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**THE ARGUMENT AGAINST A PHYSICIAN'S DUTY TO WARN  
FOR GENETIC DISEASES: THE CONFLICTS CREATED  
BY *SAFER V. ESTATE OF PACK*<sup>1</sup>**

I. INTRODUCTION

The Superior Court of New Jersey, in *Safer v. Estate of Pack*, held that a physician has a duty to warn individuals known to be at risk of avoidable harm from a genetically transmissible condition.<sup>2</sup> The Superior Court stated that there was no essential difference between genetic diseases and other contagious or infectious diseases and, therefore, imposed a duty on physicians to warn a patient's family members at risk of contracting a genetic disease.<sup>3</sup> The court avoided addressing whether it is practical for a physician to warn a patient's family members and whether there is an unrealistic burden on physicians forced to warn a patient's family members, particularly with respect to young children at risk, as was the case in *Safer*.<sup>4</sup> In concluding that a physician has a duty to warn for genetic diseases, the Superior Court of New Jersey has created serious implications for a patient's privacy rights, patient-physician confidentiality, as well as a patient's health and safety.

II. THE CASE

In the 1950s and 1960s, Robert Batkin, father of Donna Safer, was a patient of Dr. George Pack, a specialist in treating and removing cancerous tumors.<sup>5</sup> In 1964, Mr. Batkin died when Donna Safer was ten years old.<sup>6</sup> In 1969, Dr. Pack died.<sup>7</sup> More than twenty years later, in 1990, Mrs. Safer was diagnosed with a cancerous blockage of the colon and polyposis.<sup>8</sup> She underwent numerous surgeries and chemotherapy to treat the cancer.<sup>9</sup> The next year, Mrs. Safer learned her

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1. 677 A.2d 1188 (N.J. Sup. Ct. App. Div. 1996), *cert. denied*, 683 A.2d 1163 (N.J. 1996).

2. *See id.* at 1192-93.

3. *See id.*; *see also infra* notes 49-53 and accompanying text.

4. *See id.* at 1192.

5. *See id.* at 1190.

6. *See id.*

7. *See id.*

8. *See id.* Polyposis is a hereditary condition marked by multiple polyps lining the intestines, especially the colon, and it has a high potential for malignancy. *See Miller-Keane's Encyclopedia & Dictionary of Medicine, Nursing, & Allied Health* 1189 (5th ed. 1992) [hereinafter MILLER-KEANE'S ENCYCLOPEDIA].

9. *See Safer*, 677 A.2d at 1190.

father had polyposis, a hereditary condition that leads to metastatic colorectal cancer if left untreated.<sup>10</sup> Mrs. Safer and her husband sued Dr. Pack's estate alleging Dr. Pack knew of the hereditary nature of the disease yet negligently failed to warn her of the risk of contracting the genetic disease.<sup>11</sup>

The trial court dismissed the case for lack of evidence regarding whether or not Dr. Pack had warned Mrs. Safer's father about the heritability of the disease.<sup>12</sup> Having none of Dr. Pack's medical records, the trial court relied on the testimony of medical experts of both parties and Mrs. Safer's mother's testimony.<sup>13</sup> According to the trial court, Dr. Pack had no duty to Mrs. Safer because a physician has a duty to warn in only two situations: when there is a physician-patient relationship or when there are circumstances requiring the protection of the public's health.<sup>14</sup>

In this case, Mrs. Safer was not a patient of Dr. Pack.<sup>15</sup> The court held that Dr. Pack's duty to warn extended only to his patient, Mrs. Safer's father.<sup>16</sup> As for protecting the public health, the trial court acknowledged that contagious or infectious diseases, which may be easily spread between persons, warrant public health protection.<sup>17</sup> However, the trial court believed genetic diseases to be threats which are already present in an individual, do not spread between individuals, and, thus, do not rise to the public health level of contagious or infectious diseases.<sup>18</sup>

On appeal, the Superior Court held that there is

[N]o impediment . . . to recognizing a physician's duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition . . . . [T]here is no essential difference between the type of genetic threat at issue here and the menace of infection, contagion or a threat of physical harm.<sup>19</sup>

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10. See *id.* For a detailed explanation of metastatic cancer, see THE MERCK MANUAL at 1211-12 (15th ed. 1987).

11. See *Safer*, 677 A.2d at 1190.

12. See *id.*

13. See *id.*

14. See *id.*

15. See *id.*

16. See *id.*

17. See *Safer*, 677 A.2d 1190.

18. See *id.* at 1190-91. The trial court relied on *Pate v. Threlkel* which held that a physician did not owe a duty to warn a patient's child of the threat of a genetic disease. 661 So.2d 278, 282 (Fla. 1995). The trial court stated that *Pate* was the only case on point regarding genetically transmissible diseases. See *Safer*, 677 A.2d at 1191.

19. See *Safer*, 677 A.2d at 1192.

The Superior Court reversed the trial court's order dismissing the complaint and remanded the case for further proceedings consistent with their above holding.<sup>20</sup>

### III. LEGAL BACKGROUND

Courts have held physicians and psychiatrists liable for failing to warn patients and third parties. For example, in 1976, the Supreme Court of California held that a therapist had a duty to warn third parties known to be at risk of immediate danger in *Tarasoff v. Regents of the University of California*.<sup>21</sup> And, in New Jersey, even before *Safer*, the Superior Court of New Jersey followed *Tarasoff's* non-binding precedent and applied the same duty to warn in *McIntosh v. Milano*.<sup>22</sup>

In malpractice cases, courts have consistently held that physicians have a duty to third parties for injuries inflicted as a result of the physician's failure to properly diagnose a contagious disease.<sup>23</sup> For instance, in 1959, in *Wojcik v. Aluminum Company of America*,<sup>24</sup> an employer, who had tuberculosis subjected his employees to chest X-rays.<sup>25</sup> The physician who performed the X-rays failed to inform the employees if they had developed tuberculosis.<sup>26</sup> The Supreme Court of New York held the physician liable to an employee's wife who contracted the disease.<sup>27</sup> In 1974, the Supreme Court of New Jersey in *Fosgate v. Corona*,<sup>28</sup> held a physician liable to a patient's husband and

20. *See id.*

21. 551 P.2d 334, 340-53 (Cal. 1976) (holding psychologist liable because he was aware of his own patient's intent to kill plaintiffs' daughter, Tatiana Tarasoff, but did not detain the patient, nor warn Ms. Tarasoff of the patient's intent to kill her).

22. 403 A.2d 500, 503 (N.J. Super. Ct. Law Div. 1979) (applying the duty established in *Tarasoff* even though it "is nonbinding authority in this jurisdiction . . .").

23. *See, e.g.*, Tracy A. Bateman, *Liability of Doctor or Other Health Practitioner to Third Party Contracting Contagious Disease from Doctor's Patient*, 3 A.L.R. 5th 370, *passim* (1993) (discussing the liability of physicians for failing to diagnose contagious diseases and subsequently failing to inform third parties of the contagious nature of the disease); *see also* Sonia M. Suter, *Whose Genes Are These Anyway? Familial Conflicts Over Access to Genetic Information*, 91 MICH. L. REV. 1854, 1874 n.121 (1993).

24. 183 N.Y.S.2d 351 (1959).

25. *See id.* at 353.

26. *See id.*

27. *See id.* at 357-58. The court held:

It is the duty of a physician who is attending a patient afflicted with a *contagious or infectious* disease to exercise care in advising and warning members of the family and others who are liable to exposure of the existence and nature of the danger from the disease, to avoid doing any act which would tend to spread the infection, and to take all necessary precautionary measures to prevent its spread to other patients attended. A physician who fails to give such a warning is negligent . . . .

*Id.* at 358 (emphasis added).

28. 330 A.2d 355 (N.J. 1974).

children who later contracted tuberculosis when the physician failed to diagnose and treat the patient's tuberculosis.<sup>29</sup> In 1990, in *Britton v Soltes*,<sup>30</sup> the Appellate Court of Illinois held a physician liable when his negligence in diagnosing tuberculosis resulted in a third party contracting the disease.<sup>31</sup> In 1995, in *Reisner v. Regents of University of California*,<sup>32</sup> a physician never told his patient she received a blood transfusion contaminated with the human immunodeficiency virus (HIV).<sup>33</sup> The California appellate court held the physician liable to the patient's boyfriend, who contracted HIV from the patient.<sup>34</sup> And in 1996, in *Garcia v. Santa Rosa Health Care Corporation*,<sup>35</sup> a health care provider never told a patient he may have been infected with HIV from a blood transfusion. The Court of Appeals of Texas held the physician liable to the patient's wife.<sup>36</sup>

These cases demonstrate that a health care provider may be held liable for a third party's injuries when the provider is somehow responsible for the initial injury to the patient. Although the cases indicate that many jurisdictions have adopted a duty to warn, there is little authority regarding the liability of physicians for failure to warn third parties *at risk of genetically transmissible disease*.<sup>37</sup> In *Safer*, not only did the trial court and Superior Court rely on cases from other states, but also, those same cases had nothing to do with genetics.<sup>38</sup> The only New Jersey case the Superior Court cited regarding genetic disclosure dated back to 1981, *Schroeder v. Perkel*.<sup>39</sup> In *Schroeder*, the Supreme Court of New Jersey held that physicians may have a duty to warn a patient's immediate family members who may be at risk of contracting a genetic disease.<sup>40</sup> In this case, the physician failed to diagnose a

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29. *See id.* at 359.

30. 563 N.E.2d 910 (Ill. App. Ct. 1990).

31. *See id.* at 912 (holding that "a duty will be extended only where the relationship between the patient and the third party is such that negligence to the patient necessarily results in injury to the third party").

32. 31 Cal. App. 4th 1195 (1995).

33. *See id.* at 1197.

34. *See id.*

35. 925 S.W.2d 372 (Tx. Ct. App. 1996).

36. *See id.* at 375.

37. *See Safer v. Estate of Pack*, 677 A.2d 1188, 1191 (N.J. Super. Ct. App. Div. 1996), *cert. denied*, 683 A.2d 1163 (1996).

38. *See id.* at 1191-93 (citing the Florida Supreme Court's decision in *Pate* and the California Supreme Court's decision in *Tarasoff*). Neither of the New Jersey cases cited by the Superior Court involved disclosure for genetic diseases. *See id.*; *see also Fosgate v. Corona*, 330 A.2d 355 (N.J. 1974) (medical malpractice case regarding the diagnosis and treatment of tuberculosis); *McIntosh v. Milano*, 403 A.2d 500 (N.J. Super. Ct. Law Div. 1979) (wrongful death action about a psychiatrist's duty to warn).

39. 432 A.2d 834 (N.J. 1981).

40. *See id.* at 835-36.

four-year-old child with cystic fibrosis.<sup>41</sup> Because the child was not properly diagnosed, the parents gave birth to another child who also suffered from cystic fibrosis.<sup>42</sup> The Supreme Court held that the physician had, not only a duty to correctly diagnose the four-year-old child, but also an independent duty to the patient's parents to disclose to them that the child suffered from cystic fibrosis.<sup>43</sup>

Fourteen years later, in *Pate v. Threlkel*,<sup>44</sup> the Supreme Court of Florida held that a physician's duty to warn the children of a patient with a hereditary genetic disease was satisfied by simply warning the patient.<sup>45</sup> The plaintiff in *Pate* was diagnosed with medullary thyroid carcinoma, a genetically transferable disease that can be prevented and most often curable.<sup>46</sup> Although the court concluded that a reasonably prudent health care provider has a duty to warn family members at risk of a genetically transferable condition, because of confidentiality concerns and practicality, the court stated: "in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient" who can ordinarily be expected to pass on the warning.<sup>47</sup> The *Safer* court rejected *Pate* by stating that there may be some circumstances in which the duty to warn will not be satisfied by informing the patient alone.<sup>48</sup>

#### IV. ANALYSIS

Although not exactly similar,<sup>49</sup> there are many comparable qualities between HIV-related and genetic information.<sup>50</sup> Both circum-

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41. See *id.* Cystic fibrosis is a "generalized hereditary disorder associated with widespread dysfunction of the exocrine glands, with accumulation of excessively thick and tenacious mucus and abnormal secretion of sweat and saliva," and may eventually cause chronic obstructive lung disease. MILLER-KEANE'S ENCYCLOPEDIA, *supra* note 8, at 380-81.

42. See *Schroeder*, 432 A.2d at 835-36.

43. See *id.* at 839.

44. 661 So.2d 278 (Fla. 1995).

45. See *id.* at 282. Because the court did not define "warning," it is unclear whether a letter, a phone call, or a conversation constitutes proper warning. See *id.*

46. See *id.* at 279.

47. *Id.* at 282.

48. See *Safer v. Estate of Pack*, 677 A.2d 1188, 1192-93 (N.J. Super. Ct. App. Div. 1996), *cert. denied*, 683 A.2d 1163 (1996).

49. See Paul A. Lombardo, *Genetic Confidentiality: What's the Big Secret?*, 3 U. CHI. L. SCH. ROUNDTABLE 589, 593 (1996) (stating that the need to protect confidentiality of HIV information is not comparable to genetic information because most genetic diseases "do not elicit stigma, fear, or discomfort evoked by an inevitably deadly disease linked to socially marginal populations . . .").

50. See Brian R. Gin, *Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406 (1997) (comparing Huntington's disease and HIV

stances involve highly personal and sensitive information; both may be indicative of a person's future; and both may lead to negative consequences as a result of disclosure, such as discrimination.<sup>51</sup> Because of these concerns, state and federal legislatures have attempted to regulate procedures for obtaining or disclosing information regarding HIV as well as genetics.<sup>52</sup> Generally, all state and federal statutes emphasize the importance of informed consent before *any* disclosure.<sup>53</sup>

Given the similarities between genetics and HIV testing, and the dearth of precedent regarding disclosure of genetic testing results, the remainder of this article analyzes information regarding disclosure for HIV testing and relates it to disclosure of genetic testing results. Section A analyzes the potential benefits commonly cited to support a duty to warn for genetic diseases. These presumed benefits include early detection and treatment, knowledge, and disease prevention. Section B analyzes possible negative consequences of mandated disclosure to third parties, such as employment and insurance discrimination, and potential domestic violence.

## A. *The Benefits and Detriments of Genetic Testing and Disclosure*

### 1. *Early Detection and Treatment*

One suggested benefit of warning an individual who may be at risk of developing a genetic disease is the hope that they will seek early monitoring and, if necessary, early treatment. If physicians have a duty to warn family members of patients at risk of contracting genetic diseases, it should be in the narrow circumstance where the disease is *treatable*. The *Safer* court's imposed duty to warn can and should be

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infection); see also Wendy E. Parmet, *Legislating Privacy: The HIV Experience*, 23 J.L. MED. & ETHICS, No. 4 at 371 (1995); Ilise Levy Feitshans, *Foreshadowing Future Changes: Implications of the AIDS Pandemic for International Law and Policy of Public Health*, 15 MICH. J. INT'L L. 807 (1994). Feitshans states:

The new approach developed in response to AIDS may have implications for other areas of public health where the results of a blood test bear great emotional freight, such as genetics. For example, in the Institute of Medicine Report, . . . the National Academy of Sciences Institute of Medicine describes a possible future form of prenatal diagnosis, where a mother's blood may be drawn to reveal the genetic composition of fetal cells found in maternal serum. Such blood tests could reveal information about inherited disease in a given fetus, which may be as emotionally charged as an HIV test result.

Feitshans, *supra* at 815-16 (citation omitted).

51. See Parmet, *supra* note 50, at 373.

52. See *id.* at 371; see also *infra* notes 99-108 and accompanying text.

53. See Andrews, *supra* note 41, at 997; see also Karen H. Rothenberg, *Breast Cancer, the Genetic "Quick Fix," and the Jewish Community*, 7 HEALTH MATRIX 97, 106 (1997).

read this narrowly.<sup>54</sup> The *Safer* court imposed a “duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition.”<sup>55</sup> The court also recognized the importance of early treatment by criticizing the lower court for not recognizing the significance of early monitoring and early treatment.<sup>56</sup>

Notifying an individual who may be at risk for a genetic disease or HIV infection may prompt the person to seek preventive care, early monitoring, and early treatment. However, some commentators have suggested that there is no real benefit to genetic testing for some people because the vast majority of detectable genetic diseases are incurable.<sup>57</sup> Some commentators argue that genetic testing only leads to worry.<sup>58</sup> Upon receiving a test result indicating the presence of a genetic disorder or “disease gene,” carriers may often experience confusion, alienation, and depression after being tested.<sup>59</sup> They may feel that their relatives blame them for imposing a genetic risk on them.<sup>60</sup> Some people feel “survivor’s guilt.”<sup>61</sup> Parents who have passed the disease gene causing their child to have a genetic disorder may suffer

54. See *Safer v. Estate of Pack*, 677 A.2d 1188, 1191-92 (N.J. Super. Ct. App. Div. 1996), cert. denied, 683 A.2d 1163 (1996) (implying there are various types of genetic disease including those that are treatable and those that are not); see also Ellen Wright Clayton, *Screening and Treatment of Newborns*, 29 Hous. L. Rev. 85, 109 (1992) (discussing the significant difference between a diagnosis of a newborn for which there is effective treatment compared to when the diagnosis can only be used to prepare the parents for the imminent deterioration in their child’s health).

55. *Safer*, 677 A.2d at 1192 (emphasis added).

56. See *id.* (concluding that the trial court’s characterization of this case as one involving an “unavoidable genetic condition” gave too little significance to the fact that early monitoring of patients at risk could avert some of the more serious consequences that a patient with multiple polyposis might otherwise experience).

57. See Alexandra K. Glazier, *Genetic Predispositions, Prophylactic Treatments and Private Health Insurance: Nothing is Better Than a Good Pair of Genes*, 23 AM. J.L. & MED. 45, 68 n.1 (1997) (suggesting that early detection for breast cancers may only give individuals a greater number of years of knowing that they are sick but does not necessarily extend their lives); see also Suter, *supra* note 23, at 1900.

58. See Suter, *supra* note 23, at 1893.

59. See Andrews, *supra* note 41, at 975; Richard A. Bornstein, *Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes*, 4 J.L. & POL’Y 551, 574-75 (1996). Carriers, in particular pregnant women, experience much anxiety, and may feel “defective” or that they have “failed” society because they will probably not produce healthy children. Andrews, *supra* note 41, at 976 n.37.

60. See Suter, *supra* note 23, at 1880.

61. Andrews, *supra* note 41, at 977. Andrews compares this type of survivor’s guilt with “soldiers whose buddies have died in war. . . .” *Id.* Like soldiers who have survived by chance, individuals who have not inherited the diseased gene wonder why they have been spared when other family members have inherited the gene and contracted the disease. See *id.*



emotional stress "because their psychological well-being is affected and they cannot blame an external cause to alleviate their guilt."<sup>62</sup>

## 2. Knowledge of Carrying a Disease Gene

When there is no available treatment or when treatment does not completely eliminate the risk of disease, knowledge is often assumed to benefit individuals psychologically. However, this assumption is not true for all individuals. Therefore, courts should recognize the right *not* to know.<sup>63</sup> For example, one study has shown that less than fifty percent of people with a family history of breast or ovarian cancer *wanted to know* if they carried a gene linked to the disease.<sup>64</sup>

Similarly, many individuals choose not to know whether they carry the gene for Huntington's disease, a disease that has no cure and will ultimately cause death.<sup>65</sup> In fact, it may be unethical for a physician to force knowledge of an incurable disease on a person,<sup>66</sup> because the suicide rate among people who know they may contract Huntington's disease is four times higher than the general population.<sup>67</sup> Despite the increased chance of suicide, fifty-eight percent of geneticists said they would disclose the risk of Huntington's disease to a relative without the patient's consent regardless of the fact that it is untreatable.<sup>68</sup> It appears that these geneticists have decided for others that it is better to know than not to know.

For many people, knowledge of a genetic disorder affects notions of identity.<sup>69</sup> In fact, the term "shattered self-adequacy syndrome" has

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62. Clayton, *supra* note 54, at 112.

63. See Suter, *supra* note 23, at 1893. "Genetic testing is often intimately connected with personal reproductive decisions, and thus no one should decide which choice is best for another." *Id.*; see Marleen Temmerman et al., *The Right Not to Know HIV Test Results*, 345 LANCET 969 (1995) (arguing for the right of HIV-infected women to not obtain test results due to retaliatory violence).

64. See Richard H. Underwood & Ronald G. Cadle, *Genetics, Genetic Testing, and the Specter of Discrimination: A Discussion Using Hypothetical Cases*, 85 Ky. L.J. 665, 681 n.63 (1996-97).

65. See *id.* Huntington's disease causes degeneration of the nervous system and does not usually appear until a person is in his or her late forties. See Andrews, *supra* note 41, at 969 n.7 & 976.

66. See Andrews, *supra* note 41, at 976; see also Lindsay A. Farrer, *Suicide and Attempted Suicide in Huntington's Disease: Implications for Preclinical Testing of Persons at Risk*, 24 AM. J. MED. GENETICS 305, 305 (1986).

67. See Andrews, *supra* note 41, at 976.

68. See *id.* at 989.

69. See Regina H. Kenen, *Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs*, 68 AM. J. PUB. HEALTH 1116, 1117 (1978); see also Suter, *supra* note 23, at 1860. "Knowledge of genetic predisposition for a disease, verification of carrier status, or antenatal diagnosis of a genetic disorder may create feelings of inadequacy or strangeness that are themselves damaging to health." Kenen, *supra* at 1117.

been devised to describe the chronic stress that the diagnosis of a genetic disorder creates.<sup>70</sup> Specifically for women, it was found that “[d]ecisions to undergo genetic testing—and control or lack of control over dissemination of the results of such testing—affect a woman’s self-image, her personal relationships, and how she is regarded by institutions such as insurers and employers.”<sup>71</sup>

### 3. Disease Prevention

Another often cited benefit of notifying a person carrying a disease gene that they may develop a genetic disease is so they may make “responsible” reproductive decisions.<sup>72</sup> The notion is that better information allows individuals to better plan for their future.<sup>73</sup> For instance, if Dr. Pack had warned Mrs. Safer that she may have inherited a genetic disease from her father, her procreative decisions may have been affected.

Arguably, the very purpose of prenatal genetic screening is to “permit pregnant women to abort fetuses with genetic anomalies.”<sup>74</sup> However, upon notification of a genetic defect in her fetus, a pregnant woman may feel stigmatization<sup>75</sup> or social and economic pres-

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70. See D. Marianne Brower Blair, *Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption*, 70 N.C. L. REV. 681, 697 (1992).

71. Andrews, *supra* note 41, at 967.

72. See generally Elena A. Gates, *Prenatal Genetic Testing: Does It Benefit Pregnant Women?*, in WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 183 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

73. See Rothenberg, *supra* note 53, at 106.

74. Lois Shepherd, *Sophie’s Choices: Medical and Legal Responses to Suffering*, 72 NOTRE DAME L. REV. 103, 112 (1996) (citing early attempts by laboratories to make amniocentesis availability contingent on the agreement to abort if an anomaly was detected).

75. See Andrews, *supra* note 41, at 979. Health care providers conducted a study of sickle cell anemia in a small farming village in Greece. See *id.* Sickle cell anemia is a blood disorder primarily affecting African Americans and causes severe anemia as red blood cells are destroyed by abnormal “sickling” of the hemoglobin protein. The researchers thought that sickle cell anemia testing would decrease the number of affected children. See *id.*; see also Catherine J. Damme, *Controlling Genetic Disease Through Law*, 15 U.C. DAVIS L. REV. 801, 824 (1982); Kenen, *supra* note 69, at 1117; George Stamatoyannopoulos, *Problems of Screening and Counseling in the Hemoglobinopathies*, in BIRTH DEFECTS: PROCEEDINGS OF THE FOURTH INTERNATIONAL CONFERENCE 268, 272 (Arno G. Motulsky & Widukind Lenz eds., 1974). Instead, the birth rate of affected children did not decrease. See Andrews, *supra* note 41, at 979. The researchers explained that the birth rate stability was due to stigmatization. See *id.* In some instances, a carrier of the sickle cell trait would only marry another carrier. See *id.* Similar studies conducted in the United States seem to indicate that such stigmatization may not develop as strongly in American society. See Kenen, *supra* note 69, at 1117 (comparing the results of the study conducted in Greece with the results of a Tay-Sachs screening program in Baltimore, Maryland and Washington, D.C. and attributing some of the

sure to abort the affected fetus.<sup>76</sup> In *The Genetic Revolution*, Daniel Callahan states:

It takes a tough and determined woman these days not to exercise the "free choice" of choosing prenatal diagnosis, and a still tougher and more determined woman not to have an abortion if a serious defect is discovered in her fetus. Here as elsewhere, social pressure can accomplish quite nicely what could never be legislated.<sup>77</sup>

The pressure to abort affected fetuses may come from health insurance companies as well.<sup>78</sup> Even genetic counselors and other health care providers who counsel using non-directive counseling techniques

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differences to the fact that the studies in the United States were conducted in urban settings whereas the sickle cell study in Greece was conducted in a rural community).

76. See Barbara Katz Rothman, *Women Feel Social and Economic Pressures to Abort Abnormal Fetuses*, 17 BIRTH 81, 81 (1990). Rothman states:

The pressures here tend to be economic: by providing little —and ever less— support to families and to people with disabilities, women are made to feel little choice but to abort fetuses . . . . The pressures are also social: women are increasingly held responsible . . . for the health of their children . . . . The women I interviewed who were making decisions about using prenatal diagnosis . . . felt enormous pressure toward using all available technology to detect "defects" in their fetuses . . . .

*Id.* Oliver Wendell Holmes' infamous remark that "three generations of imbeciles are enough" also shows the judicial system's justification of involuntary sterilization in order to "prevent those who are manifestly unfit from continuing their kind." *Buck v. Bell*, 274 U.S. 200, 207 (1927).

77. Daniel Callahan, *The Genetic Revolution*, 66 N.Y. ST. B.J. 30, 31 (1994) (citation omitted). Callahan also states:

New medical technologies rarely remain discretionary for long. If they are not legally imposed on people, something hard to do in our society, they can just as effectively be imposed by social pressure. When prenatal diagnosis was being introduced in the late 1960s, every assurance was given that no woman would be forced to have such a diagnosis, much less be forced into an abortion if the diagnosis turned up a terrible genetic defect. The worry about coercion was misplaced. Social pressure and developing mores on prenatal diagnosis soon turned it into a routine procedure, as common and standard as taking blood pressure for women over the age of 35.

*Id.*

78. See Paul R. Billings et al., *Discrimination As a Consequence of Genetic Testing*, in CONTEMPORARY ISSUES IN BIOETHICS 637, 641-42 (Tom L. Beauchamp & LeRoy Walters eds., 4th ed. 1994) (discussing the threat of losing health insurance pressures women to abort affected fetuses); see also Underwood & Cadle, *supra* note 64, at 687 (stating that there appear to have been cases of insurance companies expressing their preference that affected fetuses be aborted); Susan L. Waysdorf, *Families in the AIDS Crisis: Access, Quality, Empowerment, and the Role of Kinship Caregivers*, 3 TEX. J. WOMEN & L. 145, 179 (1994) (discussing the pressure pregnant women with AIDS often receive, including the threat of insurance benefits being terminated if they choose to give birth).

may inadvertently pressure pregnant women to abort affected fetuses.<sup>79</sup>

In *Atakpa v. Perimeter Ob-Gyn Associates*,<sup>80</sup> a pregnant woman's prenatal care provider terminated her care when she refused to take an HIV test.<sup>81</sup> During the physician's testimony, he also admitted to discharging patients for not undergoing genetic testing.<sup>82</sup> He stated, "I have discharged other patients from my care for refusing to comply with diagnostic testing. For instance, I discharged a patient in 1992 who refused to undergo fetal monitoring for her pregnancy which was complicated by hypertension."<sup>83</sup> Despite this testimony, the *Atakpa* court dismissed the case stating that the plaintiff lacked standing because she did not allege that she will ever seek services from the defendant health care provider in the future.<sup>84</sup>

After *Atakpa*, it appears that a pregnant woman seeking prenatal care must submit to genetic and/or HIV testing or find another pro-

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79. See Andrews, *supra* note 41 at 981 (discussing the pressure by physicians to abort affected fetuses and the dilemma a woman may feel that she will be judged too harshly by others for aborting); see also Angus Clarke, *Is Non-Directive Genetic Counseling Possible?*, 338 LANCET 998, 998 (1991); Shepherd, *supra* note 74, at 112-13 (citing interviews conducted by Barbara Katz Rothman that revealed genetic counselors' biases regarding abortion depending on the severity of the perceived genetic anomaly).

80. 912 F. Supp. 1566 (N.D. Ga. 1994).

81. See *id.* at 1575. The court concluded the plaintiff was denied treatment even though the health care provider attempted to argue that the patient voluntarily left. See *id.* Even though the HIV test is "voluntary," it is unclear how many prenatal care providers have denied pregnant women prenatal care for asserting their right not to take an HIV test. It has been documented that some prenatal care providers test patients for HIV without any discussion, leaving some patients unsure of whether they had in fact been tested for HIV. See Gail Kennedy & Bethany Young, *The Alameda County Prenatal HIV Testing Demonstration Project: Final Evaluation Report 18-19* (Jan. 1997) (unpublished report, on file with the California Department of Health Services, Office of AIDS).

82. See *Atakpa*, 912 F. Supp. at 1574.

83. *Id.* There are numerous types of fetal monitoring including amniocentesis, fetal blood sampling, chorionic villi sampling, and fetal cell sorting. See Andrews, *supra* note 41, at 968. The most common technique used in prenatal diagnosis is amniocentesis in which a long needle penetrates the abdominal and uterine wall to draw amniotic fluid for diagnostic testing. See Janet A. Kobrin, *Confidentiality of Genetic Information*, 30 U.C.L.A. L. REV. 1283, 1290 (1983). Amniocentesis causes spontaneous abortion in approximately one or two per thousand pregnancies and involves a physical risk to the pregnant woman, particularly risks of infection. See Andrews, *supra* note 41, at 968. Fetal blood sampling, which involves sampling blood from the fetus while in utero, is associated with a 3% to 6% risk of fetal death. See *id.* Chorionic villi sampling, which involves sampling the fetus' tissue between eight and twelve weeks gestation, is associated with a 2% to 5% spontaneous abortion rate, shortened or missing limbs, fingers, and toes, and tongue and jaw malformations. See *id.* at 968 n.4; see also John A. Robertson, *Book Note: The Invisible Women*, 108 HARV. L. REV. 953, 958 n.14 (1995). Fetal cell sorting, which involves a simple blood test on the pregnant woman, does not create a physical risk to either the fetus or the pregnant woman. See Andrews, *supra* note 41, at 970.

84. See *Atakpa*, 912 F. Supp. at 1574.

vider who will respect her refusal to submit to voluntary testing. If she submits to testing and it is determined that she carries a disease gene, under *Safer*, her physician has a duty to warn family members known to be at risk.<sup>85</sup> Each scenario presents significant concerns that may ultimately deter women from seeking prenatal care.<sup>86</sup>

### B. *The Consequences of Imposing a Duty to Warn*

#### 1. *Employment and Insurance Discrimination May Result from Disclosure*

Information obtained from genetic testing may result in employment and insurance discrimination.<sup>87</sup> The Council for Responsible Genetics, a national bioethics advocacy organization, has documented more than two hundred cases where healthy people were denied health insurance or employment because of their genetic makeup.<sup>88</sup> In a survey of people having a known genetic condition in their family, "22% indicated that they had been refused health insurance coverage because of their genetic status, whether they were sick or not."<sup>89</sup>

85. See *supra* notes 19-20 and accompanying text.

86. See Andrews, *supra* note 41, at 984-85. At the very least, *Atakpa* and *Safer* may decrease testing rates. See Suter, *supra* note 23, at 1880. Using HIV as a comparison, "experience . . . shows . . . when HIV testing is perceived to be forced on an individual, or when testing is done without the proper consent, people react negatively due to the stigma associated with HIV, concern about how the test results will be used, [and] lack of understanding about the meaning of the test results . . . ." John M. Naber & David R. Johnson, *Mandatory HIV Testing Issues in State Newborn Screening Programs*, 7 J.L. & HEALTH 55, 66 (1993).

87. See Feitshans, *supra* note 50, at 820; see generally Bornstein, *supra* note 59; Glazier, *supra* note 57. In assessing health and social policy, Feitshans states:

[E]mployment and insurance discrimination against people with genetic disabilities may affect the insurability and health status of families and dependents in much the same manner that early AIDS case law reflected a concern for family members with AIDS. Not only the concerns for discrimination issues, but also the mechanisms for framing the issues clearly follow the emerging AIDS paradigm . . . . Similar issues regarding privacy, confidentiality, mandatory testing, and protection against discrimination in insurance and employment have been raised in the context of genetic discoveries in the wake of the human genome project . . . . In the case of genetic diseases, mandatory testing has been criticized as a potential tool for eugenics by enabling the State to filter out undesirable genetic traits through obligatory testing. These critics clearly rely on the AIDS precedent for their view that informed consent, as a part of pretest and posttest counseling, should be required for all genetic testing.

Feitshans, *supra* note 50, at 820-21; see also generally LORI B. ANDREWS, *ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY* (Lori B. Andrews et al. eds., 1994).

88. See Julie Forster, *New Jersey: Bill that Bans Genetic Discrimination on Governor's Desk*, June 25, 1996, available in WEST'S LEGAL NEWS 6019 (citing state legislation regarding genetic information).

89. See Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE 391, 391 (1995) (citing E.V. Lapham & J.O. Weiss, *The Alliance of*

Health insurance companies can lawfully exclude people based upon pre-existing conditions, and the insurers use genetic testing as "an enormous loophole" to do it.<sup>90</sup> For example, a pregnant woman was diagnosed as a carrier for cystic fibrosis, and her health maintenance organization informed her that it would not pay for the health care costs of the child if she chose not to abort.<sup>91</sup> Similarly, a health insurer told a woman whose mother had breast cancer that it would not cover the cost of any treatment if she developed breast cancer.<sup>92</sup> Likewise, an insurer denied benefits to a healthy eight-year-old child, successfully diagnosed and treated for phenylketonuria (PKU)<sup>93</sup> as a newborn, when her father changed jobs.<sup>94</sup>

Another example of both employment and insurance discrimination occurred in the 1970s when states mandated testing African Americans for sickle cell anemia.<sup>95</sup> Airlines grounded African American employees because of unfounded fears that a sickling crisis might occur if a plane depressurized.<sup>96</sup> Others were encouraged to undergo sterilization.<sup>97</sup> In addition, insurance companies charged higher premiums to sickle cell carriers even though there was no data supporting such an increase.<sup>98</sup>

Due to serious insurance discrimination, some states have passed statutes forbidding the denial of health insurance for carriers of sickle cell anemia or Tay-Sachs disease.<sup>99</sup> Federal statutes are also beginning

Genetic Support Groups, Human Genome Model Project, preliminary results of a survey of persons with a genetic disorder in the family).

90. Andrews, *supra* note 41, at 986; see Underwood & Cadle, *supra* note 64, at 665 n.21; see also Jill Gauldin, *Race, Sex, and Genetic Discrimination in Insurance: What's Fair?*, 80 CORNELL L. REV. 1646, 1668 (1995).

91. See Andrews, *supra* note 41, at 985-86.

92. See *id.* at 986.

93. PKU is caused by the absence of an enzyme which usually leads to severe mental retardation. See DORLAND'S MEDICAL DICTIONARY 1278 (28th ed. 1994); see also Damme, *supra* note 75, at 821. PKU is cured with a special diet low in phenylalanine. See Damme, *supra* note 75, at 821. Because the test consists of drawing a small amount of a newborn's blood and the disease is curable, there has been very little opposition to PKU statutes that require the screening of newborns. See *id.* at 821-23.

94. See Andrews, *supra* note 41, at 986.

95. See *id.* at 978 & 987; see also Kobrin, *supra* note 83, at 1292. Similar problems arose in the 1960s when states mandated the screening of newborns for PKU. See Suter, *supra* note 23, at 1908 n.6.

96. See Kobrin, *supra* note 83, at 1292 n.60; see also P. REILLY, GENETICS, LAW, AND SOCIAL POLICY 154 (1977).

97. See Lombardo, *supra* note 49, at 596-97.

98. See *id.*

99. See Underwood & Cadle, *supra* note 64, at 686 n.84 (citing Alabama and Maryland statutes). Tay-Sachs is a disorder of the nervous system that affects mostly Eastern European Jews that usually leads to death by age three. Andrews, *supra* note 41, at 969 n.10.

to address genetic discrimination.<sup>100</sup> The Health Insurance Portability and Accountability Act of 1996<sup>101</sup> is the first federal law addressing genetic discrimination.<sup>102</sup> The Act prohibits insurers and employers from denying health insurance based upon genetic information.<sup>103</sup> However, the Act does not cover life or disability insurance and does not prevent insurance companies from charging higher premiums or from limiting coverage based upon genetic information.<sup>104</sup> "It also does not require insurers to obtain authorization before disclosing genetic information."<sup>105</sup> The Americans with Disabilities Act (ADA)<sup>106</sup> prohibits employers from refusing to hire someone based upon genetic information.<sup>107</sup> However, the ADA allows employers to order genetic testing of potential employees without their permission, as long as the information is not used in some type of unfair or unjust fashion.<sup>108</sup>

## 2. Domestic Violence May Result from Disclosure

In addition to various discrimination that may result from disclosure of genetic information, the widespread problem of domestic vio-

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100. See Lombardo, *supra* note 49, 601-12; see also generally Bornstein, *supra* note 59 (describing recent federal and state legislation addressing genetic discrimination); Burk Burnett, *Genetic Discrimination: Legislation Required to Keep Genetic Secrets*, 21 SETON HALL LEGIS. J. 502 (1997).

101. Health Insurance Portability and Accountability Act of 1996, 104 Pub. L. No. 104-191, § 701, 110 Stat. 1936 (1996).

102. See Kyle G. French, *The Elderly and the Discriminatory Use of Genetic Information*, 5 ELDER L.J. 147, 168 (1997).

103. See *id.*

104. See *id.* Commentators have argued that the fundamental structure of the life insurance industry would be jeopardized if genetic information could not be used to classify risks. See Robert J. Pokorski, *Commentary: Genetic Information and Life Insurance*, 376 NATURE 13, 14 (1995). The argument is that because life insurance premiums are based on relative mortality risk, not using genetic information would increase prices, disproportionately affecting lower income families and creating an incentive for people in the highest mortality risk to buy more life insurance. See *id.* But see Hudson et al., *supra* note 89, at 391 (discussing the costs of medical treatment for genetic diseases to be absorbed under the current health insurance system of shared risk and shared costs). Hudson states: "our understanding of the relation between a misspelling in a gene and future health is still incomplete, thus limiting the ability of insurers to incorporate genetic risks into actuarial calculations on a large scale." Hudson et al., *supra* note 89, at 391.

105. Rothenberg, *supra* note 53, at 113.

106. 104 Stat. 327 (1990) (codified at 42 U.S.C. §§ 12-101 to 12-213 (1997)); see also 2 EQUAL EMPLOYMENT OPPORTUNITY COMM'N, COMPLIANCE MANUAL, § 902, Order 915.002, 902-45 (1995).

107. See Lori Andrews, *As Medical Research Unlocks the Secrets of Genetics, the Battle Over Who Can Have Access to Your Personal Life Story is Just Getting Under Way in Courts and Legislatures*, 83 A.B.A. J. 44, 47 (1997).

108. See *id.*

lence is a serious concern that may be in conflict with a health care provider's duty to warn for genetic diseases. In the context of HIV, mandated disclosure is a serious concern for HIV infected individuals, particularly women, because they may be subject to retaliatory violence from their partner(s).<sup>109</sup> Indeed, scholars have recognized the "special" problems with HIV partner notification.<sup>110</sup> For example, a study in Nairobi, Kenya evaluated some of the effects on pregnant women being told they were HIV positive.<sup>111</sup> Counseling provided by a trained counselor after a positive test result included informing the partners of the HIV infected patient.<sup>112</sup> Twenty-seven percent of the women in the study communicated their positive test result to their partner.<sup>113</sup> Approximately six percent of those women experienced physical violence from their partner after they disclosed their HIV status.<sup>114</sup> The researchers concluded that individuals have a right not to know test results and that partner notification of HIV status may directly lead to an episode of violence.<sup>115</sup>

Physical violence due to HIV disclosure has also been documented in the United States.<sup>116</sup> A survey of 136 health care providers in Baltimore, Maryland, showed that twenty-four percent of providers had at least one female patient who experienced physical violence following disclosure of her HIV status to a partner.<sup>117</sup> Moreover, thirty-seven percent of providers had at least one female patient who experienced emotional abuse and abandonment following HIV disclosure.<sup>118</sup>

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109. See, e.g., Vivian B. Brown et al., *Mandatory Partner Notification of HIV Test Results: Psychological and Social Issues for Women*, 9 AIDS & PUB. POL'Y J. 86, 86 (1994).

110. *Id.* at 86-92.

111. See Temmerman, *supra* note 63, at 969.

112. *See id.*

113. *See id.*

114. *See id.* Specifically, eleven women were chased away from their house or replaced by another wife, seven were beaten up, and one committed suicide. *See id.* The six percent violence rate may be underestimated because the researchers were unable to follow up with all of the women in the study, and the data reflected only spontaneous reports by women or their relatives. *See id.* at 970. Alarmed by the physical violence against women as a consequence of disclosure, the study changed its protocol. *See id.*

115. *See id.*

116. See, e.g., Karen H. Rothenberg et al., *Domestic Violence and Partner Notification: Implications for Treatment and Counseling of Women with HIV*, 50 JAMA 87 (1995).

117. *See id.* at 89.

118. *See id.* Examples of emotional abuse range from "partners spitting on patients to threats of violence and death against both women and their children . . . . Patients [are] commonly rejected, ostracized, and abandoned by family, friends, and partners. One woman returned home to find her belongings in the street, while others lost access to their children." Karen H. Rothenberg & Stephen J. Paskey, *The Risk of Domestic Violence and Wo-*



Although the data for genetic testing disclosure is not as abundant as that for HIV disclosure, a few studies indicate that disclosure of genetic testing results may lead to similar abandonment.<sup>119</sup> After premarital sickle cell anemia testing, seven percent of non-carriers avoided marrying a carrier and some broke off their engagement upon learning that their potential spouse was a carrier.<sup>120</sup> Similarly, nine percent of pregnant women surveyed felt that carriers of cystic fibrosis should avoid marriage.<sup>121</sup> In another study of carriers of Tay-Sachs disease, men were found to be more likely than women to say they would change their marriage plans if they learned their fiancée was also a carrier of Tay-Sachs.<sup>122</sup>

It may also be inferred that the disclosure of genetic test results could lead to physical violence and/or emotional abuse. A woman may believe that the father of the fetus will blame her if something goes wrong with the pregnancy.<sup>123</sup> In addition, genetic testing increases stress, which, coupled with blame, may lead to domestic violence.<sup>124</sup> While it is not suggested that the disclosure of genetic testing results will *cause* domestic violence, in relationships where domestic violence is already present, the mandatory disclosure of genetic test results may lead to negative consequences not previously envisioned by any court.

## V. CONCLUSION

In contrast to contagious diseases or violent behavior, a patient with a genetic defect does not pose a risk to family members or other

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*men with HIV Infection: Implications for Partner Notification, Public Policy, and the Law*, 85 AM. J. PUBLIC HEALTH 1569, 1570 (1995).

119. See Andrews, *supra* note 41, at 979 n.55; see also George Stamatoyannopoulos, Problems of Screening and Counseling in the Hemoglobinopathies, in BIRTH DEFECTS: PROCEEDINGS OF THE FOURTH INTERNATIONAL CONFERENCE 268 (Aino G. Motulsky & Widukind Lenz eds., 1974.); Jeffrey R. Botkin & Sonia Alemagno, *Carrier Screening for Cystic Fibrosis: A Pilot Study of the Attitudes of Pregnant Women*, 82 AM. J. PUB. HEALTH 723 (1992); Susan Zeesman et al., *A Private View of Heterozygosity: Eight Year Follow-Up Study on Carriers of the Tay-Sachs Gene Detected by High School Screening in Montreal*, 18 AM. J. MED. GENETICS 769 (1984).

120. See Andrews, *supra* note 41, at 979 (citing Stamatoyannopoulos, *supra* note 119).

121. See *id.* (citing Botkin & Alemagno, *supra* note 119).

122. See *id.* (citing Zeesman et al., *supra* note 119). Ninety-five percent of female carriers of the Tay-Sachs trait responded that they would not alter marriage plans upon discovering that their fiancée was also a carrier; however, only sixty-nine percent of male carriers responded they would not change marriage plans if their fiancée was also a carrier. See Zeesman et al., *supra* note 119, at 773.

123. See Gates, *supra* note 72, at 192.

124. Five couples in a study of nineteen couples who participated in predictive testing for Huntington's disease reported higher levels of marital stress twelve months after receiving the test results. See Andrews, *supra* note 49, at 979.

members of society.<sup>125</sup> Family members “have no risk of becoming carriers; they only have the risk of *finding out* that they are carriers.”<sup>126</sup> Carriers of disease genes present no foreseeable harm to society, unlike violent or contagious people.<sup>127</sup>

The *Safer* court has imposed a duty on physicians to warn family members known to be at risk of potential harm from a genetic disease without considering the practicalities such a holding imposes or other negative consequences such disclosures may cause. In some instances, there are numerous, serious negative consequences that may arise as a result of mandated disclosure. Until more is known about the risks of genetic disclosure,<sup>128</sup> other jurisdictions should not adopt *Safer's* holding.<sup>129</sup> In determining whether to inform family members of their risk of genetic disease, physicians should be able to rely on the courts to consider numerous factors rather than impose liability based on the scanty amount of case law.<sup>130</sup>

Physicians not only have a duty of confidentiality to their patients, but should also consider the likelihood the disease will actually manifest itself in a particular patient, whether there is treatment available for the genetic disease, the reasons a patient may not want to disclose information (i.e., for fear of discrimination, or possible domestic violence), and whether family members at risk are minor children. Courts should consider these practicalities before imposing a duty on physicians. Because the negative consequences of disclosing to family members may be as devastating as not disclosing, the *Safer* Court should re-evaluate its broad holding to consider all of the potential consequences of disclosure.

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125. See Suter, *supra* note 23, at 1883; see also Underwood & Cadle, *supra* note 64, at 683.

126. Suter, *supra* note 23, at 1881 (emphasis added).

127. See *id.* at 1883-86 (contrasting genetics with AIDS because an HIV-infected individual puts his sex or needle sharing partners at an unreasonable risk of harm if he or she engages in behavior that can transmit the virus).

128. See Rothenberg, *supra* note 53, at 125 (concluding that “until we have a better understanding of the benefits and risks of genetic testing, . . . we must strive to resist a genetic ‘quick fix’ mentality that promotes genetic testing . . .”).

129. Or, if other jurisdictions do adopt a duty to warn, they should adopt it in the narrow circumstance where the genetic disease is treatable. See *supra* notes 54-62 and accompanying text.

130. See Suter, *supra* note 23, at 1906. Suter concludes that legislatures or courts should not mandate genetic disclosure to high-risk relatives unless they consider numerous factors including the significance of the risk, the severity of the potential harm, social stigma, and the patient's reasons for failing to disclose. See *id.*

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