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Whose Genes Are These Anyway?: Familial Conflicts over Access to Genetic Information

Sonia M. Suter

INTRODUCTION

In the latter part of this century, scientists began to determine the genetic bases of many diseases.¹ Recently, the identification of disease genes has escalated dramatically, particularly in the last decade.² To support such research, Congress decided to fund the Human Genome Project: a three-billion-dollar effort to map and sequence the entire human genome.³ One of the project's major goals is to identify all disease genes to help test for, understand, and, ultimately, cure genetic disease.⁴

The ability to "decode" what is to many the basis of a person's identity — one's genes — has significant implications for individuals, families, and society at large. Although many applaud genetic research and the Human Genome Project,⁵ others are concerned about potential misuse of genetic information⁶ or at least the legal and ethi-

1. Victor A. McKusick, *The Human Genome Project: Plans, Status, and Applications in Biology and Medicine*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES 18, 22-26 (George J. Annas & Sherman Elias eds., 1992) [hereinafter GENE MAPPING].

2. *Id.* at 20 (fig. 2-1), 21 (fig. 2-2), 25-26.

3. The genome is the pattern of deoxyribonucleic acid (DNA) that codes for proteins and physical processes. Funding for the Project began in 1990 and is expected to continue until 2005. See James D. Watson, *The Human Genome Project: Past, Present, and Future*, 248 SCIENCE 44 (1990).

4. In addition, scientists hope to use this information to understand the disease process in general. James D. Watson & Robert M. Cook-Deegan, *The Human Genome Project and International Health*, 263 JAMA 3322 (1990). The more distant goal of curing genetic disease involves the development of gene therapy, in which the defective gene or its product is altered. See A. Dusty Miller, *Human Gene Therapy Comes of Age*, 357 NATURE 455 (1992); Inder M. Verma, *Gene Therapy*, SCI. AM., Nov. 1990, at 68.

5. *Genetics and the Public Interest*, 356 NATURE 365, 365 (1992) [hereinafter *Public Interest*]; Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 110 (1991). This is not to say that the Project does not have vociferous opponents who claim it is bad science and a waste of scarce and valuable funding resources. See, e.g., Robert N. Proctor, *Genomics and Eugenics: How Fair is the Comparison?*, in GENE MAPPING, *supra* note 1, at 57, 65; Leslie Roberts, *Genome Backlash Going Full Force*, 284 SCIENCE 804 (1990).

6. Gostin, *supra* note 5, at 110, 112; Proctor, *supra* note 5, at 58-59; Jody W. Zylke, *Examining Life's (Genomic) Code Means Reexamining Society's Long-Held Codes*, 267 JAMA 1715 (1992). This fear is not unfounded, as the history of genetic science has been plagued with abuse. Around the turn of the century, several states passed legislation allowing the involuntary sterilization of people with mental retardation. Proctor, *supra* note 5, at 61; Zylke, *supra*, at 1715. Similarly, the Nazis abused and misrepresented genetics in pursuit of eugenic goals. Theodore Friedmann, *Opinion: The Human Genome Project — Some Implications of Extensive "Reverse Genetic" Medicine*, 46 AM. J. HUM. GENETICS 407, 411 (1990); *Public Interest*, *supra* note 5, at 365; Evelyne Shuster, *Determinism and Reductionism: A Greater Threat Because of the Human*

cal issues it creates.⁷ As genetic information becomes increasingly available, control of that information gains importance. For example, if third parties, especially institutional third parties such as insurers or employers, have access to genetic data, they might discriminate on the basis of that information.⁸

Genetic testing presents equally problematic issues regarding access to genetic information by private third parties, specifically, family members. Conflicts of interest may arise between an individual and her relatives, who may personally benefit from learning about the individual's genetic status.⁹ Similarly, when genetic testing requires the involvement of other family members, people may try to compel unwilling relatives to participate.

These issues arise in at least two contexts involving competing interests between family members.¹⁰ Numerous conflicts may arise regarding the disclosure of results when testing has already been performed. The person tested — the proband — may want to avoid harm from disclosure, while the relative may be able to prevent harm to herself by receiving the information. Physicians and genetic counselors may feel bound to inform the relative and also bound to protect patient confidentiality. Second, when genetic testing of one person can benefit another family member, privacy and autonomy interests of the former may collide with the relative's interests in protecting her health or planning her future. Such questions have not yet come before the courts. However, as more people are faced with these problems, they

Genome Project?, in GENE MAPPING, *supra* note 1, at 115, 116; Zylke, *supra*, at 1715. Other, more subtle, forms of misuse occurred in the 1970s when states instituted screening programs for sickle cell anemia. Poor planning and inadequate education created misunderstandings regarding the difference between carriers of sickle cell disease and those who actually had the disease. Consequently, many carriers suffered from insurance and employment discrimination, as well as unfounded fear and anxiety with regard to their own health. Leslie Roberts, *One Worked; The Other Didn't*, 247 SCIENCE 18 (1990); Benjamin S. Wilfond & Norman Fost, *The Cystic Fibrosis Gene: Medical and Social Implications for Heterozygote Detection*, 263 JAMA 2777, 2778 (1990). Similar problems arose in the 1960s when states mandated phenylketonuria (PKU) screening for newborns even though the technique was unperfected. As a result, some children with PKU received improper treatment and some unaffected children were incorrectly identified as having the disease. Wilfond & Fost, *supra*, at 2778.

7. Frequently discussed concerns involve insurance and employment discrimination, access to genetic information, and issues of privacy. See, e.g., Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75 (1991); John C. Fletcher & Dorothy C. Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome Is Mapped*, 39 EMORY L.J. 747 (1990); Marvin R. Natowicz et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS 465 (1992).

8. Already, some health maintenance organizations have told families they would not provide for the care of children born with prenatally diagnosed cystic fibrosis. Zylke, *supra* note 6, at 1715.

9. See, e.g., Fletcher & Wertz, *supra* note 7, at 763-64; Judith Hall, *The Concerns of Doctors and Patients*, in ETHICAL ISSUES IN HUMAN GENETICS 23, 27 (Bruce Hilton et al. eds., 1973).

10. This Note focuses only on these discrete issues, recognizing, however, that many other interests are at stake in the genetic testing context, for example, insurance companies' and employers' interests. See *supra* note 7.

may try to argue that the state has the authority to compel genetic testing or that a court may order the disclosure of test results.¹¹

This Note argues first that courts and legislatures should follow a presumption against mandating disclosure of a person's genetic information to third parties. Second, genetic testing for the benefit of a third party should not, and constitutionally cannot, be compelled. Part I presents an overview of genetics and discusses the special legal and ethical issues genetic testing poses. Part II examines the issue of nonconsensual disclosure to family members, who could potentially use the information from tests that have already been performed. This Part concludes that there should be a presumption against disclosure. Part III examines a related, but different, question regarding the constitutionality of mandatory genetic screening of an individual for the benefit of her family. It contends that such compulsory testing is unconstitutional and that public policy argues against it. Part IV offers legislative and judicial guidelines that prohibit mandatory genetic testing for the benefit of another family member and allow disclosure of test results only when the harm in failing to disclose significantly outweighs the harm from disclosure.

I. OVERVIEW OF GENETICS AND GENETIC TESTING

To illustrate how genetic testing may lead to conflicts of interest between family members, this Part presents an overview of genetics. Any judicial or legislative decisionmaking should take into account the concepts described. Section I.A explains basic genetic concepts, including the modes of inheritance for various genetic diseases. Section I.B discusses the ways in which genetic data are different from other types of medical data. Section I.C examines how genetic data can be used to test for disease and explores the limitations of current methods of genetic testing. Finally, section I.D presents hypothetical situations in which conflicts of interest regarding genetic testing and data might arise among family members. The hypotheticals will illustrate the legal and ethical issues discussed in Parts II and III.

A. *Inheritance and Genetic Disease*

Genetics largely dictates who a human being is physically and, to some extent, psychologically. The human *genome* is composed of twenty-three pairs of chromosomes, forty-six in all,¹² which carry thousands of genes. The set of genes each person inherits constitutes

11. This Note grew out of the author's two years of experience as a genetic counselor. Many of the examples and concerns discussed are based on actual cases.

12. The 46 chromosomes exist in 23 homologous pairs. The twenty-third pair is responsible for gender: females have two X chromosomes; males, an X and Y. See ALAN E.H. EMERY & ROBERT F. MUELLER, *ELEMENTS OF MEDICAL GENETICS* 108-09 (7th ed. 1988). Everyone inherits one of each pair of chromosomes from each parent. *Id.* at 108.

her *genotype*, and a person's observable traits — eye color, height, hair type, and so forth — comprise her *phenotype*.¹³ Genes regulate the body's production of individual proteins,¹⁴ which ultimately determine phenotype. Genotype alone controls much of a person's phenotype, especially traits that are not immediately apparent, like blood type. Other physical traits, such as height, weight, and intelligence, are influenced by environmental factors¹⁵ and are only partially linked to genotype. Very few traits, for instance, hairstyle, are completely independent of genotype. This Note concentrates on a particular phenotype, genetic disease, which is fundamentally dependent on genotype.

Genetic diseases arise from mutations, that is, alterations in the DNA. Mutations occur infrequently when genes pass from one generation to another.¹⁶ They are often harmless, either because the change within a gene does not affect protein production or because the mutation occurs in a region of DNA that does not encode proteins. Mutations can be deleterious, however, if they disrupt a gene's normal function. If parts of a gene are missing, rearranged, substituted, or even supplemented with extra DNA, the body will make an altered or deficient protein or sometimes will produce no protein at all. When that protein is crucial to biological function, disease results.¹⁷

Because everyone has two sets of each gene, one on each pair of chromosomes, it is possible for a person to have both a "normal," functioning gene and a homologous, nonfunctioning gene. Often the normal gene compensates for the deficient gene so that the person is completely healthy with respect to that gene. Such people are *carriers* for the nonworking gene, which is recessive to the working gene. Autosomal recessive diseases occur only when both genes in a pair func-

13. Similarities between the phenotypes of family members exist because a significant percentage of genetic material is shared among them. A person shares 50% of her genes with her mother and 50% with her father. On average, a person also shares 50% of the same genetic material with each sibling, although that number varies depending on the particular genes each received from the parents. PETER S. HARPER, *PRACTICAL GENETIC COUNSELLING* 113 (3d ed. 1988).

14. Proteins are essential for biological processes and are found in everything from the enzymes that break down food to muscle tissue. EMERY & MUELLER, *supra* note 12, at 19-22.

15. See EMERY & MUELLER, *supra* note 12, at 199; *MEDICAL GENETICS: PRINCIPLES AND PRACTICE* 353-54 (James J. Nora & F. Clarke Fraser eds., 2d ed. 1981).

16. John B. Stanbury et al., *Inborn Errors of Metabolism in the 1980s, in THE METABOLIC BASIS OF INHERITED DISEASE* 3, 9-10 (John B. Stanbury et al. eds., 5th ed. 1983); Friedrich Vogel, *Mutation in Man, in 1 PRINCIPLES AND PRACTICE OF MEDICAL GENETICS* 53, 53 (Alan E.H. Emery & David L. Rimoin eds., 2d ed. 1990) [hereinafter *PRINCIPLES AND PRACTICE*].

17. The severity of the disease depends on the role of the protein. Sickle cell anemia, for example, is caused by a mutation in the gene for hemoglobin, which is essential to the transport of oxygen throughout the body. The substituted DNA pattern causes the red blood cells to deform into a sickle shape, which can prevent normal circulation of blood throughout the system. Many people with sickle cell anemia suffer from pain crises, infection, serious health problems, and sometimes early death. See John A. Phillips III & Haig H. Kazazian, Jr., *Haemoglobinopathies and Thalassaemias, in 2 PRINCIPLES AND PRACTICE, supra* note 16, at 1315, 1324-25.

tion improperly.¹⁸ In other circumstances, a single nonworking gene causes disease, even when the homologous gene functions properly. The nonworking gene and the resulting disease are said to be dominant.¹⁹ A third type of single-gene, or *monogenic*, disease²⁰ is X-linked and generally only affects males. If a male carries a recessive disease gene on the X chromosome, he has no complementing gene on the Y chromosome to compensate. Consequently, he will develop the disease. A female who carries the same disease gene on one X chromosome will usually have a homologous, functional gene on the other X chromosome. As a result, she will be an unaffected carrier.

Everyone probably carries between three and nine deleterious or disease genes, most of which are recessive.²¹ Most people are unaware of the deleterious genes they carry because the genes can pass through a family for generations without manifesting as disease. A couple can have children with an autosomal recessive disease only if both parents are carriers for the same recessive disease gene.²² Even then, there is only a 25% chance that each child will be affected.²³ If one of the deleterious genes is dominant, the individual will generally know she is a carrier because the gene causes disease. The carrier's risk of passing the dominant gene to future offspring is 50%.²⁴ Some dominant genes, however, usually do not produce observable effects until late in life. Illnesses like Huntington's disease and adult polycystic kidney disease have long latency periods.²⁵ Those who carry such genes can, therefore, unwittingly pass them to their children, who will eventually develop the disease if they live long enough.

18. Rosalind Skinner, *Unifactorial Inheritance*, in 1 PRINCIPLES AND PRACTICE, *supra* note 16, at 95, 99. Autosomal genetic diseases involve mutations on the autosomal chromosomes — the first 22 pairs of chromosomes — as opposed to x-linked genetic diseases that involve mutations on the sex chromosomes. See *supra* note 12 and *infra* text accompanying notes 20-21.

19. *Id.* at 97.

20. Monogenic diseases, or single gene disorders, involve a single gene locus as opposed to polygenic diseases, which involve many gene loci. See *infra* note 31 and accompanying text.

21. The number is a rough estimate. Catherine J. Damme, *Controlling Genetic Disease Through Law*, 15 U.C. DAVIS L. REV. 801, 808 (1982); James R. Sorenson, *Some Social and Psychologic Issues in Genetic Screening: Public and Professional Adaptation to Biomedical Innovation*, in ETHICAL, SOCIAL AND LEGAL DIMENSIONS OF SCREENING FOR HUMAN GENETIC DISEASE 165, 178 (Daniel Bergsma ed., 1974) [hereinafter ETHICAL, SOCIAL AND LEGAL DIMENSIONS].

22. This presumes that no new mutations will occur in the sperm or egg cell.

23. On average, 50% of the offspring will be carriers and unaffected like the parents, 25% will be affected, and the remaining 25% will be completely free of the gene. These percentages, of course, reflect the odds every time a child is conceived. It is possible for individual families to have completely different percentages of affected, carrier, and noncarrier children.

24. This assumes that the carrier's partner is not a carrier for the same dominant mutation, which is generally the case. If, however, the partner carries the same dominant gene, there will be a 75% chance that the offspring will carry at least one of the dominant genes and only a 25% chance of having a child who will be free of the disease gene and the disease. It is quite rare, however, to find individuals who are *homozygous*, — that is, who carry two similar alleles or DNA patterns for a particular gene — for dominant disease genes. Skinner, *supra* note 18, at 97.

25. HARPER, *supra* note 13, at 22.

Monogenic diseases have been the most commonly studied diseases in classical, or "Mendelian,"²⁶ genetics. There are, however, other types of genetic disease.²⁷ The inheritance of extra or deficient amounts of chromosomal material results in the addition or loss of hundreds or thousands of genes.²⁸ The duplication or deletion of so many genes generally causes syndromes that adversely affect many systems of the body.²⁹ The most common chromosomal abnormality is trisomy 21, or Down's syndrome,³⁰ in which the affected person carries not two but three chromosome number 21s.³¹

B. Uniqueness of Genetic Data

The various types of genetic disease share common features that distinguish them from other diseases. First, there are significant differences between genetic and contagious diseases. Genetic disease is inherited and can only be vertically transmitted through generations. Contagious disease, however, can be horizontally transmitted within generations.³² That is, in genetics, the connections depend on biological relations between people; in contagious disease contexts, the impact on others is through some form of contact. In addition, the methods of control between the two types of disease differ. Contagious disease is controlled through isolation of the affected people or avoidance of whatever contact causes infection; genetic disease is con-

26. Mendel, a Moravian monk who lived in the 1800s, is considered the father of genetics for his work with the garden pea, which demonstrated recessive and dominant patterns of inheritance. See EMERY & MUELLER, *supra* note 12, at 2-6.

27. See Arno Motulsky, *The Significance of Genetic Disease*, in ETHICAL ISSUES IN HUMAN GENETICS: GENETIC COUNSELING AND THE USE OF GENETIC KNOWLEDGE 59, 59-60 (Bruce Hilton et al. eds., 1973). Motulsky considers a fourth category of genetic disease — immunologic materno-fetal incompatibility — which he notes physicians do not usually consider a genetic disease.

28. The 46 chromosomes carry a total of 50,000 - 100,000 pairs of genes. Victor A. McKusick, *Mapping and Sequencing the Human Genome*, in LEGAL AND ETHICAL ISSUES RAISED BY THE HUMAN GENOME PROJECT 2, 5 tbl. B (Mark A. Rothstein, ed., 1991) (proceedings of conference held in Houston, Tex., Mar. 7-9, 1991).

29. See EMERY & MUELLER, *supra* note 12, at 124-2; HARPER, *supra* note 13, at 49-62. More or less than the normal amount of genetic material can cause severe defects and health problems. See BERNICE L. MUIR, ESSENTIALS OF GENETICS FOR NURSES 195 (1983).

30. HARPER, *supra* note 13, at 53.

31. Another category of genetic disease includes polygenic and multifactorial diseases, such as diabetes, cancer, and hypertension. Polygenic diseases are caused by a combination of genes; multifactorial diseases result from a combination of genetic and environmental factors. See EMERY & MUELLER, *supra* note 12, at 199; Lee Ehrman & Marc Lappe, *Screening for Polygenic Disorders*, in ETHICAL, SOCIAL AND LEGAL DIMENSIONS, *supra* note 21, at 101; Motulsky, *supra* note 27, at 60.

32. Damme, *supra* note 21, at 814. Of course, a person from one generation can infect a person of another generation with a contagious disease; for example, a mother can give her daughter a cold and vice versa. The distinction indicates that while infectious diseases are spread to those who are alive at the same time, regardless of biological relationship, genetic disease can only be passed unidirectionally, from parent to child, not vice versa. Moreover, it cannot be passed within generations from sibling to sibling or cousin to cousin, for example.

trolled through reproductive decisions and actions.³³ In the future, genetic disease will also be controlled to some extent by gene therapy: replacing nonworking genes with functional genes.³⁴

Genetic data are also unique in how they may affect self-identity.³⁵ Empirical evidence shows that the knowledge or assumption that one carries certain disease genes can affect self-perception. Such evidence has important consequences for the management of genetic testing. Research on presymptomatic testing for Huntington's disease, for example, indicates that people who assume that they do or do not carry the gene develop notions about themselves and their role in the world, based on these assumptions.³⁶ Many are troubled by test results that contradict these assumptions and challenge their self-perceptions. Although researchers expected individuals to struggle with news that they carried the gene, it was surprising that 10% of the potential carriers experienced difficulty when they learned they did *not* carry the gene.³⁷

A particularly poignant example involved a woman who struggled with the new information that she had a very low risk of Huntington's. Because she had lived as though she would develop the disease, the knowledge of the low risk changed her self-perception, causing her to ask "If I'm not at risk — who am I?"³⁸ Follow-up counseling revealed that she

ha[d] derived much of her sense of identity through her close relationship with her older brother [who had Huntington's] and the expectation that she would develop [the] disease. She saw her role as both helping her brother and coping positively with [Huntington's]. When she was found to have a low risk . . . she was forced to reevaluate her identity and her role in the family³⁹

Not only does genetic knowledge potentially affect notions of identity, but its implications extend beyond the individual.⁴⁰ A person

33. *Id.* at 814.

34. Clifford Grobstein & Michael Flower, *Gene Therapy: Proceed with Caution*, HASTINGS CENTER REP., Apr. 1984, at 13, 13; Miller, *supra* note 4, at 455. For examples of progress being made in the area of gene therapy in animal models, see Stephen C. Hyde et al., *Correction of the Ion Transport Defect in Cystic Fibrosis Transgenic Mice by Gene Therapy*, 362 NATURE 250 (1993); Shoushu Jiao et al., *Long-Term Correction of Rat Model of Parkinson's Disease by Gene Therapy*, 362 NATURE 450 (1993).

35. Richard M. Glass, *AAAS Conference Explores Ethical Aspects of Large Pedigree Genetic Research*, 267 JAMA 2158 (1992). Knowing whether one carries a disease gene can affect the way one perceives oneself and one's relationship to family and the world. For a fuller discussion see *infra* note 249.

36. Marlene Huggins et al., *Predictive Testing for Huntington Disease in Canada: Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk*, 42 AM. J. MED. GENETICS 508, 508, 514-15 (1992).

37. *Id.* at 508.

38. *Id.* at 510.

39. *Id.* at 511.

40. Glass, *supra* note 35, at 2158.

with a genetic disease has a significant risk of passing the nonworking gene to future offspring. Further, genetic disease is usually caused by the inheritance of a familial disease gene.⁴¹ Therefore, whenever a disease gene is detected, there is a good probability that some siblings, parents, aunts, uncles, or other relatives may also carry the gene, particularly if it is recessive and lies unexpressed for many generations. This unique feature creates the legal and ethical dilemmas that this Note discusses.

C. Types of Genetic Testing and Their Limitations

In the past, most genetic diseases were detected through clinical diagnosis alone.⁴² Now, genetic screening can confirm or replace clinical diagnosis for many genetic diseases.⁴³ There are four different types of genetic testing,⁴⁴ depending on who is tested — and for what purpose. Carrier testing determines whether a healthy individual carries a disease gene.⁴⁵ People often use the information to ascertain the risks of having children with the disease.⁴⁶ Genetic counselors might offer such testing because of a patient's ethnic background⁴⁷ or family

41. There are, however, genetic syndromes in which a significant percentage of affected individuals carry a new mutation. That is, the disease gene does not pass through the family but arises as the result of a new mutation in either the sperm or egg cell. This phenomenon is most common in dominantly inherited syndromes, see Skinner, *supra* note 18, at 99, such as neurofibromatosis, see *infra* note 55, and achondroplasia (a particular form of dwarfism, in which the limbs are disproportionately short). See David L. Rimoïn & R.S. Lachman, *The Chondrodysplasias*, in 2 PRINCIPLES AND PRACTICE, *supra* note 16, at 895, 910-11 tbl. 56.1. 1990.

42. See C. Thomas Caskey, *Genetic Predisposition and the Human Genome Project: Case Illustrations of Clinical Problems: Presymptomatic Genetic Diagnosis — A Worry for the United States*, in GENE MAPPING, *supra* note 1, at 177, 178. For a nice summary of the way in which clinical diagnoses are made, see THADDEUS E. KELLY, CLINICAL GENETICS AND GENETIC COUNSELING 257-341 (2d ed. 1986).

43. See Caskey, *supra* note 42, at 178; Edward R.B. McCabe, *Genetic Screening for the Next Decade: Application of Present and New Technologies*, 64 YALE J. BIOLOGY & MED. 9, 9 (1991); McKusick, *supra* note 1, at 36-39.

44. See *Ethics, Law, and the Human Genome*, 256 SCIENCE 549 (1992) (discussing three types of genetic testing).

45. KELLY, *supra* note 42, at 74-75.

46. See *id.* at 250; Richard West, *Ethical Aspects of Genetic Disease and Genetic Counseling*, 14 J. MED. ETHICS 194, 194-95 (1988).

47. Certain ethnic groups, by virtue of sharing a greater percentage of genetic material, are more prone to carry particular disease genes. See generally KENNETH L. GARVER & SANDRA G. MARCHESE, GENETIC COUNSELING FOR CLINICIANS 60-68 (1986). People of African descent, for example, have a one in eight to twelve chance of carrying the gene for sickle cell anemia. HARPER, *supra* note 13, at 256; Phillips & Kazazian, *supra* note 17, at 1324. One in 25 to 30 people of Ashkenazi Jewish heritage carries a copy of the gene for Tay-Sachs, a progressive neurological disorder that usually strikes in infancy and results in death by the age of two to three years. Severe retardation develops into "dementia, blindness, paralysis, and death." MEDICAL GENETICS: PRINCIPLES AND PRACTICE, *supra* note 15, at 223; John S. O'Brien, *The Gangliosidoses*, in THE METABOLIC BASIS OF INHERITED DISEASE, *supra* note 16, at 945, 949 (John B. Stanbury et al. eds., 5th ed. 1983). It is thought that heterozygous carriers for some of these diseases may have had a selective advantage. Thus in Africa, where malaria is so widespread, heterozygous carriers of sickle cell anemia are better equipped to battle the disease. LUBERT STRYER, BIOCHEMISTRY 95-96 (2d ed. 1981). Some have theorized that Tay-Sachs carriers were

history of the disease. It also may involve presymptomatic or predictive testing when people at risk for late onset diseases, like Huntington's, are tested for the likelihood of carrying the gene.⁴⁸

Second, prenatal testing is used to determine whether a fetus will be affected with a genetic disease.⁴⁹ Prenatal testing is often performed after one or both parents have been identified as carriers. Couples do not always choose prenatal testing with a view to terminate an affected fetus. They may simply desire the information to prepare psychologically for either outcome or to help the obstetrician prepare for potential complications in delivery.⁵⁰ Often couples are tested without knowing what they will do if the fetus is affected.⁵¹ Regardless of the ultimate decision, prenatal testing directly influences reproductive decisions and care.

Related to prenatal testing is newborn screening. As the name suggests, this form of genetic testing is performed on neonates. State legislatures regulate such screening; different states require screening for different diseases in which environment plays a large role.⁵² Finally, the least common type of testing is for susceptibility to disease, such as alpha-1-antitrypsin deficiency.⁵³ Screening in this area will increase as scientists learn more about multifactorial diseases such as diabetes, cancer, and heart disease.

Genetic screening has weaknesses, however, some of which are re-

more resistant to tuberculosis, which ran rampant among many Ashkenazi Jews in urban settings. Lynn B. Jorde, *Genetic Diseases in the Ashkenazi Population: Evolutionary Considerations*, in *GENETIC DIVERSITY AMONG JEWS* 305, 313 (Batsheva Bonn -Tamir & Avinoam Adam eds., 1992). Selective advantage may not entirely explain why certain ethnic groups are more likely to share certain genetic diseases. It may simply be that the common ancestry has allowed a single mutation to pass "silently" through a multitude of generations because recessive genes remain unexpressed unless paired with another similar recessive gene. This mechanism is referred to as the *founder effect*. KELLY, *supra* note 42, at 76.

48. See generally Marguerite A. Chapman, *Canadian Experience with Predictive Testing for Huntington Disease: Lessons for Genetic Testing Centers and Policy Makers*, 42 *AM. J. MED. GENETICS* 491 (1992); see *infra* notes 66-70 and accompanying text.

49. KELLY, *supra* note 42, at 365-93.

50. Ray M. Antley, *Genetic Counseling for Parents of a Baby with Down's Syndrome*, in *GENETIC COUNSELING: PSYCHOLOGICAL DIMENSIONS* 115, 123 (Seymour Kessler ed., 1979) [hereinafter *PSYCHOLOGICAL DIMENSIONS*]; see also *infra* note 253.

51. Antley, *supra* note 50, at 123.

52. Commonly screened-for diseases include PKU and hypothyroidism, for which treatment is available. See *infra* note 309 and accompanying text. Many states also screen for sickle cell anemia, although there is no cure. The justification, however, is that antibiotic prophylactic treatment can be given at a young age to help battle the recurrent infections to which children with sickle cell are prone. PUBLIC HEALTH SERV., U.S. DEPT. OF HEALTH & HUM. SERVS., *MANAGEMENT AND THERAPY OF SICKLE CELL DISEASE 1* (Samuel Charache et al. eds., 1984); McCabe, *supra* note 43, at 10.

53. Individuals with alpha-1-antitrypsin deficiency are especially prone to emphysema. Smoking and certain work environments exacerbate this risk. Andrews & Jaeger, *supra* note 7, at 76; P. Michael Conneally, *The Genome Project and Confidentiality in the Clinical Setting*, in *LEGAL AND ETHICAL ISSUES RAISED BY THE HUMAN GENOME PROJECT*, *supra* note 28, at 184, 188.

lated to the distinctive features of genetic data and the limits of technology. There is often uncertainty regarding how a disease will manifest because there can be great variability in gene expression. Some genetic diseases, like Tay-Sachs, have characteristic etiologies.⁵⁴ Others range in severity. Prenatal studies indicating a fetus has neurofibromatosis, for example, cannot determine how severely the fetus will be affected.⁵⁵

Genetic testing can become complicated when it is impossible to identify directly the gene or its product. Although some disease genes are detected by a single test on the proband,⁵⁶ testing for many genetic diseases requires linkage analysis: tracing DNA regions, or markers, near the disease locus to determine whether the same marker pattern in an affected family member is present in the proband.⁵⁷ Often affected individuals in one family will have different marker patterns from those in affected individuals in other families. The marker associated with the disease gene in a family is used to identify other carriers in the family.⁵⁸ This indirect method of testing only provides statistical probabilities that one does or does not carry the gene, leaving results uncertain.⁵⁹

54. See *supra* note 47.

55. Current genetic technology cannot always predict when, or to what extent, genetic disease will manifest. Neurofibromatosis is an autosomal dominant disease with great variability in expression. It can cause severe cosmetic deformity and serious medical problems, such as intracranial tumors, bone deformities, and neurofibromas (tumors of the nerve sheath) that develop into malignancies. In contrast, many people with the disease only develop café-au-lait spots (light brown pigmentation), nonmalignant neurofibromas, mild learning disabilities, or some combination thereof. See MEDICAL GENETICS: PRINCIPLES AND PRACTICE, *supra* note 15, at 173; Skinner, *supra* note 18, at 98.

56. Sickle cell anemia, PKU, and Tay Sachs are examples of genetic diseases for which carriers can be identified on the basis of a single test in some families. The number of such diseases increases as scientists identify more mutations that cause disease. Cf. *infra* note 68, 70.

57. This method has been used to detect the Huntington's gene, adult polycystic kidney disease, and breast cancer, among other disease genes. See James F. Gusella et al., *A Polymorphic DNA Marker Genetically Linked to Huntington's Disease*, 306 NATURE 234 (1983); Jeff M. Hall et al., *Linkage of Early-Onset Familial Breast Cancer to Chromosome 17q21*, 250 SCIENCE 1684 (1990); Stephen T. Reeders et al., *A Highly Polymorphic DNA Marker Linked to Adult Polycystic Kidney Disease on Chromosome 16*, 317 NATURE 542 (1985); Stephen T. Reeders et al., *Regional Localization of the Autosomal Dominant Polycystic Kidney Disease Locus*, 3 GENOMICS 150 (1988); Leslie Roberts, *Zeroing In on a Breast Cancer Susceptibility Gene*, 259 SCIENCE 622 (1993).

58. Linkage studies are not useful for families when the marker patterns among different family members are indistinguishable and therefore uninformative.

59. Cf. *Ethics, Law, and the Human Genome*, *supra* note 44. The proband may inherit the DNA marker pattern associated with the disease gene in her family. Because of biological *crossing-over*, however, the proband may have received a chromosome from one parent in which the marker associated with the disease gene switched with the marker on the homologous chromosome. See MUIR, *supra* note 29, at 13-14; Jean-Marc Lalouel & Ray L. White, *Analysis of Genetic Linkage*, in 1 PRINCIPLES AND PRACTICE, *supra* note 16, at 149, 149-152. Consequently, the marker is no longer linked to the disease gene and its presence is erroneously interpreted as indicating that the proband has the disease gene. Unless the actual gene is sequenced to identify the mutation, it is virtually impossible to determine if crossing-over occurred. For example, because crossing-over between the D16S63 marker and the adult polycystic kidney gene occurs

Even for some diseases whose genetic bases have been identified, the study of an affected relative's DNA may be useful in determining which particular mutation exists in the family. If such a study is uninformative, linkage analysis may be required.⁶⁰ The necessary involvement of certain family members in these instances can create some of the conflicts this Note discusses.

D. *Competing Interests in the Context of Genetic Testing*

Potential competing interests of family members further complicate the process of genetic screening when linkage analysis or family studies are required. In these cases, one person's test results necessarily have an impact on other family members; thus the genetic data of one relative are of great consequence to other relatives. Beyond the simple logistical problems in coordinating various family members to perform and explain linkage analysis and its implications, psychological and interpersonal repercussions arise. Four hypotheticals illustrate the conflicting interests.

1. *Sarah's Case*

Imagine Sarah, whose brother and maternal uncle have X-linked Duchenne's muscular dystrophy (DMD). Based on her family history, she has a 50% chance of being a carrier for the disease.⁶¹ In planning for future pregnancies or once she becomes pregnant, Sarah may decide she wants to learn whether she carries the disease gene. If she does, she has a one in two chance of having an affected son.⁶² To

four percent of the time, test results using this marker will be only 96% certain. Four percent of the time it will appear that a person does not carry the gene, even though she actually does carry it, or vice versa. G.G. Germino et al., *Identification of a Locus Which Shows No Genetic Recombination with the Autosomal Dominant Polycystic Kidney Disease Gene on Chromosome 16*, 46 AM. J. HUM. GENETICS 925, 926 (1990). The use of more than one marker, however, can increase the probability of accuracy through linkage studies. See Kathy A. Hodgkinson et al., *Adult Polycystic Kidney Disease: Knowledge, Experience, and Attitudes to Prenatal Diagnosis*, 27 J. MED. GENETICS 552, 552-53 (1990). Testing for polycystic kidney disease is further complicated by the fact that 4% of affected families do not appear to carry the gene that lies on chromosome 16. In other words, there may be a second gene in another part of the genome causing the disease. Patrick S. Parfey, *The Diagnosis and Prognosis of Autosomal Dominant Polycystic Kidney Disease*, 323 NEW ENG. J. MED. 1085, 1085 (1990).

60. Cystic fibrosis is an example of such a disease. Although the gene was discovered several years ago, see *infra* note 202, some families do not have any of the identified mutations. In those cases, linkage analysis can be used. See also *infra* notes 63-64 and accompanying text.

61. The odds are virtually 100% that her mother is a carrier, that is, that one of her X chromosomes has the disease gene. Consequently, Sarah has a 50% chance of having inherited the X-chromosome with the DMD gene from her mother; her other X chromosome came from her father, who does not carry the gene.

62. On average, 50% of her children would be sons, 50% of whom would be affected because they would receive from her the X chromosome that carries the disease gene; the other 50% of her children would be unaffected daughters (although 50% of them would be carriers), assuming the father does not carry the gene. Therefore, of all possible combinations, 25% (or one in four) of her children would be affected males.

determine Sarah's risks, the ideal approach is to study her brother's DNA to identify his mutation.⁶³ If, as is sometimes the case, his mutation is not detectable, a single test on Sarah would be inconclusive.⁶⁴ In that situation, it would be necessary to resort to linkage studies, which would involve her mother, father, and uncle.

Asking Sarah's brother to undergo testing may raise difficulties. Depending on what her reproductive decisions would be, her brother may feel offended or hurt that she would consider terminating a pregnancy with an affected fetus. The existence of such an option implicitly suggests he might not have been born had such testing been available during his mother's pregnancy.⁶⁵

2. Bob's Case

Complexities multiply when the family members required for genetic studies do not yet know if they carry the gene in question. Such scenarios are most likely to arise with diseases that present late in life, such as Huntington's disease, polycystic kidney disease, or familial breast cancer. Huntington's disease creates particular difficulties. In addition to the physical deterioration it induces, psychological disturbances and mental decline⁶⁶ increase the anxiety of genetic testing because of the potential knowledge that both health and mental well-being may be lost.⁶⁷ The need to use linkage analysis further complicates Huntington's testing because it only provides probabilities of carrier status⁶⁸ and therefore increases uneasiness.

63. If the brother cannot or will not participate, studies on Sarah are likely to be inconclusive. If testing reveals no detectable mutation, this does not mean that she does not carry the gene. It is possible that the gene in her family is not detectable without linkage analysis.

64. The absence of a mutation in this case could mean that Sarah did not carry the disease gene or that she carried the gene, but, as with her brother, it cannot be detected.

65. This Note's author confronted this situation in providing genetic counseling for a woman whose brother had DMD, and who participated in both the counseling and genetic testing.

66. The disease causes progressive motor abnormalities, mental impairment, and often chorea. Gusella et al., *supra* note 57, at 234.

67. See, generally, Maurice Bloch et al., *Predictive Testing for Huntington Disease in Canada: The Experience of Those Receiving an Increased Risk*, 42 AM. J. MED. GENETICS 499 (1992); Chapman, *supra* note 48, at 491; Huggins et al., *supra* note 36, at 508.

68. See *supra* note 59 and accompanying text. Just before publication of this Note, after a frustrating ten-year struggle, scientists discovered the gene for Huntington's. The Huntington's Disease Collaborative Research Group, *A Novel Gene Containing Trinucleotide Repeat That is Expanded and Unstable on Huntington's Disease Chromosomes*, 72 CELL 971 (1993); Natalie Angier, *Team Pinpoints Genetic Cause of Huntington's*, N.Y. TIMES, Mar. 24, 1993, at A1. The implications of this discovery are not yet certain. The isolated gene carries a repeated sequence of DNA — a polymorphic trinucleotide repeat — that varies in length. Initial studies suggest that the length of the repeat is inversely correlated with the age of onset; that is, shorter repeats are associated with later ages of onset. The Huntington's Disease Collaborative Research Group, *supra*, at 972. The research also suggests that if the repeat length is greater than or equal to a certain threshold level, an individual has the disease gene. See *id.* at 976. More detailed studies will be necessary before the repeat sequence can be used for the prognosis of at-risk individuals, although it is expected that the new discovery will eliminate the need to use linkage analysis for Huntington's. *Id.* at 980. Until that time, however, linkage analysis will still be required for

All of these factors make genetic testing more complex than many other medical tests. Imagine Bob, whose paternal grandfather has been diagnosed with Huntington's. Without additional information, Bob has a 25% chance of carrying the gene and eventually developing symptoms.⁶⁹ If Bob wants to determine whether he has the gene, either to plan a family or to make other major life decisions, he will need to involve his grandfather and father in genetic studies.⁷⁰ Many people at risk for Huntington's, however, do not want to know whether they have the gene,⁷¹ especially because there is no cure. Consequently, Bob's father might be unwilling to participate in a family study.⁷² The situation creates a clear conflict of interests and demonstrates how genetic data affect persons other than the proband. Situations such as Bob's raise the issue of whose interest should prevail and whether the law should compel genetic screening for the benefit of another: that is, whether Bob's father should be required to undergo testing so that Bob can make reproductive or other decisions.

3. *Mary's Case*

A related issue involving disclosure arises once an individual has

Huntington's families. When linkage analysis becomes unnecessary for the identification of the Huntington's gene, family studies may sometimes be necessary to compare the repeat lengths of various family members. Even if the need to involve family members becomes obsolete for Huntington's testing, linkage analysis or other studies that require the testing of family members remain necessary for the testing of a number of other genetic diseases, such as adult polycystic kidney disease and familial breast cancer. *See supra* notes 57 & 59 and accompanying text.

69. Bob's father has a 50% chance of having inherited the gene from his father. If he did, there would have been a 50% chance of passing the gene to Bob. In total, Bob's risk is 25% because the probabilities are multiplied. Of course, after testing, Bob will face a dramatically higher or lower risk depending on the result of linkage studies.

70. If linkage studies are necessary for Bob, it might also be necessary to test his mother to help determine which chromosomes Bob inherited from each parent. *See* Conneally, *supra* note 53, at 193-94. Linkage analysis has been used, and may continue to be used for some families, for presymptomatic Huntington's testing. *See supra* note 68. Because so many studies have addressed the issues regarding genetic testing generally, and presymptomatic testing in particular, in the Huntington's context, *see, e.g., supra* text accompanying notes 36-39, *infra* note 71 and accompanying text, Huntington's provides the best illustration of the complexities that often arise with genetic testing. Consequently, despite the discovery of the Huntington's gene and the possibility that, in the foreseeable future, Huntington's may no longer present the problems described in this Note, the Huntington's example remains the best way to illustrate the issues this Note discusses. Therefore, this Note is written as if linkage analysis were still necessary for Bob to learn whether he has Huntington's. These issues apply equally well to genetic testing for diseases such as adult polycystic kidney disease and breast cancer. *See supra* note 68.

71. Before linkage studies were available, 70% of people at risk for Huntington's stated that they would use predictive testing. Yet, once the test became available, only 13% took advantage of it. Conneally, *supra* note 53, at 193.

72. Linkage analysis would require determining the Huntington's status of Bob's father, even before Bob's is determined. Even if the test results were not revealed to his father, it is likely that on the basis of decisions that Bob did or did not make, his father could infer whether Bob was a likely carrier or noncarrier. If Bob were a carrier, his father would necessarily also be a carrier. If Bob were not a carrier, however, his father may or may not be a carrier. Bob might not be a carrier either because his father did not pass the gene to Bob or because his father did not have the gene in the first place.

been tested. Suppose that Mary has a daughter with primary amenorrhea, meaning that she has not begun her menstrual cycle. Tests indicate her daughter has complete testicular feminization, a syndrome in which a female with normal external female genitalia has a 46,XY karyotype, the male pattern of chromosomes, rather than the female 46,XX karyotype. As a result, the internal genitalia are absent with the exception of undescended testes, which can become malignant if not removed.⁷³ Females with testicular feminization syndrome (TFS) are genetically male and cannot reproduce. Yet, because there is complete resistance to testosterone, they develop as females in outward appearance.⁷⁴ The pattern of inheritance is X-linked recessive. Therefore, Mary is a likely carrier of the TFS gene.⁷⁵ If the gene had passed silently through the family and was inherited by Mary, who would be a carrier, there is a 50% chance that her daughters and sisters without the syndrome are also carriers with a 25% chance of having an afflicted child.⁷⁶ Because of the social stigma associated with this syndrome,⁷⁷ Mary may refuse to inform her sisters of the risk to their daughters, even though removal of inguinal testes could prevent malignancies. Some might argue that Mary has a moral or legal duty to inform her sisters, the nieces who are potentially affected, and more distant relatives of their genetic risks. In addition, the genetic counselor or physician faces the dilemma of possible conflicting duties. In such cases, a duty to maintain patient confidentiality may clash with a duty to protect third parties, namely, the at-risk relatives.⁷⁸

4. Jane's Case

The issues raised by testicular feminization overlap with those presented by genetic diseases that carry less social stigma but that have more serious medical consequences. Many genetic diseases fall into this category. Consider Jane, for example, who is found to have a balanced chromosomal rearrangement⁷⁹ after having had multiple miscarriages and a child with severe and multiple birth defects. She is

73. Joe L. Simpson, *Disorders of Gonads and Internal Reproductive Ducts*, in 2 PRINCIPLES AND PRACTICE, *supra* note 16, at 1593, 1601.

74. *See id.*

75. An exception would occur if a new mutation in Mary's daughter caused the syndrome. In that case, Mary would not be a carrier.

76. The 25% risk is based on the 50% probability of a carrier passing the gene to a child, multiplied by a 50% risk that the child will have an 46,XY karyotype and will therefore be affected. *See supra* note 62 for more details regarding the inheritance of X-linked disorders.

77. *See infra* note 154.

78. *See infra* Part II.

79. A chromosomal rearrangement occurs when part or all of a chromosome trades positions with part or all of another chromosome. A balanced rearrangement results in no loss or gain of chromosomal material. Conversely, an unbalanced rearrangement causes the individual to have an excessive amount of some chromosomal material, a paucity of some chromosomal material, or both. *See HARPER, supra* note 13, at 56-69.

healthy because she has the proper *amount* of genetic material, but her chromosomes are rearranged in such a way that her offspring may inherit excessive quantities of some chromosomal material, deficient quantities of other chromosomal material, or both, resulting in miscarriage, stillbirth, or severe and multiple birth defects.⁸⁰ Chromosomal rearrangements or translocations can arise *de novo* — as a new event — or be inherited.⁸¹

Jane's relatives are therefore potentially at risk for carrying the rearrangement and having children with severe and multiple birth defects. Relatives who learn they have the rearrangement may wish to receive genetic counseling to explore their reproductive options. One alternative is prenatal testing, with the option to terminate pregnancies in which the fetus has an unbalanced rearrangement.⁸² Others are ovum or sperm donation, adoption, or acceptance of the risks.⁸³ In other families, the genes for single gene disorders may be found unexpectedly, though siblings and more distant relatives are completely unaware of their potential risks.⁸⁴ These cases raise questions regarding the duties of the identified carrier and health care professionals to relatives who have no knowledge of their genetic risk.

Relatives may want the information not just for reproductive decisions, but also for other major choices, such as whether to get married or what career to choose. These decisions are more likely to be influenced by finding out whether one carries a dominant gene for a late-onset disease, as opposed to a recessive disease gene. Someone at risk for Huntington's, myotonic dystrophy, or other genetic diseases affecting neurological function might avoid professions that require honed motor skills such as neurosurgery or aviation. More importantly, genetic information can sometimes give one the opportunity to use preventive measures to lessen or prevent morbidity or mortality, even when no cure is available.⁸⁵ If a child carries the gene for retinoblastoma, he has a 95% chance of developing cancer of the eye by the age of five. Regular examinations every four to six weeks, however, allow

80. See *id.*; MUIR, *supra* note 29, at 195. One can have both an excessive amount of material with respect to one chromosome and a deficient amount of material with respect to another chromosome.

81. See Stanbury et al., *supra* note 16, at 13.

82. See *supra* notes 79-80 and accompanying text.

83. KELLY, *supra* note 42, at 353-55; Y. Edward Hsia & Kurt Hirschhorn, *Response to Genetic Counseling*, in COUNSELING IN GENETICS, *supra*, at 267, 270; Y. Edward Hsia & Kurt Hirschhorn, *What is Genetic Counseling?*, in COUNSELING IN GENETICS 1, 18 (Y. Edward Hsia et al. eds., 1979).

84. Many genetic diseases such as Tay-Sachs and sickle cell anemia are known to be most common among certain ethnic groups. See *supra* note 47. Geneticists would offer appropriate genetic testing for individuals in the relevant ethnic groups even when there is no family history of the disease. There are instances, however, when a disease gene is identified in an individual who had no prior indication of risk factors.

85. The availability of such measures, however, is by no means the norm for genetic diseases yet.

physicians to detect and successfully treat lesions, which can bring survival close to 100%.⁸⁶ Thus relatives can avoid an untimely death by discovering their risks and using preventive measures.

Genetic testing, as evidenced by the scenarios above, poses special problems with regard to who has a right to genetic information. Individual interests can conflict: the desire to know versus the desire not to know, and the right to confidentiality versus the right to be warned. Conflicts need not necessarily arise, however.⁸⁷ If Bob's father were willing to be tested or if Mary and Jane informed their at-risk relatives, such issues would never develop. When family interests clash, however, these cases raise significant issues. This Note explores how the legal system should resolve such conflicts by asking two related questions. First, should test results be released to those who are potentially at risk and who can benefit from the information, as in Mary's and Jane's cases? Second, should the law ever compel testing for the benefit of another, as in Bob's case?

II. DISCLOSURE OF GENETIC TEST RESULTS

This Part addresses whether and, under what circumstances, there is a legal right or ethical obligation to disclose genetic test results to a relative when individuals have already undergone genetic testing.⁸⁸ These individuals have decided they want to know whether they carry a disease gene or chromosomal translocation, or they have learned that they are likely carriers because they have affected children. Such situations present a conflict between one's right to confidentiality in the ethically and legally protected patient-physician relationship and the physician's legal duty to warn certain third parties of known risks.

These conflicts arise, for example, when Mary finds out that her daughter has complete testicular feminization syndrome or when Jane discovers she has a chromosomal rearrangement that can be inherited in such a way that the offspring has severe birth defects and mental impairment.⁸⁹ In both cases, family members are at risk, either for

86. Leslie Roberts, *Testing for Cancer Risk: Tough Questions Ahead*, 253 SCIENCE 614 (1991). Similarly, prophylactic colectomies can be performed on individuals who have a history of Gardner's syndrome, an autosomal dominant precancerous syndrome, if they have clinical features of the disease and polyposis of the colon. H.T. Lynch et al., *Genetic Counseling and Cancer*, in PSYCHOLOGICAL DIMENSIONS, *supra* note 50, at 221, 233-34.

87. In fact, in the experience of this Note's author, conflicts are far rarer than familial cooperation.

88. This Part is primarily concerned with the situation in which an individual has already learned whether she carries a particular disease gene. It should be recognized that a patient's interests in nondisclosure also arise when mandatory testing is at issue because such testing would not be useful unless the results were disclosed. Compulsory testing, however, also involves significant interests of personal identity and bodily integrity above and beyond a patient's interests in avoiding disclosure of information already in existence and known to the patient. Part III, *infra*, discusses these interests.

89. See *supra* subsections I.D.3 and I.D.4. Such conflict may also arise when one is diag-

being affected with the syndrome, like Mary's sister's daughters, or for having children with serious health problems, like Jane's siblings and cousins. Informing the family members of their risks would allow them to decide whether to have genetic testing.

This Part analyzes what legal duties the physician or genetic counselor owes to the family members and what legal duties Mary and Jane have to their family. Section II.A examines the conflicting common law duties a physician has both to protect patient confidentiality and to inform third parties at risk. Section II.B considers how the balance-of-interests approach adopted by courts applies to genetic testing. It concludes that, while physicians and genetic counselors should sometimes have a privilege to warn, they should never have a duty to do so. Finally, section II.C argues that, while an individual has a moral duty to inform at-risk relatives, no such legal duty exists.

A. *The Physician's Conflicting Duties*

The conflict between the physician's legal duties to preserve confidentiality and to warn third parties is not new. Courts, scholars, and medical practitioners have addressed these issues with regard to contagious diseases including, most recently, AIDS.⁹⁰ The conflicting duties arise from ethical standards within the medical profession, the common law, and statutory requirements in some states. This section explores the ethical and legal grounds justifying the legal duty to preserve confidentiality. It considers the limits of this duty — when the duty to protect third parties creates a privilege to breach confidentiality in good faith. Finally, it examines cases in which courts have found not just a privilege, but a legal duty, to warn.

1. *Duties to Preserve Confidentiality*

The legal duty to preserve confidentiality emerges from a long history of ethical and legal principles. This section explores the ethical and legal origins of this legal duty. In addition, it argues that the duty

nosed with a genetic disease, but in this case, the diagnosis is harder to keep hidden from relatives than the finding that one is an asymptomatic or presymptomatic carrier.

90. See, e.g., Bruce A. McDonald, *Ethical Problems for Physicians Raised by AIDS and HIV Infection: Conflicting Legal Obligations of Confidentiality and Disclosure*, 22 U.C. DAVIS L. REV. 557; David P.T. Price, *Between Scylla and Charybdis: Charting a Course to Reconcile the Duty of Confidentiality and the Duty to Warn in the AIDS Context*, 94 DICK. L. REV. 435 (1990); Michael B. McVickar, Note, *To Disclose or Not To Disclose the Presence of AIDS: Resolving the Confidentiality Concerns of Patients, Physicians, and Third Parties*, 23 VAL. U. L. REV. 341 (1989); Joseph D. Piorkowski, Jr., Note, *Between a Rock and a Hard Place: AIDS and the Conflicting Physician's Duties of Preventing Disease Transmission and Safeguarding Confidentiality*, 76 GEO. L.J. 169 (1987); Jill S. Talbot, Note, *The Conflict Between a Doctor's Duty to Warn a Patient's Sexual Partner that the Patient Has AIDS and a Doctor's Duty to Maintain Patient Confidentiality*, 45 WASH. & LEE L. REV. 355 (1988); Charles D. Weiss, Comment, *AIDS: Balancing the Physician's Duty to Warn and Confidentiality Concerns*, 38 EMORY L.J. 279 (1989).

is not absolute; sometimes important concerns override the duty and create a privilege to reveal otherwise confidential information.

a. *Ethical Duty To Preserve Confidentiality.* The ethical duty to maintain confidentiality in the physician-patient relationship extends as far back as the Hippocratic Oath.⁹¹ Under this oath a physician promises not to divulge whatever “ought not to be spoken of abroad.”⁹² The American Medical Association reinforces this moral obligation by prohibiting physicians from revealing patient information unless “required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community.”⁹³ Thus there is an ethical duty for physicians not to disclose information obtained in their capacity as medical professionals.

b. *Legal Duty To Preserve Confidentiality.* Although some courts fail to recognize any legal duty to preserve patient confidentiality,⁹⁴ most states require physicians to maintain patient confidentiality under a number of theories.⁹⁵ Courts do not rely on the ethical duty alone as a basis for finding a corresponding legal duty, although such principles inform many courts’ reasoning.⁹⁶ One basis of a legal obligation evolves from statutes relating to testimonial privileges or licensing requirements.⁹⁷ Among the earliest cases to apply such principles is *Simonsen v. Swenson*.⁹⁸ The Nebraska Supreme Court derived a legal duty from a licensing statute, which authorized the revocation of medical licenses when a physician “betray[ed] . . . a professional secret to the detriment of a patient.”⁹⁹ The court viewed this statute as

91. Harold P. Green & Alexander M. Capron, *Issues of Law and Public Policy in Genetic Screening*, in *ETHICAL, SOCIAL AND LEGAL DIMENSIONS*, *supra* note 21, at 57, 62; McVickar, *supra* note 90, at 348; Weiss, *supra* note 90, at 286.

92. Oath of Hippocrates, 400 B.C., *quoted in* *Horne v. Patton*, 287 So. 2d 824, 829 (Ala. 1973) (plurality opinion), and *quoted in* *Hague v. Williams*, 181 A.2d 345, 347 (N.J. 1962).

93. AMERICAN MEDICAL ASSN., *PRINCIPLES OF MEDICAL ETHICS* § 9 (1957), *quoted in* *Horne*, 287 So. 2d at 829, and *quoted in* *Hague*, 181 A.2d at 347.

94. In *Collins v. Howard*, 156 F. Supp. 322 (S.D. Ga. 1957), the United States District Court did not find such a duty under statutory or common law in Georgia. Consequently, the physician’s and hospital’s disclosure of the plaintiff’s blood test results to the plaintiff’s employer was not grounds for recovery. Applying similar reasoning, the Supreme Court of Tennessee found that there was neither common law nor statutory protection of patient confidentiality in the doctor-patient relationship. *Quarles v. Sutherland*, 389 S.W.2d 249 (Tenn. 1965). Therefore, the physician breached no duty in disclosing the patient’s medical information to the store where the patient was injured and against whom the patient brought suit.

95. *See infra* text accompanying notes 96-108.

96. *See, e.g.,* *Horne v. Patton*, 287 So. 2d at 828-29 (plurality opinion); *Hague v. Williams* 181 A.2d at 345; *Clark v. Geraci*, 208 N.Y.S.2d 564 (Sup. Ct. 1960).

97. *Munzer v. Blaisdell*, 49 N.Y.S.2d 915 (Sup. Ct. 1944) *affd. mem.*, 58 N.Y.S.2d 359 (App. Div. 1945); *Humphers v. First Interstate Bank*, 696 P.2d 527, 534-35 (Or. 1985).

98. 177 N.W. 831 (Neb. 1920) (per curiam).

99. 177 N.W. at 832 (quoting NEB. REV. STAT. § 2721 (1913)).

evidence of a public policy interest in treating the patient-physician relationship as highly confidential.

Even when a state has no such statute, courts have found a legal basis to protect patient confidentiality. Some courts apply implied contract theory to find liability for breach of confidentiality.¹⁰⁰ Still others find more than a contractual relationship between the patient and physician. The Supreme Court of Oregon, in *Humphers v. First Interstate Bank*,¹⁰¹ held the physician to a nonconsensual duty of confidentiality, which "is determined by standards outside the tort claim for its breach."¹⁰²

Courts disagree, however, whether the duty not to disclose can be based on a tort claim for invasion of privacy.¹⁰³ One court asserted that "the preservation of the patient's privacy is no mere ethical duty upon the part of the doctor; there is a legal duty as well."¹⁰⁴ Another court distinguished between secrets and confidentiality.¹⁰⁵ Thus one who divulges information "without an obligation of secrecy" commits no tort.¹⁰⁶ Because the patient-physician relationship is founded on confidentiality, however, the court imposed a duty to protect information obtained through the relationship.¹⁰⁷

Consequently, where states have licensing or testimonial privilege statutes, courts can easily find that the statutes express a policy of protecting patient-physician confidentiality. In the absence of such laws, theories of implied contract and the confidential or fiduciary nature of the relationship¹⁰⁸ generally suffice to impose a duty to protect patient information.

c. *Privilege To Disclose.* Virtually all courts that impose a duty to preserve patient confidentiality describe it as nonabsolute.¹⁰⁹ One

100. The Supreme Court of Alabama, in *Horne v. Patton*, 287 So. 2d 824 (Ala. 1973), identified an implied contractual duty not to disclose patient information as one of several legal justifications for protecting patient confidentiality. 287 So. 2d at 831-32 (plurality opinion); see also *Doe v. Roe*, 400 N.Y.S.2d 668 (Sup. Ct. 1977).

101. 696 P.2d 527 (Or. 1985).

102. 696 P.2d at 535.

103. See Judy E. Zelin, Annotation, *Physician's Tort Liability for Unauthorized Disclosure of Confidential Information About Patient*, 48 A.L.R.4th 668, 681-83 (1986 & Supp. 1992).

104. *Hammonds v. Aetna Casualty & Sur. Co.*, 243 F. Supp. 793, 801-02 (N.D. Ohio 1965).

105. *Humphers*, 696 P.2d at 528.

106. 696 P.2d at 533.

107. 696 P.2d at 535.

108. See *Hammonds v. Aetna Casualty & Sur. Co.*, 237 F. Supp. 96, 102 (N.D. Ohio 1965) ("[P]hysician-patient relationship is a fiduciary one," which requires the physician to protect the patient's divulgences.); *Alexander v. Knight*, 177 A.2d 142, 146 (Pa. Super. Ct. 1962) (per curiam) ("[M]embers of a profession, especially the medical profession, stand in a confidential or fiduciary capacity as to their patients."); *Berry v. Moench*, 331 P.2d 814, 817 (Utah 1958) (The doctor-patient relationship "is among those with respect to which it is the policy of the law to encourage confidence.").

109. The Supreme Court of Alabama notes that the "duty is subject to exceptions prompted

of the most common justifications for a privilege to disclose is to protect public health. The *Simonsen* court found that physicians have a "positive duty" to protect the privacy of their patients. It reasoned, however, that physicians should not be liable for disclosing information when "necessary to prevent the spread of . . . disease," even if there is no "express legal enactment" imposing a duty to report.¹¹⁰ Therefore, when the patient failed to leave a hotel after the doctor urged him to do so for the well-being of other guests, the physician was not liable for informing the hotel's proprietress of the patient's infectious, syphilitic state. The physician was immune from liability for disclosure because he acted in good faith, without malice, and did not disclose more information than was necessary.¹¹¹

Courts have also upheld disclosure to certain family members. A Louisiana court in the 1960s supported disclosure of patient information to a husband, reasoning that he, as head of the household, had a right to his wife's medical information, even though the couple lived apart.¹¹² The Supreme Court of Utah, in *Berry v. Moench*,¹¹³ extended the privilege to disclose to potential spouses. It argued that "the responsibility of the doctor to keep confidence may be outweighed by a higher duty to give out information, even though defamatory, if there is a sufficiently important interest to protect."¹¹⁴ The court did not define the limits of this privilege but noted it might apply "[w]here life, safety, well-being or other important interest is in jeopardy."¹¹⁵ Consequently, the court remanded to determine whether the physician intentionally stated a falsehood without legal justification by informing the family of the patient's fiancée that he believed the patient was mentally ill.¹¹⁶ The ruling implies that the well-being of one's fiancée may justify disclosure of patient information, as long as the doctor makes a "good faith" effort to ensure that the disclosure is truthful and to di-

by the supervening interests of society, as well as the private interests of the patient himself." *Horne v. Patton*, 287 So. 2d 824, 830 (Ala. 1973) (plurality opinion). The New Jersey Supreme Court defines the patient right to confidentiality with almost identical language, adding only that exceptions apply when "the public interest . . . so demands." *Hague v. Williams*, 181 A.2d 345, 349 (N.J. 1962). The Supreme Court of Oregon, stressing similar principles, argues that "there may be a privilege to disclose information for the safety of individuals or important to the public in matters of public interest." *Humphers*, 696 P.2d at 535 (citing *Alan v. Vickery*, Note, *Breach of Confidence: An Emerging Tort*, 82 COLUM. L. REV. 1426, 1462-68 (1982)).

110. *Simonsen v. Swenson*, 177 N.W. 831, 832 (Neb. 1920) (per curiam).

111. 177 N.W. at 833.

112. *Pennison v. Provident Life & Accident Ins. Co.*, 154 So. 2d 617 (La. Ct. App.), cert. denied, 156 So. 2d 226 (La. 1963). Courts have even justified disclosure of information expected to be used in affidavits for divorce proceedings under the theory that there is a privilege to disclose medical information to spouses, or at least husbands. *Curry v. Corn*, 277 N.Y.S.2d 470 (Sup. Ct. 1966) (mem.).

113. 331 P.2d 814 (Utah 1958).

114. 331 P.2d at 817.

115. 331 P.2d at 817.

116. 331 P.2d at 820-21.

vulge only what is necessary to those who need the information.¹¹⁷ Based on these decisions, courts might find there is a privilege to warn when harm can be prevented, even if the harm does not involve life or death.

2. Duty to Warn

The recognition that physicians may be immune from liability for disclosure is related to, but distinct from, the duty to warn. The latter duty first arose in the contagious disease context without confronting the duty to preserve confidentiality. In *Skillings v. Allen*,¹¹⁸ the Minnesota Supreme Court found that a physician who treated a girl for scarlet fever had a special duty to advise her parents of the risks they faced in caring for their infectious daughter.¹¹⁹ Similarly, in Arkansas, physicians who treated patients for typhoid fever failed to advise third parties that typhoid is infectious and neglected to tell them how to avoid contracting the disease. The Supreme Court of Arkansas consequently found that the physicians breached their duty to the third parties "who [were] ignorant of such disease, and who . . . [were] liable to be brought in contact with the patient."¹²⁰ These cases follow earlier decisions imposing liability on physicians for failing to warn third parties of their risks of contracting contagious diseases.¹²¹

Because the plaintiffs knew the patients were ill, these cases do not involve the dilemma in which a physician must breach confidentiality in order to warn. *Tarasoff v. Regents of the University of California*,¹²² however, dealt with this issue when it extended the duty to warn into the arena of psychotherapy. The Supreme Court of California found a

117. 331 P.2d at 818-19. The Supreme Court of New Jersey described the *Berry* court's position even more strongly, stating that it was the Utah court's "opinion that the happiness and well-being of the young lady were interests sufficient to warrant such a disclosure." *Hague v. Williams*, 181 A.2d 345, 348 (N.J. 1962).

118. 173 N.W. 663 (Minn. 1919).

119. 173 N.W. at 663-64.

120. *Davis v. Rodman*, 227 S.W. 612, 614 (Ark. 1921). Despite the existence and breach of such a duty, the defendants were not held liable because of the absence of proximate cause. 227 S.W. at 615.

121. See *Piper v. Menifee*, 51 Ky. (12 B. Mon.) 465 (1851) (physician found liable for treating smallpox patients and failing to warn subsequent patient-plaintiff of the risk of transmission of disease; consequently plaintiff developed smallpox); *Hewett v. Woman's Hosp. Aid Assn.*, 64 A. 190 (N.H. 1906) (finding liability for hospital's failure to warn a nursing student that her patient had diphtheria and was contagious, which resulted in the nurse's illness); *Edwards v. Lamb*, 45 A. 480 (N.H. 1899) (finding a physician liable for telling wife of patient that there was no danger in dressing her husband's infectious wound; as a result, wife became infected); *Span v. Ely*, 15 N.Y. Sup. Ct. (8 Hun) 255 (1876) (finding the doctor liable for assuring plaintiff, who contracted smallpox, that whitewashing house in which a previous patient died of smallpox was safe); see also *Hofmann v. Blackmon*, 241 So. 2d 752 (Fla. Dist. Ct. App. 1970), cert. denied, 245 So. 2d 257 (Fla. 1971) (duty to protect the minor child of physician's patient); *Jones v. Stanko*, 160 N.E. 456 (Ohio 1928) (duty to the neighbors of physician's patient who attended patient while ill and who aided in the patient's burial).

122. 551 P.2d 334 (Cal. 1976) (en banc).

valid cause of action in the claim that the defendant therapists breached their duty of care by failing to warn the plaintiff's daughter of the danger she faced from the therapists' patient.¹²³ In fact, the patient killed the plaintiff's daughter after he told the therapists he intended to murder her.

The *Tarasoff* court derived the duty to warn from the common law exception to the rule that one only has a duty to control or warn of the conduct of another if there is a special relationship between the actor and the dangerous person or between the actor and the victim. The requisite special relationship was found because the dangerous person was the therapists' patient.¹²⁴ The court argued that the balance of interests weighs in favor of protecting endangered life, even when there is a risk of harming the patient by disclosure or by inaccurately predicting violent tendencies. It found support from the American Medical Association, which allows breaches of confidence when " 'necessary . . . to protect the welfare of the individual or of the community.' "¹²⁵ The duty to warn was limited in California by *Thompson v. County of Alameda*,¹²⁶ which held physicians to such a duty only if there is an identifiable victim. A few jurisdictions, however, have extended the duty to warn beyond a known or identifiable victim.¹²⁷

Most courts would agree that interests in protecting the public or certain third parties can outweigh the duty to preserve confidentiality, although they might disagree over where to draw the line. Nevertheless many share the view that the "supervening interests" of society include preventing the spread of communicable diseases.¹²⁸ Based on *Tarasoff* and jurisdictions that apply similar reasoning,¹²⁹ the law may sometimes require a physician to warn — especially when there is an identifiable victim and a special relation between the physician and

123. 551 P.2d at 353.

124. Although prior California decisions applied such a duty only when there was a special relationship with both the victim and the dangerous person, this court determined that the duty to control another or warn of another's behavior was not limited to those scenarios. In this instance the court held that as long as either the victim or perpetrator has a special relationship with the defendant, there is a duty to warn. 551 P.2d at 343-44.

125. AMERICAN MEDICAL ASSN., *supra* note 93, § 9, *quoted in* 551 P.2d at 347.

126. 614 P.2d 728 (Cal. 1980) (en banc).

127. See Kenneth E. Labowitz, *Beyond Tarasoff: AIDS and the Obligation to Breach Confidentiality*, 9 ST. LOUIS U. PUB. L. REV. 495, 502 n.11 (1990) (citing cases). Davis v. Rodman, 227 S.W. 612 (Ark. 1921), for example, imposed a duty on physicians to warn even though third parties may not have been known. Labowitz, *supra* at 503-04. In such cases the duty presumably requires that physicians attempt to identify potential victims.

128. See *supra* note 109; see also Clark v. Geraci, 208 N.Y.S.2d 564, 567 (Sup. Ct. 1960) (when disclosure has "risen to the level of a need to safeguard the security of the government or the safety of the public, as in a case of a disclosure of a communicable disease . . . it would . . . be quite simple to find that the doctor's duty to disclose overrode his duty to remain silent").

129. See Piorkowski, *supra* note 90, at 184 n.81.

victim or potential harmer — even if it requires breaching confidentiality.

In the context of warning sexual or needle-sharing partners of a patient infected with HIV, commentators and legislatures disagree about how to apply the common law, that is, whether there should be a duty to warn, or just immunity from liability in warning, partners of a person infected with HIV.¹³⁰ State legislatures have addressed this issue variously by providing immunity without imposing a duty to warn,¹³¹ by imposing a duty to warn,¹³² or just by imposing a duty to maintain confidentiality unless a court finds there is a compelling need for disclosure.¹³³

Unlike warning third parties that smallpox or typhoid fever is contagious, warning third parties of the patient's HIV-positive status can reveal very confidential information. Society does not deal with AIDS like other infectious diseases that befall the unlucky; AIDS carries a social stigma.¹³⁴ Some view AIDS as just deserts for "immoral" behavior.¹³⁵ Because of public perceptions of AIDS, an HIV-positive test result or AIDS diagnosis may be viewed as indicative of homosexuality, illicit drug use, or sexual promiscuity. Consequently, people fear that disclosure in the AIDS context can result not only in the loss of insurance or employment, but also in the loss of social status, support from family and friends, and equal treatment in society.¹³⁶ Moreover, AIDS relates directly to sexuality because of its mode of transmission; revelations thus implicate deep personal privacy interests regardless of stigma from the disease itself.

Another distinction between AIDS and many other contagious diseases is their "visibility." Many HIV-positive individuals are generally unidentifiable, whereas someone with typhoid or scarlet fever is quite obviously ill, even if the specific diagnosis is not known. Therefore, those exposed to possible infection by a person with HIV are less likely

130. See Labowitz, *supra* note 127; McVickar, *supra* note 90.

131. See, e.g., CONN. GEN. STAT. § 19a-584 (1990); HAW. REV. STAT. § 325-101 (Supp. 1992); KAN. STAT. ANN. § 65-6004 (1992); MD. CODE ANN., HEALTH-GEN. § 18-337 (1990); R.I. GEN. LAWS § 23-6-17 (Supp. 1992).

132. See, e.g., MICH. COMP. LAWS § 333.5114a (1991).

133. See, e.g., DEL. CODE ANN. tit. 16, § 1203 (Supp. 1992); FLA. STAT. ch. 381.004(3)(f) (1991).

134. See COMM. ON AIDS RESEARCH & THE BEHAVIORAL, SOCIAL & STATISTICAL SCIENCES, NATIONAL RESEARCH COUNCIL, *Prevention: The Continuing Challenge*, in AIDS: THE SECOND DECADE, 81, 116 (Heather G. Miller et al. eds., 1990) [hereinafter *Prevention*].

135. See, e.g. *AIDS: When Fear Takes Charge*, U.S. NEWS & WORLD REP., Oct. 12, 1987, at 68; cf. Adam Nossiter, *Some Legal Experts See Intolerance as H.I.V. and Sex Are Linked to Crime*, N.Y. TIMES, Nov. 28, 1992, at A7 (suggesting that conviction could reveal society's intolerance towards AIDS).

136. See *Prevention*, *supra* note 134, at 115; COMM. ON AIDS RESEARCH & THE BEHAVIORAL, SOCIAL & STATISTICAL SCIENCES, NATIONAL RESEARCH COUNCIL, *Social Barriers to AIDS Prevention*, in AIDS: SEXUAL BEHAVIOR AND INTRAVENOUS DRUG USE 372, 391-94 (Charles F. Turner et al. eds., 1989); *AIDS: When Fear Takes Charge*, *supra* note 135, at 65.

to be aware of their risk than someone exposed to a person with scarlet fever. The problems with identifiability apply in the genetics context as well, where most unaffected carriers show no evidence of carrying a disease gene. Many who defend the overriding duty to warn, even when confidentiality is breached, would argue that this duty is limited in the AIDS context only to identifiable victims.¹³⁷ These complications are part of the dilemma physicians face in their conflicting duties to preserve confidentiality and to warn, and they provide useful insight into the similar problems and competing interests that exist in the genetics context. It is unclear how far the duty to warn extends with regard to AIDS, other contagious diseases, or psychiatric patients. Nevertheless, most jurisdictions would find a duty to warn if the physician has a special relationship with the potential victim or person who may cause harm and if the potential victim is identifiable and the harm to the victim is foreseeable.

B. *A Conditional Privilege But No Duty to Warn*

This section applies a policy analysis to argue that there should be a conditional privilege to warn in the genetics context under certain circumstances. Subsection II.B.1 argues that genetic disease may affect identifiable victims, although the more distantly related the at-risk relative, the less closely she fits this description. Subsection II.B.2 argues that legal principles support a conditional privilege to inform identifiable relatives, although such a privilege should arise only when the harm from failure to disclose outweighs the harm of disclosure. This subsection concludes that, despite the existence of a privilege to warn in the genetics context, health care professionals should be under no duty to warn.

1. *The "Identifiable" Victim*

The duty to warn requires a special relationship between the physician and the potential victim or harmer. In the genetics context, the patient and geneticist have such a special relationship, just as the therapists and the assailant did in *Tarasoff*. The *Tarasoff* court further limited the duty to warn to identifiable victims. Because genetic diseases can only be transmitted vertically — from parent to child —

137. See Labowitz, *supra* note 127, at 501-02; McVickar, *supra* note 90, at 365-66; see also CAL. HEALTH & SAFETY CODE § 199.19-199.29 (West 1990 & Supp. 1993) (prohibiting negligent and wilful disclosure of test results, with the exceptions of disclosure to health care providers, spouse, sexual partner, and needle-sharer); CAL. HEALTH & SAFETY CODE §§ 199.30-199.44 (West 1990) (protecting confidentiality of AIDS test information, but allowing disclosure of results without consent when necessary for a medical emergency; penalizing wilful or malicious disclosure of test information); N.Y. PUB. HEALTH LAW §§ 2782-2783 (McKinney Supp. 1992) (allowing, without obligating, physicians to disclose results to sexual or needle-sharing partners if they believe HIV-positive people will not inform their partners after being told of the intent to inform).

certain relatives who are potentially affected by an individual's diagnosis of genetic disease or identification as a disease gene carrier may be identifiable victims.¹³⁸

Mary, whose daughter has TFS, for example, has sisters who are potential carriers for this disease.¹³⁹ Learning about the possible familial gene may strongly affect their lives. Similarly, Jane's siblings could be carriers for the chromosomal translocation. There are other "identifiable" people: Mary's nieces on her sisters' side are at risk for being affected by, or being carriers of, TFS; her mother's sisters and their daughters have similar risks, as do her grandmother's daughters and sisters. Jane's aunts, uncles, and cousins are also at some risk for carrying the translocation.¹⁴⁰ The more distantly related one is to a carrier, however, the fewer the shared genes and the lower the risk of carrying the same disease gene or chromosomal rearrangement.¹⁴¹ Jane's siblings, for example, have a greater chance of carrying the translocation than her cousins twice removed.¹⁴² Statistically, the people most likely to benefit from information regarding genetic test results are those most closely related to the proband. Thus the "identifiable victim" becomes increasingly remote as the family tree extends.

Despite the identifiability of certain relatives, the physician or counselor should not necessarily have a legal duty to warn a patient's first- or second-degree¹⁴³ relatives, let alone those who are more distantly related. The interests in warning the relatives must be balanced against the interests of the patient, as subsection II.B.2 argues. Thus such a balancing test suggests the conclusion that physicians and counselors should only have a qualified privilege to inform closely related relatives of their risk in specific instances.

2. *Qualified Privilege to Warn*

One commentator describes the physician as having "the duty to maintain confidentiality . . . if disclosure could harm the patient, while at the same time, a duty to disclose . . . if confidentiality could cause

138. See Glass, *supra* note 35, at 2158.

139. See *supra* notes 73-76 and accompanying text.

140. See *supra* notes 79-82 and accompanying text.

141. HARPER, *supra* note 13, at 112-15.

142. In addition, the mutation could have arisen at any point in the family history, possibly even with Jane. The farther back in the family tree, the smaller the chance that the mutation existed in those generations of the family.

143. The degree of one's relatedness is based on how many "branches" away one is on the family tree or, more precisely, what percentage of genetic material is shared. For example, siblings, children, and parents share one half of their genes; they are first-degree relatives. Uncles and aunts share one fourth of their genes with their nieces and nephews and are second-degree relatives, as are grandparents and grandchildren. Cousins are third-degree relatives and share one eighth of their genes. HARPER, *supra* note 13, at 112-15.

harm to a third party.”¹⁴⁴ This approach, however, does not resolve what to do when harm is possible from the fulfillment of both duties. The cases described in subsections II.A.1 and II.A.2 suggest that if the harm from failing to warn outweighs the harm from disclosure, most jurisdictions would find a duty or privilege to warn. *Tarasoff* balanced the breach of confidentiality and possible improper diagnosis against the harm of threatened life, implying that the duty to warn only exists if the harm in failing to disclose endangers another’s life. “The risk that unnecessary warnings may be given is a reasonable price to pay for the lives of possible victims that may be saved.”¹⁴⁵ Most courts would find a privilege to disclose, if not a duty to warn, when life or health is at risk.¹⁴⁶ A few even recognize a disclosure privilege to protect against lesser harms.¹⁴⁷ Thus, analyzing whether there is a duty or privilege to disclose genetic test results requires a balancing of the interests at stake.

a. Harm from Disclosure. In one way, the harm from disclosure is less troublesome in the genetics context than in *Tarasoff*. Genetic testing, like the diagnosis of many contagious diseases, is relatively certain¹⁴⁸ or at least frequently provides objective results. In contrast, psychotherapy, as the *Tarasoff* court acknowledged, involves some uncertainty¹⁴⁹ in that the diagnoses are qualitative and subjective.¹⁵⁰ Consequently, the disclosure of the diagnosis of many genetic or contagious diseases may be less likely to cause the harm of disclosing improper diagnoses.¹⁵¹

Despite the decreased concern in that regard, the patient may refuse to comply for fear that the disclosure of test results will harm him. Just as stigmatization is a major concern in the AIDS context,¹⁵² it may well be a source of apprehension for those who carry a genetic “abnormality.”¹⁵³ Mary may fear that her daughter would be ill-treated if others learn that she is genetically “male” or that she may be

144. *McVickar*, *supra* note 90, at 341.

145. *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 346 (Cal. 1976).

146. *See supra* notes 109-11 and accompanying text.

147. *See, e.g., Berry v. Moench*, 331 P.2d 814, 817 (Utah 1958) (well-being of the fiancée sufficient justification to allow disclosure); *see also supra* notes 113-17 and accompanying text.

148. Of course, genetic testing is by no means 100% certain. *See supra* note 59 and accompanying text.

149. *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 346 (Cal. 1976) (“[t]aking note of the uncertain character of therapeutic prediction”).

150. *See Davis v. Lhim*, 335 N.W.2d 481, 487 (Mich. Ct. App. 1983) (noting the inexactness of psychiatry).

151. When technology is not available to test for specific disease genes, however, genetic diagnosis can be largely qualitative.

152. *See supra* notes 134-36 and accompanying text.

153. This view, however, ignores the fact that everyone carries a few nonworking genes, which in the proper context could cause disease. *See supra* notes 21-24 and accompanying text.

devastated by the knowledge.¹⁵⁴ Even genetic diseases that do not involve gender may carry a stigma.¹⁵⁵ Jane might feel abnormal or "damaged" because of the chromosome translocation, even though she is perfectly healthy.¹⁵⁶

A further fear of individuals in these contexts is that disclosure might harm family relations, especially because being a carrier influences procreative decisions.¹⁵⁷ The patient may feel that relatives blame her for imposing this risk on them. This concern is related to the common, though unfounded, sense of causal responsibility for bringing the disease into the family.¹⁵⁸ Other patients may refuse to divulge their test results, knowing that the relative would not choose prenatal testing and would only suffer trepidation in learning of the risk. Those who oppose abortion may fear the information would be used for pregnancy termination.

An additional worry, frequently voiced in the AIDS debate, is that disclosure would inhibit people from pursuing testing.¹⁵⁹ Because AIDS is truly becoming an epidemic,¹⁶⁰ there is a unique public interest in encouraging voluntary HIV-testing. While genetic disease is not an epidemic, most would agree that genetic testing should be available without the fear of harm from disclosure.

These concerns simply add to the general presumption in favor of protecting confidentiality: "[i]t is often necessary for the patient to give information about himself which would be most embarrassing or

154. Families often experience particular difficulty with a diagnosis of TFS. Many will avoid telling the affected children or other family members because they feel a great deal of shame in the diagnosis. See H.T. Lynch et al., *Genetic Counseling and Cancer*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 221, 235-36.

155. Andrews & Jaeger, *supra* note 7, at 77; Verle E. Headings, *Psychological Issues in Sickle Cell Counseling*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 185, 186; Sylvia Schild, *Psychological Issues in Genetic Counseling of Phenylketonuria*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 135, 141.

156. See Rose Grobstein, *Amniocentesis Counseling*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 107, 112; *supra* text accompanying note 80.

157. Schild, *supra* note 155, at 142-43; Sorenson, *supra* note 21, at 175; see also *infra* note 249.

158. Such views only underscore the need to educate patients appropriately about genetics and the modes of transmission. See PATRICIA T. KELLEY, *DEALING WITH DILEMMA* 82, 115 (1977). When genetic disease exists in a family there is often a desire to place blame or at least to understand what the family or someone else did to "cause" the outcome. Seymour Kessler, *The Process of Communication, Decision Making and Coping in Genetic Counseling*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 35, 47. Therefore, some find it is easier to explain away a seemingly random inheritance by attributing it to something that someone did or did not do. KELLEY, *supra*, at 38, 79-80, 82, 114-15; Paula E. Hollerbach, *Reproductive Attitudes and the Genetic Counselor*, in *COUNSELING IN GENETICS*, *supra* note 83, at 155, 176; Lewis B. Holmes, *Prospective Counseling for Hereditary Malformations in Newborns*, in *GENETIC COUNSELING* 241, 244; Seymour Kessler, *The Genetic Counseling Session*, in *PSYCHOLOGICAL DIMENSIONS*, *supra* note 50, at 65, 83.

159. Cf. Talbot, *supra* note 90, at 359-60.

160. See *Prevention*, *supra* note 134, at 38-80 (describing the nature of the epidemic in its second decade).

harmful to him if given general circulation.”¹⁶¹ Moreover, revealing such information “betray[s] . . . a professional secret to the detriment of a patient.”¹⁶² In addition, the patient has “sufficient justification for reasonable expectation . . . that the physician has promised to keep confidential all information given by the patient.”¹⁶³

b. Harm from Failure To Disclose. Because the common law has offered convincing arguments to find a presumption in favor of confidentiality,¹⁶⁴ a disclosure privilege should only be found if the harm in failing to disclose outweighs the harm from disclosure. There are clear differences, however, between the risks in failing to warn about a contagious disease or a violent person and failing to warn about disease genes. Someone with a contagious disease or with violent propensities can harm others by exposing them to infection or by assaulting them, respectively. Yet individuals with disease genes do not put relatives at risk by carrying the gene. Their relatives have no risk of *becoming* carriers; they only have the risk of finding out that they *are* carriers.

Informing relatives that there is a familial disease gene, however, can affect the fate of the unborn. A person with a disease gene places her unborn children at risk of carrying that gene; the offspring either will or will not carry the gene. With current technology,¹⁶⁵ the unborn child who inherits the disease gene faces the possibility of being born with the gene or being spared the disease¹⁶⁶ though abortion.¹⁶⁷ In contrast, a person who avoids exposure to an infectious disease can remain disease free. Moreover, the risk in the genetics context deals with individuals who do not yet exist. Although courts have held that individuals can owe duties to the unborn,¹⁶⁸ it is impossible to hold

161. *Simonsen v. Swenson*, 177 N.W. 831, 832 (Neb. 1920) (per curiam).

162. 177 N.W. at 832 (quoting NEB. REV. STAT. § 2721 (1913)).

163. *Horne v. Patton*, 287 So. 2d 824, 832 (Ala. 1973) (plurality opinion).

164. See *supra* subsections II.A.1.a and II.A.1.b.

165. When gene therapy becomes available for certain genetic diseases, the argument becomes quite different. In that case, the unborn child has the possibility of being born alive without the disease if gene therapy is used. Gene therapy, however, is still fairly remote for most genetic diseases. See *Miller, supra* note 4, at 455; *Verma, supra* note 4, at 68.

166. This assumes that the fetus carries either two recessive disease genes, a single dominant disease gene, or an unbalanced translocation, all of which can cause disease, not simply a single recessive disease or balanced translocation, which does not cause disease.

167. This situation mirrors the dilemma courts face with wrongful life challenges, in which individuals sue for negligence in counseling or genetic testing that allows the child to be born with a birth defect or genetic disease. The claim is that, but for the physician's or counselor's negligence, the child would not have been born and therefore would have been spared suffering from the defect. See, e.g., *Curlender v. Bio-Science Lab.*, 165 Cal. Rptr. 477 (Ct. App. 1980); *Siemieniec v. Lutheran Gen. Hosp.*, 512 N.E.2d 691 (Ill. 1987). Most courts deny compensation on the grounds that any life is better than no life at all. See, e.g., 512 N.E.2d at 696-97.

168. See *Renslow v. Mennonite Hosp.*, 367 N.E.2d 1250 (Ill. 1977) (holding physician liable for giving an Rh negative woman a blood transfusion with Rh positive blood so that years later the mother's Rh sensitization damaged her Rh positive child during pregnancy); *Monusko v. Postle*, 437 N.W.2d 367 (Mich. Ct. App. 1989) (holding physician liable for birth defects in the

that there is a duty to warn one who does not yet, and may never, exist.

Despite the informed relatives' inability to avoid carrying an inherited gene, warnings would allow them to prevent certain harms. If informed of their risk, for example, some of Jane's siblings might have prenatal testing if they are found to have the translocation. They may plan to terminate pregnancies in which the fetus inherits an unbalanced form of the translocation, or they may simply want the option.¹⁶⁹ Alternatively, they may want the information to be emotionally prepared and to inform the obstetrician that the fetus may be affected.¹⁷⁰ Awareness of the relative's disease gene or chromosomal abnormality could prevent the harm in giving birth to a child with a genetic disease or in being unprepared for such an outcome. Failure to disclose, therefore, may lead to varying degrees of harm depending on the values and beliefs of the relative. By the *Tarasoff* standard, the imbalance of interests is not great enough to impose a duty to warn, although courts may find it sufficient to create a privilege to disclose under *Moench*.¹⁷¹

Failure to disclose in other situations may pose more significant threats. Mary's nieces, for instance, are not only at risk for being carriers, but also for having TFS. Serious harm could befall them if the syndrome remains undiagnosed and they develop malignant, inguinal tumors.¹⁷² Similarly, if the patient carries the gene for a form of cancer, like retinoblastoma, which early detection can prevent, informed relatives may be able to avoid developing cancer.¹⁷³ Preventive care may ameliorate some incurable genetic diseases. Those with Marfan syndrome can significantly reduce the risk of heart aneurysms and death by taking medications and avoiding heavy exercise.¹⁷⁴ In these and related situations, disclosure of genetic information may save lives, resulting in a balance of interests that warrants a duty to warn under *Tarasoff*, or at least a privilege to disclose.

c. No Duty, but a Qualified Privilege, to Warn. The duty to warn does not only require that the balance of interests favors saving a life over preserving patient confidentiality. The *Tarasoff* court also argued that therapists have a duty to prevent foreseeable harm by controlling

patient's child resulting from a rubella infection during pregnancy because the physician failed to immunize the patient against rubella before her pregnancy).

169. See *supra* text accompanying notes 50-51. Of course, other siblings might prefer to leave their pregnancy outcome to fate and opt not to have any testing at all. In those cases, the information might create anxiety, but it would also prepare them for the possibility of disease.

170. See *supra* text accompanying note 50.

171. See *supra* notes 145-47 and accompanying text.

172. See *supra* text accompanying note 73.

173. See *supra* notes 85-86 and accompanying text.

174. R.E. Pyeritz, *Marfan Syndrome*, in 2 PRINCIPLES AND PRACTICE, *supra* note 16, at 1047, 1060-61.

the actions of the dangerous patient or by warning the third party.¹⁷⁵ The court's reasoning implies that when the patient himself poses a risk to a third party, his confidentiality may be violated unless the patient can be controlled. A genetics patient, in contrast, does not pose a risk to her relatives; her actions, unlike those of contagious or violent people, do not present foreseeable harm. Rather it is the disease gene and ignorance regarding carrier status that pose a risk to the relative. Thus a strict application of *Tarasoff* does not result in the finding of a duty to warn, even when the relative faces a risk of death.

Case law, however, supports a privilege to warn in certain cases.¹⁷⁶ Although the privilege to disclose derives from contagious disease cases in which the patients pose a threat of infection,¹⁷⁷ courts base the privilege to disclose on the likelihood of harm in failing to disclose, fairly consistently justifying disclosure for the protection of public health or another's life. Even if life is not at risk, disclosure can prevent a lesser degree of harm if relatives could use genetic information to make reproductive decisions or to decrease the risk of future illness. In these cases, there should be a privilege to disclose only if there is a clear imbalance of harm in favor of disclosure. Given the importance of patient confidentiality, the presumption should lie against disclosure unless it can prevent foreseeable and significant harm.

Physicians and genetic counselors should therefore have the privilege to disclose genetic information to at-risk relatives or their physicians, in certain cases.¹⁷⁸ Courts or legislatures, however, should never compel them to disclose.¹⁷⁹ When there is a significant risk that certain relatives carry the gene or chromosome rearrangement, available technology might allow the relatives to receive important medical benefits or make important reproductive decisions. Yet, only when harm from disclosure is significantly less should courts or legislatures grant the physician or counselor the privilege to warn the relatives and

175. *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 343 (Cal. 1976).

176. See *supra* section II.A.1.c.

177. See *supra* notes 109-11, 118-121 and accompanying text.

178. PRESIDENT'S COMM. FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING, AND COUNSELING FOR GENETIC CONDITIONS: A REPORT ON THE ETHICAL, SOCIAL, AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING, AND EDUCATION PROGRAMS (1983) makes similar recommendations in terms of ethical duties:

A professional's ethical duty of confidentiality to an immediate patient or client can be overridden only if several conditions are satisfied: (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.

Id. at 44.

179. But see Janet A. Korbin, Comment, *Confidentiality of Genetic Information*, 30 UCLA L. REV. 1283, 1307-15 (1983), for the argument that there should be a duty to warn.

breach the patient's confidentiality. Moreover, physicians or genetic counselors who lack the necessary information to weigh the competing interests should not be accorded the privilege to disclose. They should never disclose patient information without first trying to discover the patient's concerns and to impress upon the patient her moral duty to inform relatives. Ideally, the patient should be the one to inform family members.¹⁸⁰ Finally, physicians and genetic counselors should try to warn without breaching patient confidentiality, that is, by informing the relative's physician of the relative's risk without identifying the patient.¹⁸¹

C. *The Carrier's Duty to Inform*

Establishing whether a person with a disease gene or chromosomal translocation has a legal duty to inform high risk relatives is less straightforward than determining whether physicians and counselors have such a duty. The patient arguably has a moral duty, even if no such legal duty exists. One commentator notes, "[o]n the ground of preserving the life and welfare of the family, it may be argued that every family member has the general obligation to inform other relevant family members of matters relating to their welfare and more broadly to the value of preserving the family."¹⁸² This commentator notes the conflict with privacy issues if such a moral obligation exists.¹⁸³ He points out exceptions to these legal protections when the public health is at stake. Therefore, "an argument may plausibly be mounted on the basis that an individual's genetic make-up may impinge on the welfare of other family members and is not therefore purely personal in character."¹⁸⁴ To sustain such a view, he suggests, one must find that genetic diseases constitute a public health concern. The commentator fails to recognize that courts have made exceptions to the right to confidentiality not only for public health reasons, but also for the well-being of another.¹⁸⁵ Even accepting that the individual right to privacy could not be infringed upon except for public health reasons, one could make a strong claim that genetic diseases are a public health concern given the interests discussed in subsection

180. See *infra* notes 182-88 and accompanying text.

181. This presupposes that the relative's physician is different from the patient's. If this is not true, the relative may be able to discern who the patient is. In balancing the interests at stake, courts or legislatures should consider these circumstances among the possible harms to the plaintiff.

182. Sumner B. Twiss, *Ethical Issues in Genetic Screening: Models of Genetic Responsibility*, in *ETHICAL, SOCIAL AND LEGAL DIMENSIONS*, *supra* note 21, at 225, 237. Twiss examines the moral obligations related to genetic testing in the context of five models: the parental, parent-family, parent-citizen, parent-species, and parent-ethnic population models. He applies the second in finding a duty to provide genetic information to relatives at high risk. *Id.* at 237-38.

183. *Id.* at 249.

184. *Id.*

185. See *supra* notes 109-122 and accompanying text.

II.B.2.b,¹⁸⁶ the scarcity of medical resources, the use of public funding for newborn screening, and the human suffering involved.¹⁸⁷

These arguments, therefore, support the notion that one has a moral responsibility to provide high-risk relatives with relevant genetic information. But the existence of a moral duty does not require that there be a corresponding legal duty. Since this issue has never come before the courts, one can find a helpful analogy in the AIDS context. Legislatures and courts have begun to struggle with whether HIV-positive people should be required to inform others of their status. Some legislatures have made it a felony to withhold knowingly such information from partners and to engage in behavior that puts another at risk.¹⁸⁸ Along similar lines, courts and legislatures have compelled disclosure of HIV test results to the alleged victims of individuals who have been convicted or accused of sexual crimes.¹⁸⁹

Recognizing how the issues in the AIDS context are distinct from those in the genetics context is useful in determining whether the patient should have a legal duty to inform relatives of her test results. In the former scenario, the HIV-positive individual is capable of actually causing harm to the party who desires disclosure. In the latter, the patient does not cause the relative's genetic risks; she simply does not help the relative learn of his risk. This distinction between potential misfeasance and nonfeasance play out differently in tort law, thus resulting in differences regarding the duty to inform.

If someone infected with HIV fails to disclose, whether before or after exposing his partner, the partner may not be able to protect adequately against infection or receive early, more beneficial medical treatment. Thus the infected individual subjects the other to the risk

186. See *supra* notes 164-74 and accompanying text.

187. See Damme, *supra* note 21, at 820-23; Twiss, *supra* note 182, at 249-250.

188. See, e.g., MICH. COMP. LAWS. § 333.5114a (1991); State v. Stark, 832 P.2d 109 (Wash. Ct. App. 1992) (affirming the conviction of a man found guilty of "intentionally exposing his sexual partners to . . . HIV").

189. See, e.g., MICH. COMP. LAWS § 333.5129 (1991) (requiring HIV testing of defendants convicted of sexual crimes, unless court determines it is inappropriate, and requiring disclosure to defendants' victims); see also *Virgin Islands v. Roberts*, 756 F. Supp. 898 (D.V.I. 1991) (holding that the Fourth Amendment permits HIV testing of defendant for benefit of rape victim), *affd. mem.*, 961 F.2d 1567 (3d Cir. 1992); *People v. Anonymous*, 582 N.Y.S.2d 350 (County Ct. 1992) (holding that defendant who stated that she was HIV-positive after biting a police officer could be compelled to have HIV test if results were disclosed only to attorneys); State v. Stark, 832 P.2d 109 (Wash. Ct. App. 1992) (holding that there was no error in refusing to suppress information of HIV test results of defendant convicted of intentional HIV exposure); cf. *Harris v. Thigpen*, 941 F.2d 1495 (11th Cir. 1991) (holding that although isolation of HIV-positive inmates would identify their HIV status, this was not a violation of privacy rights); *Doe v. Roe*, 444 N.W.2d 437 (Wis. Ct. App. 1989) (holding that probative value of HIV test result was greater than the stigma from disclosure). But see *St. Hilaire v. Arizona Dept. of Corrections*, No. 90-15344, 1991 U.S. App. LEXIS 11620 (9th Cir. May 30, 1991) (unpublished opinion) (mem.), (affirming decision to deny motion to segregate and identify HIV-positive inmates) *cert. denied*, 112 S. Ct. 255 (1991); *Doe v. Hirsch*, 731 F. Supp. 627 (S.D.N.Y. 1990) (denying request for HIV status of deceased intravenous drug abuser with whose blood police officers came into contact).

of contracting a serious and life-threatening disease or of failing to forestall the harm from infection.

In the AIDS case, the duty to warn would derive from the exception to the tort rule that one need not actively aid another.¹⁹⁰ Here, there is an affirmative duty to act because one *has* endangered another.¹⁹¹ That is, when one has created an unreasonable risk of harm to another, the actor has a duty to exercise reasonable care to avert the harm that is likely to follow.¹⁹² Before the sexual act, there is arguably a special relationship, because providing the opportunity to have sex might be viewed as creating a danger against which there is a duty to protect. Someone infected with HIV puts his partners at an unreasonable risk of harm if he engages in behavior that can transmit the virus. Warning them of the infection so that they can take preventive measures would fulfil his duty of reasonable care.¹⁹³

In the genetic disease context, the carrier does not put others at risk for becoming carriers. The risk of harm is simply a function of nature. Therefore the carrier does not have an affirmative duty to warn her relatives because she has not put them at risk. One is not liable for nonfeasance if one is not responsible for the peril.¹⁹⁴ Thus she would have a duty to take "reasonable action to protect [the other] against unreasonable risk of physical harm" only if there is a special relationship.¹⁹⁵ The nonexclusive list of relationships that warrant this exception includes those in which one has custody over another,¹⁹⁶ which presumably encompasses the parent and minor-child relationship. The law is gradually adding to the list relationships in which there is mutual dependence, which could include husband and wife.¹⁹⁷ The nature of the relationships between parent and minor-child and between husband and wife involves a level of dependence that does not exist between a person and her siblings, aunts, uncles, and so forth. Parents clearly have a custodial role that places their child in a position of dependence vis-à-vis the parents.¹⁹⁸ The criminal law recognizes the mutual dependence of the spousal relationship by

190. RESTATEMENT (SECOND) OF TORTS § 314 (1965) [hereinafter RESTATEMENT].

191. *Id.* § 321.

192. *Id.* This is true whether or not the act is tortious or innocent. *Id.*

193. There are, however, very good policy reasons against imposing such a duty, which are beyond the scope of this Note. The discussion is merely meant to contrast the contagious disease situation from the genetic situation, not to argue that there should be tort liability for exposing someone to the AIDS virus. In fact, this Note's author believes that while there is a moral duty to inform sexual and needle-sharing partners, there should not be tort liability for failure to do so.

194. See RESTATEMENT, *supra* note 190, § 314.

195. *Id.* § 314A.

196. *Id.*

197. *Id.* cmt. b. The tort law has not yet recognized the duty of protective action between spouses. *Id.*

198. See 59 AM. JUR. 2D *Parent and Child* §§ 10, 23 (1987 & Supp. 1993).

imposing special duties to take positive action to aid one another.¹⁹⁹ Tort law, however, has not yet imposed such a duty within the marital relationship.²⁰⁰ It therefore seems very unlikely that tort law would find such a duty between siblings and more distant relatives. Consequently, when there is no basis for an affirmative duty to protect relatives, carriers cannot be held to a duty to warn relatives of their risk of carrying a disease gene.

III. CONSTITUTIONALITY OF MANDATORY TESTING

The issues regarding the disclosure of test results to relatives relate directly to the issues of mandatory testing for the benefit of a relative. The latter necessarily involves disclosure if the purpose of compulsory testing is to provide beneficial information to the relative. There are, however, additional concerns and competing interests that must be considered along with the disclosure issues when addressing the constitutionality of compulsory testing. In fact, the interests of the potential proband become significantly greater in this context: not only may the proband have disclosure concerns, but she now faces potential harm from being forced to discover whether she carries a disease gene after she has consciously decided not to learn this information. This Part will argue that her combined interest in not knowing and in avoiding bodily intrusion is fundamental.

Current technology has made this conflict possible because scientists can now discover the genetic bases of some diseases before identifying the protein defect.²⁰¹ For example, scientists discovered the genes for cystic fibrosis,²⁰² neurofibromatosis,²⁰³ and Marfan syn-

199. See RESTATEMENT, *supra* note 190, § 314A cmts. a-c.

200. *Id.*

201. This is possible by studying many large families in which a particular genetic disease has been prevalent. By testing several different markers from the various chromosomes, scientists look for statistical evidence that one of the markers, each of which corresponds to a particular region on a chromosome, is associated with the disease. The research then focuses on a narrow area of the relevant chromosome until the actual DNA region that codes for the deficient, disease-causing protein is found. See Friedmann, *supra* note 6, at 408-09.

202. See Bat-Sheva Kerem et al., *Identification of the Cystic Fibrosis Gene: Genetic Analysis*, 245 SCIENCE 1073 (1989); John R. Riordan et al., *Identification of the Cystic Fibrosis Gene: Cloning and Characterization of Complementary DNA*, 245 SCIENCE 1066 (1989). Cystic fibrosis is an autosomal recessive disorder in which affected individuals develop excessive mucus accumulation that causes lung disease, pancreatic insufficiency, and growth impairment. Eitan Kerem et al., *The Relation Between Genotype and Phenotype in Cystic Fibrosis Analysis of the Most Common Mutation*, 323 NEW ENG. J. MED. 1517, 1517 (1990); Lap-Chee Tsui & Manuel Buchwald, *Biochemical and Molecular Genetics of Cystic Fibrosis*, 20 ADVANCES IN HUM. GENETICS 153-54 and tbl. 1 (1991).

203. See Richard M. Cawthon et al., *A Major Segment of the Neurofibromatosis Type 1 Gene: cDNA Sequence, Genomic Structure, and Point Mutations*, 62 CELL 193 (1990); David Viskochil et al., *Deletions and a Translocation Interrupt a Cloned Gene at the Neurofibromatosis Type 1 Locus*, 62 CELL 187 (1990); Margaret R. Wallace et al., *Type 1 Neurofibromatosis Gene: Identification of a Large Transcript Disrupted in Three NF1 Patients*, 249 SCIENCE 181 (1990). See *supra* note 55 for a description of neurofibromatosis.

drome²⁰⁴ without knowledge of the disease mechanisms. As a result, for many genetic diseases, testing is currently only possible through linkage analysis.²⁰⁵ As a greater number of genetic diseases are detectable through linkage analysis, more situations like Bob's may arise, in which a family member who is needed for testing simply refuses to participate. Even when direct testing is sometimes possible, linkage analysis may be required, as in Sarah's case.²⁰⁶

This Part examines the constitutionality of compelling a person to have genetic testing for the benefit of a relative and concludes that the state may not use its police power to do so. Section III.A reasons that the police power gives states the authority to legislate with regard to genetic testing. Section III.B argues, however, that substantive due process under the Fourteenth Amendment requires that access to decisions to have genetic testing should be treated as a fundamental privacy right. Therefore, section III.C concludes, courts must apply the two-part scrutiny analysis to any potential infringement of this right. Section III.D contends that, under strict scrutiny, the first part of the analysis is not fulfilled: there is no compelling state interest when the intrusiveness of forced testing is weighed against the remoteness of the benefit. Therefore compulsory testing in these scenarios is unconstitutional. The section then demonstrates that, even if a court found the state interest compelling, legislation cannot be narrowly tailored when incurable diseases are at issue, though testing for curable diseases could potentially be so drawn. Nevertheless, this section contends normative and public policy reasons mandate that genetic testing for the benefit of a relative remain voluntary, even for curable genetic diseases.

A. *The State's Police Power*

The Court has long recognized the power of the states to promote the health, welfare, and safety of the public as a constitutional power derived from the Tenth Amendment of the Federal Constitution.²⁰⁷ The Supreme Court distinguished between areas that the states and

204. See Harry C. Dietz et al., *Marfan Syndrome Caused by a Recurrent de Novo Missense Mutation in the Fibrillin Gene*, 352 NATURE 337 (1991). Marfan syndrome is an autosomal dominant — that is, it is not carried on the sex chromosomes — connective tissue disorder that usually manifests with disproportionately long extremities, tall stature, lankiness, and joint laxity. Individuals are at risk for aortic aneurysms and dislocation of the lenses and joints. See Pyeritz, *supra* note 174, at 1047.

205. See *supra* notes 57-59 and accompanying text.

206. Depending on the details of the discovery of the Huntington's gene, linkage or family studies may still be required for many Huntington's families. See *supra* notes 68 & 70.

207. See *Hill v. Wallace*, 259 U.S. 44, 67-68 (1922) (states have jurisdiction of "subjects of public interest . . . which are reserved to them by the Tenth Amendment"); *Hamilton v. Kentucky Distilleries & Warehouse Co.*, 251 U.S. 146, 156 (1919) ("That the United States lacks the police power, and that this was reserved to the States by the Tenth Amendment, is true."); *Leisy v. Hardin*, 135 U.S. 100, 127 (1890) (Gray, J., joined by Harlan & Brewer, JJ., dissenting) ("Among the powers . . . reserved to the several States [by the Tenth Amendment] is what is

Congress control.²⁰⁸ While it held that states do not have the right to regulate interstate commerce, it acknowledged that they have an “immense mass of legislation, which embraces every thing within the territory of a state, not surrendered to the general government . . . [including i]nspection laws, quarantine laws, [and] health laws of every description.”²⁰⁹

One justification for the use of the police power is to protect the general health of the citizens. In *Jacobson v. Massachusetts*,²¹⁰ the Supreme Court held that a local health regulation requiring adults to undergo smallpox vaccinations was a legitimate exercise of the police power. While recognizing that vaccinations infringe upon liberty to some degree, the Court noted that “liberty . . . does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint.”²¹¹ The community’s “right to protect itself against an epidemic . . . which threatens the safety of its members” legitimized the minor infringement.²¹² The Court further noted that quarantines to prevent the spread of contagious diseases like cholera or yellow fever might be constitutional even though they would restrict liberty to some extent.²¹³ Notable was the Court’s view that “public health is a primary obligation of the state.”²¹⁴

More recently, state legislatures have imposed mandatory testing schemes for venereal diseases, generally in the context of awarding marital licenses.²¹⁵ Courts have upheld statutes requiring premarital testing for syphilis under the theory that such legislation is within the realm of the police power.²¹⁶ Although the Supreme Court recognized

commonly called the police power.”); LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* § 5-20, at 379 (2d ed. 1988).

208. *Gibbons v. Ogden*, 22 U.S. (9 Wheat.) 1 (1824).

209. 22 U.S. (9 Wheat.) at 203. In *Railroad Co. v. Husen*, 95 U.S. 465 (1878), the Court supported the notion of a limited, but clearly defined police power: “While we unhesitatingly admit that a State may pass sanitary laws, and laws for the protection of life, liberty, health, or property within its borders . . . it may not interfere with transportation into or through the State, beyond what is absolutely necessary for its self-protection.” 95 U.S. at 472.

210. 197 U.S. 11 (1905).

211. 197 U.S. at 26.

212. 197 U.S. at 27.

213. 197 U.S. at 29.

214. *Damme*, *supra* note 21, at 809. Earlier, in *Husen*, the Court also recognized a state’s right to pass legislation to protect the welfare of the people by restricting animals and people with infectious disease from entering its borders, as long as the laws were not more restrictive than necessary and did not invade the domain of the federal government. *Railroad Co. v. Husen*, 95 U.S. 465, 471-73 (1878).

215. *See, e.g.*, ALA. CODE § 22-11A-15 (1990); CAL. CIV. CODE § 4300 (Supp. 1993); CONN. GEN. STAT. § 46b-26 (1990); GA. CODE ANN. § 19-3-40 (1991); N.J. STAT. ANN. § 37:1-20 (West 1968); PA. CONS. STAT. ANN. § 1305 (1991); R.I. GEN. LAWS § 15-2-3 (1988).

216. *See, e.g.*, *Fisher v. Sweet*, 35 A.2d 756 (Pa. Super. Ct. 1944) (holding that a syphilis testing requirement is within the state’s power); *In re Kilpatrick*, 375 S.E.2d 794 (W. Va. 1988) (upholding the constitutionality of statutes requiring premarital serological testing for marriage license); *see also Kraus v. City of Cleveland*, 127 N.E.2d 609, 611 (Ohio 1955) (“Regulations

that marriage is a fundamental right in *Zablocki v. Redhail*,²¹⁷ Justice Stewart argued in his concurrence that venereal disease testing requirements are legitimate prerequisites to obtaining a marriage license.²¹⁸

Given the constitutionality of using the police power to regulate matters related to public health and the general well-being of the community, states arguably have the authority to legislate certain genetic testing statutes. Although genetic diseases cannot be spread through contact and therefore do not affect the public in the way contagious diseases do, they legitimately concern the state because they affect the well-being of some of its citizens. Newborn screening legislation to detect and treat specific genetic diseases has never been challenged,²¹⁹ bolstering the presumption that this activity is an appropriate exercise of the state's police power.

Merely defending genetic testing legislation as a valid use of the police power, however, does not suffice. The issue is not simply whether the state has power to protect "life, liberty, health, or property,"²²⁰ but whether such legislation withstands constitutional scrutiny. As argued below, any legislation regarding mandatory genetic testing involves fundamental privacy rights and therefore must survive strict scrutiny analysis.

B. Genetic Testing and Fundamental Privacy Rights

Although states clearly have the power to enact legislation to protect the welfare of their people, any such legislation is subject to some level of constitutional scrutiny.²²¹ Public health measures related to infectious disease generally receive only a minimal level of scrutiny,²²² which requires that there be a reasonable relation between a legitimate state interest and the statute. If a public health measure appears "capricious, arbitrary, or otherwise unreasonable and oppressive," the statute cannot stand.²²³ The standard is necessarily lenient.

The Supreme Court has applied minimal scrutiny even to highly invasive public health measures. In one of the most controversial ex-

relating to control of venereal disease [and] blood tests for marriage licenses . . . have all been held valid as based on police power exercised in regard to public health.").

217. 434 U.S. 374 (1978).

218. 434 U.S. at 392 (Stewart, J., concurring).

219. See Damme, *supra* note 21, at 820-23.

220. *Railroad Co. v. Husen*, 95 U.S. 465, 472 (1878).

221. *TRIBE*, *supra* note 207, § 15-1, at 1306.

222. Damme, *supra* note 21, at 805.

223. *Id.* In support of this view the *Jacobson* Court stated, if a public health statute "has no real or substantial relation to [its] objects, or is, beyond all question, a plain, palpable invasion of rights secured by the fundamental law," the courts must determine this to "give effect to the Constitution." *Jacobson v. Massachusetts*, 197 U.S. 11, 31 (1905).

amples, *Buck v. Bell*,²²⁴ the Supreme Court upheld a court order for the involuntary sterilization of a “feebleminded” woman who was both the daughter of a “feebleminded” woman and the mother of an “illegitimate feebleminded” child on the grounds that “the welfare of society may be promoted in certain cases by the sterilization of mental defectives”²²⁵ In his very short opinion, Justice Holmes compared the social benefits of sterilization to those of vaccination: “[t]he principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.”²²⁶ Suggesting that societal harm had already been too great, Holmes coldly declared, “[t]hree generations of imbeciles are enough.”²²⁷

While some state courts have also supported involuntary sterilization of the mentally impaired,²²⁸ *Skinner v. Oklahoma*²²⁹ suggests that such invasiveness might not always be constitutionally acceptable. In *Skinner*, the Court held unconstitutional a statute requiring the sterilization of habitual criminals who had been convicted three times of felonies “‘involving moral turpitude.’”²³⁰ In condemning the statute, the Court proclaimed that procreation is “one of the basic civil rights of man” and “fundamental to the very existence and survival of the race.”²³¹ Although *Skinner* did not overrule *Buck v. Bell*, it reflects the beginning of the Court’s expanding interpretation of the protection of fundamental rights.

Many public health measures require some form of intrusion upon personal liberty, whether they involve mandatory vaccination, quarantine, blood testing, or sterilization. Although the Court often allows such invasions, it has not consistently applied the same level of judicial scrutiny.²³² This inconsistency may simply reflect evolving attitudes over time. It also may stem from the various levels of personhood the measures violate. Some levels of personal identity and privacy may be accorded greater protection against governmental intrusions because they are deemed fundamental. Others may be more susceptible to en-

224. 274 U.S. 200 (1927).

225. 274 U.S. at 205.

226. 274 U.S. at 207.

227. 274 U.S. at 207.

228. See, e.g., *In re Sterilization of Moore*, 221 S.E.2d 307 (N.C. 1976); *Cook v. State*, 495 P.2d 768 (Or. Ct. App. 1972). But see *Ruby v. Massey*, 452 F. Supp. 361, 365-68 (D. Conn. 1978) (holding that the right to privacy means that not even the severely mentally retarded can be sterilized absent “valid consent”).

229. 316 U.S. 535 (1942).

230. 316 U.S. at 536 (quoting OKLA. STAT. tit. 57, § 173 (1935)).

231. 316 U.S. at 541. The Court’s basis for invalidating the statute was its violation of the Equal Protection Clause by discriminating against habitual criminals.

232. Compare *Buck v. Bell*, 274 U.S. 200 (1927) (applying minimal scrutiny to reproductive rights) with *Roe v. Wade*, 410 U.S. 113 (1973) (applying strict scrutiny to reproductive rights); see also *infra* notes 256-61 and accompanying text.

croachment.²³³ Not all forms of bodily intrusion are necessarily "violations of the self or usurpations of personality."²³⁴ Professor Tribe emphasizes the need to determine when "governmental intrusion reaches a level of significance sufficient to invoke strict scrutiny as an invasion of personhood."²³⁵ This argument suggests that the level of scrutiny should depend on how vital to one's personhood, or individual identity, the liberty or threatened privacy right is.

Courts have accorded certain liberty and privacy rights significant protection under the "substantive" component of the Due Process Clause of the Fourteenth Amendment.²³⁶ There is no language that describes precisely which interests qualify as fundamental rights.²³⁷ Nevertheless, actions and decisions that are central to personal identity and personhood, such as those involving the rearing of children, procreation, vocation, and marriage, have been held fundamental under substantive due process.²³⁸ The Court recently declared in *Planned Parenthood v. Casey*,²³⁹

[M]atters . . . involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.²⁴⁰

Closely related to personhood is the notion of identity, which can mean different things. Identity may simply mean that which defines each individual, that is, "being the same with something described."²⁴¹ In that sense, identity remains fixed. Identity, however, may implicate one's sense of self and one's role in the world. Understood in that way, identity becomes closely linked to personhood. The Court ex-

233. Compare *Whalen v. Roe*, 429 U.S. 589 (1977) (upholding New York statute that requires that copies of prescriptions for certain drugs be submitted to the state) with *Griswold v. Connecticut*, 381 U.S. 479 (1965) (upholding the fundamental right of marital privacy in making contraceptive decisions).

234. TRIBE, *supra* note 207, § 15-9, at 1330.

235. *Id.*

236. See *id.* § 15-3, at 1308-09. "[I]t is settled that the due process clause of the Fourteenth Amendment applies to matters of substantive law as well as to matters of procedure. Thus all fundamental rights comprised within the term liberty are protected by the Federal Constitution from invasion by the States." *Planned Parenthood v. Casey*, 112 S. Ct. 2791, 2804 (1992) (quoting *Whitney v. California*, 274 U.S. 357, 372 (1927) (Brandeis, J., concurring)).

237. "[T]he full scope of the liberty guaranteed by the Due Process Clause cannot be found in or limited by the precise terms of the specific guarantees elsewhere provided in the Constitution." 112 S. Ct. at 2805 (quoting *Poe v. Ullman*, 367 U.S. 497, 543 (1961) (Harlan, J., dissenting)).

238. See TRIBE, *supra* note 207, § 15-1, at 1303-04.

239. 112 S. Ct. 2791 (1992).

240. 112 S. Ct. at 2807.

241. WEBSTER'S THIRD NEW INTERNATIONAL DICTIONARY 1123 (1986).

pressed this second meaning of identity, in *Whalen v. Roe*,²⁴² when it described identity as “the interest in independence in making certain kinds of important decisions.”²⁴³

Some types of genetic data may influence personhood and the latter, more complex definition of personal identity.²⁴⁴ While contracting chicken pox has virtually no effect on identity, the knowledge that one carries a disease gene may influence one’s self-perception and definition of “one’s own concept of existence” in a way most infectious diseases do not.²⁴⁵ Consequently, compelling an adult to have genetic testing does not merely involve the bodily intrusion of collecting a blood sample; it can also determine whether one is forced to learn something about herself she may have good reason to avoid, thus violating “the interest in independence in making certain kinds of important decisions.”²⁴⁶

Among those important decisions is the right *not* to know whether one carries a disease gene.²⁴⁷ People may resist testing to avoid the potential for genetic discrimination by insurers and employers,²⁴⁸ personal crisis,²⁴⁹ or difficult personal decisions.²⁵⁰ Many families find it burdensome to face the reproductive options and tests available to them today.²⁵¹ Some believe testing only leads to worry: one may have a late onset gene for which there is no cure, or one may be at risk of passing a disease gene to one’s child. In the latter case, the only choices may be failure to reproduce, accepting the risk of having an affected child, artificial insemination from a donor or ovum donation,

242. 429 U.S. 589 (1977).

243. 429 U.S. at 599-600.

244. See *supra* notes 35-39 and accompanying text.

245. Of course, some infectious disease, such as AIDS, syphilis, and gonorrhea, may be important to one’s identity given that these diseases are generally contracted through sexual contact or intravenous drug use, and therefore, for some people may be a reflection of behavior and identity. These diseases may be as intimately connected with one’s identity as genetic diseases, but for different reasons.

246. *Whalen v. Roe*, 429 U.S. 589, 599-600 (1977).

247. This is not to claim that the right is absolute. See *infra* text accompanying note 277.

248. See *supra* note 8 and accompanying text.

249. See *supra* text accompanying notes 36-39. Finding that one is a carrier, even if one will not develop a disease, can affect self-image or self-esteem. KELLEY, *supra* note 158, at 111-12; Grobstein, *supra* note 156, at 112; Schild, *supra* note 155, at 141. Identification of genetic disorders or carrier status can be a contributing factor in marital discord, divorce, or other family problems. Hollerbach, *supra* note 158, at 179-80; Audrey T. McCollum & Ruth L. Silverberg, *Psychosocial Advocacy*, in COUNSELING IN GENETICS, *supra* note 83, at 239, 241-42.

250. See John Pearn, *Decision-Making and Reproductive Choice*, in COUNSELING IN GENETICS, *supra* note 83 at 223, 223. One scholar notes the different personal meaning genetic testing can have for different people depending on their beliefs, social relationships, and place in life. Sorenson, *supra* note 21, at 174-178.

251. Many families expressed to this Note’s author the anxiety they experienced in having reproductive options available to them, such as prenatal testing. Some felt overwhelmed by the choice; others felt an obligation to avail themselves of prenatal testing despite uncertainty about what they would do with the information.

or prenatal testing with an option to terminate.²⁵² For families who oppose manipulating the genetic outcome of their offspring, genetic testing may imply a desire to alter the outcome, which would violate their strongly held principles.²⁵³

The genetic counseling community strongly believes that individuals should make their own determinations about whether to have genetic testing.²⁵⁴ Nondirective counseling, the guiding principle in genetic counseling, is based on informed consent: once people learn their risks and options, they can make educated decisions based on personal values and beliefs.²⁵⁵ Genetic testing is often intimately connected with personal reproductive decisions, and thus no one should decide which choice is best for another. Even deciding to learn whether one carries a deleterious gene, irrespective of possible reproductive decisions, is deeply personal. Given the very personal nature of genetic data, the right to decide whether to learn if one carries a disease gene should be accorded the status of a fundamental privacy right.

C. *Mandatory Genetic Testing Infringes Fundamental Rights*

When the "aspect of personhood" at stake is sufficient — or when the right involved is fundamental — the Due Process Clause requires that invasions of privacy receive more than minimal scrutiny.²⁵⁶ Courts have used intermediate scrutiny in criminal cases in which the violation of privacy involved bodily intrusions, such as blood testing for alcohol levels and the removal of contraband from a suspect's body cavities.²⁵⁷ The Supreme Court has deemed other aspects of personal

252. See *supra* notes 82-83 and accompanying text.

253. There are reasons, however, to have testing even if one would do nothing to alter the outcome. Testing allows one to be emotionally prepared for a child with a genetic disease, and it gives the obstetrician the opportunity to make special delivery provisions or to be prepared for complications. See *supra* text accompanying note 50.

254. See Grobstein, *supra* note 156, at 108-10; Kessler, *supra* note 158, at 85-89; Ruth L. Silverberg & Lynn Godmilow, *The Process of Genetic Counseling*, in *COUNSELING IN GENETICS*, *supra* note 83, at 281, 287-88.

255. See HARPER, *supra* note 13, at 13; Kessler, *The Genetic Counseling Session*, *supra* note 158, at 85-87; Silverberg & Godmilow, *supra* note 254, at 283-84, 286-88. For a new perspective on the meaning of nondirective counseling, see Mark Yarborough et al., *The Role of Beneficence in Clinical Genetics: Non-Directive Counseling Reconsidered*, 10 *THEORETICAL MED.* 139 (1989). For the view that nondirective counseling is unattainable, see Angus Clarke, *Is Non-Directive Genetic Counselling Possible?*, 338 *LANCET* 998 (1991).

256. *TRIBE*, *supra* note 207, § 15-9, at 1331-32.

257. The Supreme Court did not find the use of medical testing to determine blood alcohol levels in a man arrested for intoxicated driving unreasonable. *Schmerber v. California*, 384 U.S. 757 (1966). In this case, the Court rejected Schmerber's substantive due process claim. In addition, the Court argued that although "[c]ompelled submission fails on one view to respect the 'inviolability of human personality,'" 384 U.S. at 762 (quoting *Miranda v. Arizona*, 384 U.S. 436, 460 (1966)), the Fifth Amendment self-incrimination prohibition was not violated because "[n]ot even a shadow of testimonial compulsion . . . was involved." 384 U.S. at 765. An earlier decision, however, found impermissible policemen's attempts to remove capsules from the mouth

autonomy that are more deeply related to one's personhood — such as certain privacy rights — sufficiently fundamental to apply the strict scrutiny test.²⁵⁸ Examples of such constitutionally protected private decisions include marriage,²⁵⁹ procreation,²⁶⁰ and childrearing.²⁶¹ A strict scrutiny standard requires that the state's justification be compelling and that its infringement be narrowly tailored to that interest.²⁶²

The Supreme Court has applied strict scrutiny to analyze legislation that encroaches on certain fundamental rights, although it has not always explicitly defined its approach as such. For example, it struck down a Connecticut birth control statute in *Griswold v. Connecticut*²⁶³ because it impinged upon the marital relationship, which is within the "zone of privacy created by several fundamental constitutional guarantees," including substantive due process.²⁶⁴ The Court's vehemence in defining the right as fundamental hinted at a strict scrutiny approach.²⁶⁵

Perhaps the clearest example of the Court's strict scrutiny approach is in *Roe v. Wade*.²⁶⁶ In *Roe*, the Court held that under the Due Process Clause the privacy right to make reproductive decisions could only be infringed upon when the state's legitimate "interests in safeguarding health, in maintaining medical standards, and in protecting potential life . . . [are] sufficiently compelling."²⁶⁷ Citing *Griswold*, the Court declared: "Where certain 'fundamental rights' are involved, the Court has held that regulations limiting these rights may be justified only by a 'compelling state interest,' . . . and that legislative enactments must be narrowly drawn to express only the legitimate state

of a suspected narcotics dealer as well as orders that a physician induce vomiting to retrieve the capsules. *Rochin v. California*, 342 U.S. 165 (1952), *overruled by* *Mapp v. Ohio*, 367 U.S. 643 (1961). The Court's criticism of the bodily intrusion was not based on the violation of a different aspect of personhood than that described above. The level of intrusion was simply more egregious — "conduct that shocks the conscience." 342 U.S. at 172.

258. See *Carey v. Population Servs. Intl.*, 431 U.S. 678 (1977); *Roe v. Wade*, 410 U.S. 113 (1973); *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Damme*, *supra* note 21, at 820; *Green & Capron*, *supra* note 91, at 70-71; see *infra* notes 263-74 and accompanying text.

259. *Loving v. Virginia*, 388 U.S. 1 (1967).

260. *Skinner v. Oklahoma*, 316 U.S. 535 (1942).

261. *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

262. See *infra* note 268 and accompanying text.

263. 381 U.S. 479 (1965).

264. The Court also derived Constitutional support for the right to privacy from the First, Fourth, Fifth, and Ninth Amendments. 381 U.S. at 483-84; see *TRIBE*, *supra* note 207, § 15-3, at 1308-09.

265. See 381 U.S. at 485. A few years later, in *Eisenstadt v. Baird*, 405 U.S. 438 (1972), the Court protected this fundamental right by condemning a Massachusetts law that prohibited the distribution of contraceptives to single people because it violated the Equal Protection Clause.

266. 410 U.S. 113 (1973).

267. 410 U.S. at 154.

interests at stake."²⁶⁸

In the recent *Planned Parenthood v. Casey*²⁶⁹ decision, the Court upheld the central premise of *Roe*.²⁷⁰ It did, however, eliminate strict scrutiny analysis of "any regulation touching upon the abortion decision,"²⁷¹ which post-*Roe* decisions had used. Instead, the Court allows regulations that do not actually prohibit abortion, if they do not impose an "undue burden" on the individual.²⁷² Consequently, the state may encourage women to consider arguments against abortion as long as the right to an abortion is not unduly burdened.²⁷³

Nevertheless, this decision does not eliminate the strict scrutiny standard as applied to the *infringement* of fundamental privacy rights. As the Court noted, "not every law which makes a right more difficult to exercise is, *ipso facto*, an infringement of that right."²⁷⁴ Thus the Court essentially held that when the right is not wholly abridged, but simply made a bit more difficult to exercise, the undue burden standard applies. Implicit in the holding is that when legislation actually denies a fundamental right — as in the proscription of abortion — only a compelling and narrowly tailored state interest, such as protecting the potentiality of viable life, can survive constitutional scrutiny.

The level of personal privacy at stake in mandatory genetic testing is fundamental in the same way as the right to make procreative decisions. The decision to receive genetic testing bears on aspects of personhood and bodily integrity in many of the ways procreative decisions do. Both irrevocably affect one's control over one's destiny, both strongly influence one's identity,²⁷⁵ and both are deeply personal

268. 410 U.S. at 155. Applying *Roe's* explicit delineation of strict scrutiny, the Court, in *Carey v. Population Servs. Intl.*, 431 U.S. 678 (1977), affirmed *inter alia* the unconstitutionality of a statute prohibiting the sale of contraceptives to minors under sixteen. While the Court did not agree on the reasons the provision was unconstitutional, it did agree that the "same test must be applied to state regulations that burden an individual's right to decide to prevent conception or terminate pregnancy." The statute must fulfil a "compelling state interest" and be "narrowly drawn" in protecting legitimate state interests. 431 U.S. at 688 (quoting 410 U.S. at 155).

269. 112 S. Ct. 2791 (1992).

270. The *Casey* Court, however, rejected the *Roe* Court's trimester framework, which held that during the first trimester, the state cannot interfere with the judgment of the woman's physician; in the second trimester, the state can regulate abortion to promote the health of the mother; and in the third trimester, it can regulate or prohibit abortion to protect the potentiality of human life. 410 U.S. at 164-65. The *Casey* Court ruled that the relevant time frame is pre- and post-viability. Thus before viability, the state cannot prohibit abortion, although it can promulgate regulations that do not impose an "undue burden on the right" to have an abortion. 112 S. Ct. at 2821 (plurality opinion). After viability, the state may "regulate, and even proscribe, abortion except where it is necessary . . . for the preservation of the life or health of the mother." 112 S. Ct. at 2821 (quoting 410 U.S. at 164-65).

271. 112 S. Ct. at 2817.

272. 112 S. Ct. at 2820.

273. 112 S. Ct. at 2818.

274. 112 S. Ct. at 2818.

275. "[P]eople have organized intimate relationships and made choices that define their views of themselves and their places in society, in reliance on the availability of abortion in the event that contraception should fail." 112 S. Ct. at 2809.

decisions.²⁷⁶ Certainly the results influence the very reproductive decisions that the Court has treated as fundamental privacy rights. Consequently, statutes infringing upon decisions whether to have genetic testing deserve strict scrutiny analysis under the Due Process Clause.

D. *Mandatory Genetic Testing Under the Strict Scrutiny Standard*

As is true with the fundamental right to make reproductive decisions, the right to make decisions regarding genetic testing is not absolute.²⁷⁷ Therefore under strict scrutiny analysis courts apply a two-part test: Is there a compelling state interest and is the legislation narrowly tailored to that interest?²⁷⁸ Subsection III.D.1 argues that the state interest in mandating genetic testing of one person for the benefit of another is not compelling and therefore it is unconstitutional. Subsection III.D.2 reasons that, even if there is a compelling state interest, mandatory testing for incurable genetic diseases cannot be sufficiently tailored to the state interest and therefore would still be unconstitutional. While legislation compelling genetic testing for curable diseases might arguably be narrowly tailored, this section argues normatively that the state should not compel such testing, even if a court found that the state interest is compelling.

1. *The State Interest*

Various justifications have been suggested for mandatory genetic testing: to gather information regarding the incidence and severity of genetic disease, to protect the public from genetic disease, to conserve health resources, and to protect future generations from genetic disease.²⁷⁹ In addition, many of the state's interests apply to the harms that may arise from nondisclosure, as discussed in subsection II.B.2.b. Among those interests is a common justification for compulsory genetic testing: some identified carriers will prevent the birth of children with detectable genetic diseases, which would benefit future generations. Although each genetic disease is relatively rare, compulsory testing could result in an overall decrease in the incidence of genetic disease, thus protecting future generations to some extent.²⁸⁰ Argua-

276. Of course, there are also differences between reproductive and genetic testing decisions. The former involves the loss of control over one's body. Another distinction is the existence of third parties with something at stake in the genetics context. In abortion cases, however, the father has some interest in the outcome of the decision whether to abort, which may conflict with the mother's desire.

277. See 112 S. Ct. at 2821 (plurality opinion); *Roe v. Wade*, 410 U.S. 113, 154 (1973).

278. See 410 U.S. at 155.

279. Green & Capron, *supra* note 91, at 69, 74.

280. This argument is less concerned with actually protecting an affected fetus than eliminating disease genes from the gene pool so that fewer fetuses would be conceived with genetic diseases. For a discussion regarding the protection of affected fetuses, see *infra* notes 292-96 and accompanying text.

bly, even if the decrease in the incidence of genetic disease is small, the state would have an interest in achieving this result. It is highly unlikely, however, that the Court would find a state's interest in future generations compelling. In fact, *Roe* and *Casey* explicitly declare that the state's compelling interest in protecting the potentiality of life begins only at the point of viability.²⁸¹ If the state's interest in protecting the unviable fetus is not compelling, surely the state must have even less interest in protecting the unconceived.

Another potentially compelling state interest is to protect existing life. One might defend legislation that mandates genetic testing as a public health measure to protect the life of the state's citizens. The Supreme Court has explicitly held that the state interest in protecting the potentiality of life is sufficiently compelling to infringe upon a fundamental right of privacy when legislation is narrowly drawn to this interest.²⁸² Certainly, one might argue, the state's interest in protecting the lives of existing persons is equally compelling; thus mandatory testing of genetic diseases that threaten one's life and well-being might be justified as a compelling legislative interest.

Yet a closer examination of the distinctions between decisions to abort and refusals to be tested for the benefit of another suggests that the interest in protecting life is not compelling with regard to the latter. Prohibiting abortion to protect a viable fetus is different from the requirement that one undergo genetic testing to provide information that may be crucial to protect another life.²⁸³ In the former instance, the state forbids an action that causes harm; in other words, it prevents misfeasance. In the latter case, the state compels one to help another through an affirmative action; that is, it prohibits nonfeasance. These distinctions are significant in the tort context in which one has a duty to avoid activities that cause harm, but in which one does not have an affirmative duty to protect others from harm one has not caused.²⁸⁴

This tort analysis is useful in balancing the harms and benefits to determine whether the state interest is in fact compelling. First, it helps establish which mandate is more intrusive. Proscription of misfeasance is less intrusive than proscription of nonfeasance. When the state's interest in protecting life requires that one avoid causing harm, the infringement is slighter than when it requires that one actively correct a harm one has not caused. In addition, the misfeasance-nonfeasance distinction reflects the immediacy of the harm the state is trying to avert. In the former instance, preventing the misfeasant act in-

281. 112 S. Ct at 2821 (plurality opinion); 410 U.S. at 164-65.

282. 410 U.S. at 155.

283. For example, if the genetic disease were curable, knowledge that one has the gene might be crucial to the administration of whatever treatment is needed before symptoms manifest.

284. See *supra* text accompanying notes 190-94.

stantly protects the threatened life. In the latter, requiring that one aid another in obtaining information that might be necessary to cure a disease does not immediately lead to that cure. The information is only the first step. Moreover, the harm the relative faces is surely less imminent than the harm the viable fetus faces when abortion is at issue. Thus, the level of intrusion is less in the genetics context than in the abortion context. Further, the harm to be averted through genetic testing is more remote and the cure less directly linked to the state's mandate. Therefore, the final balance, when applying this tort analogy, weighs against finding that the state has a compelling interest in protecting life by requiring one to undergo testing just to aid a relative.

Some lower courts have addressed the issue whether the state may compel an individual to undergo medical procedures for the sole purpose of protecting another's life — for example, the donation of bone marrow to leukemia patients or the donation of a kidney to people suffering from kidney disease. Most of these cases arise in situations in which the potential donor is incapable of providing informed consent. Consequently, the outcome often turns on who can decide, what standard of judgment should be used, and how great the harms and benefits are to the potential donee.²⁸⁵

Only one case has actually addressed whether the state can compel a competent adult to submit to medical procedures to aid another. In *McFall v. Shimp*,²⁸⁶ the court vehemently denied the plaintiff's request for a preliminary injunction to compel the only compatible donor to provide a lifesaving bone marrow transplant for the plaintiff. While noting that the defendant's refusal to help the plaintiff was "morally indefensible," the court declared

Our society . . . has as its first principle, the respect for the individual, and that society and government exist to protect the individual from being invaded and hurt by another. . . . For our law to *compel* defendant to

285. See, e.g., *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972) (declaring that parents have the right to consent to the donation of their seven-year-old daughter's kidney for the benefit of her identical twin, ostensibly under a standard of substituted judgment); *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990) (allowing mother of twins to refuse to consent to the donation of their bone marrow for the benefit of their father's son, who was their half-brother and who suffered from leukemia); *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969) (allowing the mother of an incompetent boy to consent to the removal of his kidney to save her other son, nominally under a standard of substituted judgment, although finding it to be in the incompetent son's best interest to prevent the loss of his brother); *In re Richardson*, 284 So. 2d 185 (La. Ct. App. 1973) (applying the best interest standard instead of substituted judgment to conclude that parents could not consent to the transplant of their minor, incompetent son's kidney into his sister); *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979) (allowing parents to give consent to the donation of their daughter's kidney for her brother's use because the potential harm to the proposed donor was minimal and the psychological benefits in saving her brother's life were great); *In re Guardianship of Pescinski*, 226 N.W.2d 180, 182 (Wis. 1975) (Denying the sister and guardian of adult incompetent male the power to consent to the removal of his kidney to save their sister because, when there is no benefit for the one who cannot consent, "no advantage should be taken of him.").

286. 10 Pa. D. & C.3d 90 (1978).

submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so . . . would impose a rule which would know no limits and one could not imagine where the line would be drawn. . . .

. . . For a society which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck from its sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence.²⁸⁷

McFall establishes convincing reasons why the state lacks a compelling interest in requiring a noncooperative relative to participate in genetic studies solely for the benefit of another, particularly when the compulsion would harm the defendant by forcing her to gain knowledge she has consciously avoided. Given this reasoning and the important distinction between misfeasance and nonfeasance, the state's interest in protecting life is not compelling. Consequently, mandatory testing to aid a relative is unconstitutional.

2. *The Narrowly Tailored Test*

Even assuming *arguendo*, that a court could find that the state's interest in protecting life is compelling, mandatory testing of one person for the benefit of another could only be constitutional if it were narrowly tailored to that compelling interest. To examine whether such a mandate is appropriately tailored, diseases must be distinguished on the basis of whether they are curable. This subsection argues that compulsory genetic testing can be narrowly tailored to the compelling state interest only when the disease is curable.

a. Incurable Genetic Diseases. Compulsory genetic screening of one person for the benefit of another raises many problems when the disease is incurable, as are the vast majority of detectable genetic diseases.²⁸⁸ Courts have generally upheld legislation to prevent the spread of contagious diseases.²⁸⁹ The state can more easily show, however, that it narrowly tailored such legislation to its purpose in those instances than it could for mandatory genetic testing for incurable diseases, which do not pose the immediate threat to current generations as do infectious ones.²⁹⁰ Therefore, the rationale that genetic testing is "necessary for the public health or the public safety" is much less convincing than the rationale based on the need to vaccinate a community against smallpox.²⁹¹

287. 10 Pa. D. & C.3d at 92.

288. In fact, the number of detectable genetic diseases without a cure increases as more genes are identified. Friedmann, *supra* note 6, at 412. Examples of detectable diseases without a cure include Huntington's disease, cystic fibrosis, neurofibromatosis, and some cancers. See Roberts, *supra* note 86, at 614.

289. Damme, *supra* note 21, at 803-04.

290. See *supra* notes 40-42 and accompanying text.

291. See *Jacobson v. Massachusetts*, 197 U.S. 11, 27 (1905).

Some might claim that protecting fetuses from genetic disease would be consistent with the state interest in protecting life. As long as the disease in question is incurable, however, compulsory testing could only “benefit” the fetus by giving couples the option to terminate pregnancies when fetuses are affected.²⁹² This result violates the state interest in protecting life. Given that the fetus is not considered a person under *Roe v. Wade*,²⁹³ whatever rights it has cannot supersede the rights of persons,²⁹⁴ at least when the only means of preventing its suffering is by abortion. That is, the right of the fetus not to be born, if it has such a right, cannot trump the privacy right to decide whether to have genetic testing. Notwithstanding ethical arguments that affected fetuses are spared suffering by preventing their birth,²⁹⁵ as long as they are considered nonpersons, their “right” not to be born must succumb to the rights of constitutionally recognized persons, at least before viability.

Moreover, the legal protection *Casey* offers fetuses after viability would be the very reason to find that they lack a legal right not to be born, even to prevent their suffering. Under *Casey*, the state’s interest in the viable fetus is compelling, thus justifying the state’s ability to infringe upon the mother’s right of privacy. The basis of the compelling interest, however, is to protect the potentiality of life, whether or not the fetus has a genetic disease. Thus the very reason to protect the fetus — to protect the potentiality of life — would undermine any claim that the fetus has a right not to be born.²⁹⁶ Consequently, as long as abortion is the only way to protect the fetus from genetic disease, compulsory testing is not narrowly tailored to a compelling state interest.

When incurable diseases are at issue, mandatory testing merely serves to pit one individual’s interest against another’s without fulfilling a compelling state interest. Bob’s interest in knowing whether he has the Huntington’s gene, for example, implicates his father’s interest in remaining ignorant. Superficially, the interest in gaining genetic information seems similar to the interest in avoiding genetic knowledge, but there is a striking difference. The avoidance of knowledge does not impinge on or take from another, it merely prevents another from

292. It might be argued that the fetus can be protected by the couple’s decision not to conceive. This solution, however, creates the problem of trying to protect life by preventing its existence, which boggles the imagination. “Protecting” the fetus through either means relates to the controversial wrongful life cases in which children born with detectable genetic diseases sue for their suffering in being born with such ailments. See *supra* note 167.

293. 410 U.S. 113, 157 (1973).

294. See *In re A.C.*, 573 A.2d 1235, 1244 (D.C. 1990) (en banc) (“Surely . . . a fetus cannot have rights . . . superior to those of a person who has already been born.”).

295. See James M. Gustafson, *Genetic Screening and Human Values*, in *ETHICAL, SOCIAL AND LEGAL DIMENSIONS*, *supra* note 21, at 201, 207.

296. See Damme, *supra* note 21, at 830.

gaining something. Bob's father, in refusing testing, does not deprive Bob of something he had.²⁹⁷ To fulfil Bob's interest, however, would require the violation of his father's interest. Bob's knowledge would be the source of his father's loss of chosen ignorance regarding Huntington's.²⁹⁸ In addition, it would require disclosure of personal data, which Bob's father may also want to avoid.²⁹⁹

Despite the benefits for Bob — described in detail in subsection II.B.2.b³⁰⁰ — if his father cooperated, Bob's father's privacy interests should not take second place to Bob's privacy interests. "[C]ourts have long recognized the wisdom of acting *as though* persons could never be used as means to the ends of others . . ." ³⁰¹ Whether or not judicial expression of this principle is disingenuous, it has ethical support.³⁰² To require mandatory testing in this case would be to treat Bob's father as a means to fulfil Bob's interests. While Bob's interests are significant, they do not involve a preventable disease, which presents different issues.³⁰³ If Huntington's were curable, Bob's father would probably choose to be tested to avoid succumbing to Huntington's. When there is nothing one can do to change one's fate, however, the desire not to know can be quite strong. Thus compelling Bob's father to be tested for an incurable disease does not narrowly serve a compelling state interest in protecting life.

Because Sarah's brother is already known to carry the gene for Duchenne's muscular dystrophy, however, the privacy concerns are far less compelling. Sarah's brother has not decided to avoid learning about his genetic status; he has simply chosen not to have his blood drawn to obtain a DNA sample. Thus the only arguable privacy intrusion would be the collection of a blood sample and the extraction of his DNA. Given the Supreme Court's holdings regarding bodily intrusion,³⁰⁴ his decision may not be viewed as a fundamental privacy interest so long as there are adequate safeguards against the use of the DNA sample for anything other than the determination of the characteristics of his muscular dystrophy gene: that is, if his genetic testing

297. This is much like the misfeasance-nonfeasance distinction discussed, *supra*, in the text accompanying notes 283-84.

298. The same cannot be said of Sarah's brother, which leads to a significant distinction between the two scenarios, as discussed below. *See infra* text accompanying notes 304-05.

299. *See supra* subsection II.B.2.a. This additional concern does not necessarily coexist with the desire not to know, but it potentially might.

300. *See also supra* text accompanying notes 62, 70, 82-86.

301. *TRIBE, supra* note 207, § 15-9, at 1335.

302. Immanuel Kant's moral imperative urges people to treat others as autonomous moral agents and to "[a]ct in such a way that you always treat humanity . . . never simply as a means, but always at the same time as an end." *IMMANUEL KANT, GROUNDWORK OF THE METAPHYSIC OF MORALS* 96 (H.J. Paton ed. & trans., 1964) (1785).

303. *See infra* subsection III.D.2.b.

304. *See, e.g., supra* note 257.

is purely informative.³⁰⁵ This situation more closely parallels the issues of disclosure addressed in Part II³⁰⁶ because a fundamental privacy right is not at stake.

b. *Curable Genetic Diseases.* While the state cannot narrowly tailor mandatory genetic testing of incurable diseases to its compelling interest in protecting lives — if such an interest could be found compelling, which it should not³⁰⁷ — it potentially can be so drawn for detection of a curable disease. It is important to note, however, that for two reasons the conflicts described in this Note are far less likely to arise when a cure is available. First, if Bob's father knew treatment could prevent Huntington's from developing, for example, he would have good reason to want to know if he is a carrier. Therefore, the availability of a cure may strongly motivate otherwise uncooperative relatives to participate in family studies; they would have a vested interest in finding out whether they were carriers. Disclosure issues might still arise in these settings, however.³⁰⁸ Second, as long as the cure involves gene therapy, linkage analysis probably will not be required. That is, because gene therapy involves correcting the specific genetic defect, it would almost always be necessary to have isolated the disease gene and to have identified the particular mutation in the patient. If linkage analysis is the only method to test for the gene, gene therapy is unlikely to be available for that disease. To state this conversely, when gene therapy becomes feasible for a particular disease, it almost surely will no longer be necessary to use other family members for genetic testing. Thus, in those instances, the conflicts this Part discusses would dissolve. Nonetheless, viable gene therapy is years away for most genetic diseases, especially dominant diseases such as Huntington's.

If such conflicts arise when a cure is available and a court finds that the state's interest in protecting life by requiring genetic testing is compelling, mandatory genetic testing is arguably narrowly drawn to this interest. Newborn screening statutes, for example, require the testing of select genetic diseases that can be virtually "cured" through restrictive diets or medications.³⁰⁹ Even diseases such as sickle cell anemia, which are not exactly "curable," can be significantly amelio-

305. Cf. *supra* notes 63-64 and accompanying text.

306. See *supra* text accompanying notes 88-200.

307. See *supra* text accompanying notes 283-87.

308. See *supra* Part II.

309. Preventive measures can sometimes mitigate the harm from nonworking genes. For example, providing the affected individual with a restrictive diet can virtually cure PKU. An individual with PKU has a pair of nonworking genes that, if they functioned properly, would encode the enzyme (phenylalanine hydroxylase) that breaks down an amino acid called phenylalanine. When an affected individual consumes food with phenylalanine, the body cannot metabolize the amino acid; consequently, excess stores of the compound accumulate, causing irreparable neurological damage. Diets with low levels of phenylalanine prevent the accumulation of the amino acid. STRYER, *supra* note 47, at 426-27; Ara Tourian & James B. Sidbury,

rated with prophylactic measures that greatly lengthen one's lifespan.³¹⁰ The clear purpose behind these statutes is to protect individuals from life-threatening diseases. Newborn screening statutes that involve curable diseases are probably sufficiently narrowly tailored to the state's interest in protecting life, especially because no alternative approaches exist to fulfil this state interest.³¹¹

If an individual is at risk for affliction with a curable genetic disease, requiring the appropriate relative to be screened would fulfil the state's interest in protecting that person. If the person is merely at risk for being an unaffected carrier, the question becomes more complicated. In this scenario, the potential carrier's life is not at risk, but the lives of her future children are. Under the analysis of *Roe* and *Casey*, mandatory genetic testing in this case could only be constitutional when the at-risk fetus becomes viable.

Even if both parts of the strict scrutiny analysis were fulfilled for curable diseases, however, public policy argues against mandating such testing. To use one person for the benefit of another, as the *McFall* court argued, goes against the principles upon which our country is founded.³¹² Moreover, it conflicts with the important Kantian principle that individuals should not be treated as the means to others' ends.³¹³ Although an individual's unwillingness to help another might be morally reprehensible, it does not follow that the state should compel testing when testing implicates fundamental privacy rights. Finally and most importantly, the belief in the genetic counseling community that one should never be compelled to undergo genetic testing stems from fear of repeating the abuses of genetic testing and the eugenics movements that plagued our past.³¹⁴ To prevent genetic

Phenylketonuria and Hyperphenylalaninemia, in THE METABOLIC BASIS OF INHERITED DISEASE, supra note 16, at 270, 271; see supra note 52.

310. *See supra* note 52.

311. Even if the state interest in mandating genetic testing solely for the benefit of another is not compelling, it might be for newborn screening purposes. In that case, testing is for the purpose of the testee, rather than a third party. Therefore, the concerns of using one individual for another's purpose do not apply. The problem of requiring one to undergo a procedure without one's consent remains, however. Nevertheless, this issue is different from Bob's scenario because it involves infants who are incapable of giving consent. It is possible that newborn screening is only constitutional if parents have the right to refuse testing, as they do in some states, *see, e.g.*, FLA. STA. § 383.14 (1991); LA. REV. STAT. ANN. § 40:1299.1 (West 1992); MISS. CODE ANN. § 41-21-203 (Supp. 1992); NEV. REV. STAT. § 442.115 (1991); N.H. REV. STAT. ANN. § 132:10-c (1990); N.M. STAT. ANN. § 24-1-6(A) (Michie 1991), or if they must give consent before such tests are performed. Even were a compelling state interest found in the newborn screening context, there is the additional problem that many mandatory screening statutes do not actually require medical treatment for infants identified as having one of the inborn errors of metabolism. *See Damme, supra* note 21, at 823. This potentially raises questions about how narrowly tailored the statutes are to their purpose. The discussion of these issues, however, is beyond the scope of this Note.

312. *See supra* text accompanying notes 286-87.

313. *See supra* notes 301-02 and accompanying text.

314. *See supra* note 6.

testing from stepping on a path that could potentially lead to actions just short of eugenics, we must maintain voluntary genetic testing. The notion of disease and illness is not static, nor is it void of value judgments.³¹⁵ To compel testing to help a relative learn whether she has Huntington's, for example, may rest at the top of a slippery slope that could lead to compulsory testing to help a relative learn about risks of "afflictions," such as sterility, mental disability, or dwarfing syndromes. Therefore our legal system should carefully protect the principle of voluntariness with regard to genetic testing.

Thus, to summarize this Part, under the Due Process Clause, the right to refuse to learn about one's genetic status should receive constitutional protection. Such testing involves fundamental aspects of autonomy and personhood, which are akin to other constitutionally protected privacy rights, including the right to make important decisions regarding marriage, procreation, and contraception. Because the state's interest is not compelling, mandatory genetic testing of one person for the benefit of another would fail the strict scrutiny test and would be therefore be unconstitutional.

Even assuming *arguendo* that courts would find the state interest compelling, compulsory testing for incurable diseases is not narrowly tailored to the state interest and would therefore still be constitutionally prohibited. If a curable disease is at stake, the tailoring test would arguably be met. Nonetheless, there are strong normative and policy arguments against compulsory testing in those contexts. Thus, because no case law specifically precludes mandatory genetic testing for another's benefit,³¹⁶ legislation should be enacted to protect this important privacy right and to maintain respect for the importance of voluntariness in genetic testing.³¹⁷

IV. GUIDELINES FOR COURTS AND LEGISLATURES

Courts or legislatures faced with the issues of mandatory genetic testing and the disclosure of test results should consider the legal and constitutional implications that these two issues pose. Section IV.A proposes guidelines so that courts and legislatures can protect the fundamental privacy interests involved in making decisions regarding whether to have genetic testing. Section IV.B describes the delicate balancing of interests necessary to determine when test results may be

315. For an insightful discussion of the meaning of disease in the genetics context, see Arthur L. Caplan, *If Gene Therapy Is the Cure, What Is the Disease?* in, GENE MAPPING, *supra* note 1, at 128. Particularly relevant is the fact that genetics is the study of variation. While it seems unproblematic to identify Tay Sachs as a disease, it is important to note that Tay Sachs represents a genetic variant that we call "abnormal." The line drawn between "abnormal" variation as disease, and "normal" variation as health is not always so clear. See *id.* at 131.

316. Green & Capron, *supra* note 91, at 76.

317. See *infra* Part IV.

disclosed. Any legislative proposal should recognize the competing and complex interests at stake.

A. Genetic Testing

Legislation or judicial decisions should clearly prohibit involuntary genetic testing for incurable disease.³¹⁸ People should not be compelled to have genetic testing for the benefit of a relative, particularly if they do not know their genetic status. Legislation or judicial decisions should be made with an eye toward encouraging informed consent, education, and genetic counseling services so that people can determine whether genetic testing is appropriate for them. Decisions regarding genetic testing and reproductive choices should be left entirely to the discretion of the patient because these decisions involve fundamental rights of privacy and autonomy. Consequently, the state should not interfere by compelling such testing or by imposing moral views that encourage certain decisions over others. Moreover, compulsory testing would likely fail constitutional requirements.³¹⁹

B. Disclosure of Test Results

Legislatures or courts should not mandate disclosure to high-risk relatives, even when there may be clear benefits to the relatives. Instead, physicians or genetic counselors should have the privilege to disclose test results if the interest in informing relatives strongly outweighs the interest in confidentiality. To compare these interests, courts and legislatures should consider the following criteria:

a) The physician or counselor should educate the patient about the need to inform family members at significant risk of carrying the disease gene. If the patient refuses, the physician or counselor should try to elicit the patient's concerns.

b) The family history and nature of the genetic disease should show that the relatives in question have a significant risk of carrying the gene and having an affected child, a significant risk of developing the genetic disease themselves, or a significant susceptibility to a multifactorial disease. The significance of the risk should include both the probability of carrying the gene and the severity of the potential harm.

c) At-risk relatives must have options to use the information to make reproductive decisions through prenatal testing or gene therapy; to take preventive health care measures, such as prophylactic surgery, cancer screening, diet alteration, avoidance of behavior that can cause

318. This prohibition, however, probably would not include newborn screening statutes that screen for treatable diseases or those that can be ameliorated. See *supra* notes 309-11 and accompanying text.

319. See *supra* Part III.

severe symptoms, or gene therapy; or to make lifestyle choices, particularly when late-onset diseases are involved.

d) The harm in disclosure should be assessed by considering such factors as social stigma, the effect on other people's willingness to be tested, and the patient's reasons for failing to disclose.

e) The physician or counselor should tell the patient she plans to inform the particular family members as well as the reasons for making such a decision.

f) The physician or counselor should avoid revealing the patient's identity when informing the relative or the relative's physician of the risk, whenever possible. In addition, the physician or counselor should offer referrals for genetic counseling at genetic centers in the relative's area.

Given the presumption in favor of confidentiality, a close examination of the above factors best ensures that disclosure only takes place to prevent the greater harm.

CONCLUSION

Genetic testing has the potential to affect far more people than just the proband. When conflicts arise between the patient and family members with an arguably vested interest in knowing the patient's genetic status, various legal principles must be applied. Once one has decided to learn whether one carries a particular gene, the interests at stake are based on common law principles. Thus, in carefully prescribed situations, the carrier-proband's interests may be overridden to prevent relatives from suffering harm. A presumption in favor of preserving confidentiality should prevail unless there is evidence that the harm in failing to disclose is greater than the harm from disclosure. To perform this balancing test adequately, courts and legislatures must carefully consider a number of factors. Physicians or genetic counselors, however, should never be compelled to warn relatives at risk because the patient does not create the risk. Similarly, the proband has no legal duty to warn relatives, though she may have a moral duty. The proband does not have the requisite special relationship with her siblings, cousins, and other relatives to impose such a legal duty. Moreover, she has no affirmative duty to protect others from perils she has not caused.³²⁰

When someone, for his own benefit, wants to have a relative tested, the relative's constitutional privacy and autonomy interests in deciding whether to learn of his genetic status should not be trumped by the

320. When the proband is a parent, she of course has special duties to protect her minor child, given the custodial nature of this relationship. See *supra* text accompanying note 198. When the "identifiable" victim is a living minor child, different issues arise regarding the legal principles of minors and consent in the medical context. Such issues are beyond the scope of this Note.

other's interest in gaining genetic information. It is unlikely that there is a compelling state interest in such instances, thus compulsory testing would be unconstitutional. Even if a court were to find that the state's interest is compelling, however, testing for incurable disease would not be narrowly drawn to the state interest. Consequently, mandatory tests for incurable diseases would still fail strict scrutiny analysis. Yet, even if courts found mandatory testing for curable diseases constitutional, genetic testing for the benefit of a relative should always remain voluntary for public policy and normative reasons.

Ideally, the scenarios that lead to the consideration of these principles would never arise because the interests of all family members would be consistent. Nevertheless, given human nature, such conflicts do sometimes develop. Courts or legislatures faced with these issues should follow the proposed guidelines to ensure that the applicable constitutional and common law principles properly protect the competing interests.