorders will be relegated to less privileged citizens.

Finally, and most importantly, one must keep in mind that in all but the most unusual circumstances, women will take whatever steps necessary to ensure their baby's health and well-being. Women generally act with beneficence towards the fetus they carry and are sincerely interested in doing all they can to successfully carry a healthy baby to term. This principle is the basis on which a voluntary genetic testing program will succeed.

VI. Conclusion

Although states have an interest in protecting the public's health and welfare, that interest does not supersede the right of pregnant women to be free from unwanted prenatal genetic testing. As an alternative, states should encourage physicians to offer women and their families information about testing and allow them to make informed choices. Several important points should be made in providing information, including the types of tests available, the reliability of the tests, the availability of treatment, and the alternatives to treatment. It is important that testing is offered as an alternative, not as a mandatory component of prenatal care. Paternalistic intervention by the state is unwarranted, as well as unconstitutional. The principles of beneficence and autonomy can be relied on to protect potential life, while at the same time respecting the rights of pregnant women.

