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TO TELL OR NOT TO TELL: THE SCOPE OF PHYSICIAN-PATIENT CONFIDENTIALITY WHEN RELATIVES ARE AT RISK OF GENETIC DISEASE

Andrea Sudell*

INTRODUCTION

The Human Genome Project and related advances in genetic research and biotechnology reveal new information about the role of genes in determining human traits and predisposition to certain diseases.¹ Knowledge about the effects of deoxyribonucleic acid (DNA) variations in individuals may lead to revolutionary new ways to diagnose, treat and prevent the thousands of disorders affecting the human race.²

However, moral and legal dilemmas surface surrounding the increased ability to identify human genes and link them to inherited traits and diseases.³ Specifically, physicians may face situations in which their interest in protecting third parties conflicts with the confidentiality element of the physician-patient relationship.⁴ While physicians are obligated both ethically and legally to keep information about their patients confidential, the scope of this duty has long been debated.⁵ The availability of genetic information creates a new dispute about the

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2. See id.
3. See id.

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limitations that physician-patient confidentiality places on disclosure. For example, in cases where confidential information affects the health of a patient's relatives, the argument exists that physicians have a duty to warn relatives with or without their patients' consent.

This Comment argues that patient confidentiality is not absolute and that disclosure to third parties is permissible under certain circumstances. Part I provides an overview of genetic testing. Part II discusses case law and state statutes concerning the conflict between physician-patient confidentiality and the conflicting duty to warn. Part III reviews the confidentiality requirement specifically with respect to genetic information. Part IV proposes guidelines for circumstances when disclosure by the physician to the patient's relatives is warranted. This Comment concludes that a physician's privilege to warn third parties about a patient's genetically transferable disease extends to some cases where relatives are at risk. In deciding whether to disclose, a physician must weigh the harm of failing to disclose against the harm of disclosure. This balancing should be employed on a case-by-case basis.

I. AN OVERVIEW OF GENETIC RESEARCH

A. Genetic Testing

A genome is composed of an organism's entire DNA, including its genes. Genes carry the information to create all of the proteins required by every organism. These proteins determine, among other things, how the organism looks, how the body fights infection and how it behaves. Essentially, genetic information provides the framework for an individual's traits.


7. See id.


9. See id.

10. See id.

11. See id.
Gene tests, or DNA-based tests, are utilized to check for genetic disorders. The newest and most sophisticated of these tests involves direct examination of the DNA molecule. Some tests clarify a diagnosis and direct the physician toward appropriate treatments. Other tests, however, identify parents at risk of having children with diseases or identify people at high risk for developing certain conditions that may be preventable. For example, monitoring those at risk of inheriting a gene for familial colon tumors allows for early detection and removal of colon growths, and thus saves many lives. Within the foreseeable future, a simple diagnostic gene test for iron-storage disease will enable physicians to treat this presently fatal condition.

However, the practice of gene testing is the subject of some debate. Most controversial is genetic testing for adult-onset disorders such as Alzheimer’s disease, Huntington disease, and autosomal dominant polycystic kidney disease. Targeted at healthy, pre-symptomatic individuals with a strong family medical history for the disorder, these tests only reveal one’s probability of developing the disorder.

12. See id.
13. See id.
14. See id.
15. See id.
16. Clinically referred to as familial adenomatous polyposis. Defined as the “[p]resence of several polyps...affecting more members of the same family than can be accounted for by chance.” Stedman’s Medical Dictionary (26th ed. Williams & Wilkins 1995) at 627 and 1406.
17. GENE TESTING, supra note 8.
18. See id.
19. See id.
20. “[P]rogressive mental deterioration manifested by loss of memory...confusion; disorientation. Begins in late middle life and results in death in 5-10 years.” Stedman’s Medical Dictionary (26th ed. Williams & Wilkins 1995) at 492.
21. “[A] progressive disorder usually beginning in young to middle age, consisting of a triad of choreoathetosis, dementia, and autosomal dominant inheritance.” Id. at 333.
22. “[A] progressive disease characterized by formation of multiple cysts of varying size scattered diffusely throughout both k[idneys], resulting in compression and destruction of k[idney]...there are two major types...2) with onset in adulthood, with autosomal dominant inheritance.” Id. at 919.
23. GENE TESTING, supra note 8.
Accordingly, certain people who carry the disease-associated gene mutation will never actually develop the disease.24 As with all medical testing, there also exists the possibility for laboratory errors.25 However, due to the novelty and sophistication of genetic tests, many in the medical community believe that the negative implications26 of the test may outweigh its benefits.27 Although early detection may be helpful in preventing a disease or ameliorating its effects, pursuing genetic testing can be worrisome for those in jeopardy of a genetic disorder. The prospect of learning that one suffers from a disease is daunting. Further, the potential exists for genetic knowledge to be used as a tool for discrimination or manipulation.28

B. The Human Genome Project

The United States Human Genome Project formally began in 1990 and was originally projected to last fifteen years.29 However, rapid technological advances accelerated the expected completion date to 2003.30 Today, scientists are well on their way to completing the entire human genome sequence.31 Recent analyses by two rival groups32

24. See id.
25. See id.
26. See id. Negative implications include uncertainties surrounding test interpretation, the current lack of available medical options for these diseases, the test's potential for provoking anxiety, and risks of discrimination and social stigmatization.
27. See Smith et al., Early Warning, in CASES AND ETHICAL GUIDANCE FOR PRESYMPTOMATIC TESTING IN GENETIC DISEASES 1 Ind. U. Press 1998). Genetic information “may enable individuals to avoid illness through early intervention and, potentially, gene therapy.”
28. For example, based on genetic information about susceptibility to disease, employers and insurance companies might deny employment and/or insurance benefits. See Tony McGleenan, Rights to Know and Not to Know: Is There a Need for a Genetic Privacy Law? in THE RIGHT TO KNOW AND RIGHT NOT TO KNOW 43, 50 (Ruth Chadwick et al. eds., 1997).
29. ABOUT THE HUMAN GENOME PROJECT, supra note 1.
30. See id.
31. See OAK RIDGE NAT'L LABORATORY, FREQUENTLY ASKED QUESTIONS, at http://www.ornl.gov/hgmis/project/about.htm (last visited Dec. 18, 2001). (“A rough draft of the human genome was completed in June 2000. Efforts are still underway to complete the finished, high-quality sequence.”).
32. See Nicholas Wade, Long-Held Beliefs Are Challenged by New Human
revealed their first interpretations of the human genome sequence.\textsuperscript{33} These gene sequences create a genetic map that helps predict and/or determine one's propensity to develop certain diseases.\textsuperscript{34} From these findings, biologists hope to pinpoint the variant genes that underlie many common diseases.\textsuperscript{35} This will enable physicians to recognize and treat a disease at its genetic root.\textsuperscript{36}

Although an innovative scientific advancement, the Human Genome Project also leads to complex ethical, legal and social concerns.\textsuperscript{37} These concerns include: preservation of privacy;\textsuperscript{38} introduction and use of new genetic tests;\textsuperscript{39} and outside use of genetic information by various professionals and groups who may deal with, or be influenced by, such

\newblock \textit{Genome Analysis}, N.Y. TIMES, Feb. 12, 2001, at A20. The two groups are Celera Genomics and the International Human Genome Sequencing Consortium, a group of academic centers financed largely by the National Institutes of Health and the Wellcome Trust of London. \textit{Id.}

\textsuperscript{33.} \textit{See id.} ("Though the two sides differ strongly as to which has the better strategy for decoding the genome's sequence of 3.2 billion DNA units, they largely agree in their interpretations of it.").

\textsuperscript{34.} \textit{See id.}

\textsuperscript{35.} \textit{See id.}

\textsuperscript{36.} \textit{See id.}

\textsuperscript{37.} \textit{See AB\textsc{out} \textsc{the} H\textsc{uman} G\textsc{enome} P\textsc{roject}}, supra note 1 (stating that the Project's goals include: identification of all the approximately 100,000 genes in human DNA; determining the sequences of the three billion chemical bases that make up human DNA, storing this information in databases; developing faster, more efficient sequencing technologies; developing tolls for data analysis; and addressing the ethical, legal, and social issues ("ELSI") that may arise from the project).

\textsuperscript{38.} \textit{See generally Social Policy Research Priorities for the Human Genome Project}, in \textsc{G\textit{ene M\textsc{apping}}} 269 (George J. Annas and Sherman Elias eds., 1992). Specifically, problems arise in maintaining the confidentiality of patient's genetic information with respect to informing other family members of genetic traits that they may carry.

\textsuperscript{39.} \textit{See id.} at 271. The authors point out that this issue contains numerous sub-issues. The first sub-issue involves determining how the medical standard of care should be set. This includes establishing when and who should determine the point at which new screening should become routine, and at what age it should take place. The next sub-issue concerns what information a patient should be given regarding screening tests, as well as how, when and who should present the information.
information.40

The Human Genome Project is unique in that it is the first large scientific endeavor to specifically address the moral, legal and humanistic concerns raised by the project.41 To support the work of the National Human Genome Research Institute (NHGRI), the Department of Energy (DOE) created the Ethical, Legal and Social Implications Program (ELSI).42 The focus of the ELSI Program is to study genetic privacy and to foster education in genome science.43 In carrying out these goals, DOE and NHGRI support workshops for U.S. judges who decide cases in which genetic information is introduced.44 The group has also studied a draft genetic privacy law.45

C. The Impact of Genetic Research on Society

Advances in genetic research raise questions as to the degree to which genetic information should be protected. The utilization of this information stretches the concept of privacy law.46 In disclosing genetic information to patients, medical professionals must consider potential harms.47 In addition, they must consider to whom genetic information may be disclosed.48

To properly resolve this dilemma, one must understand the interests of

40. See LIFE SCIENCE DIVISION OFFICE, BIOLOGICAL AND ENVIRONMENTAL RESEARCH, ETHICAL, LEGAL AND SOCIAL IMPLICATIONS (ELSI), at http://www.er.doe.gov/production/ober/elsi.html (last visited Dec. 18, 2001); see George J. Annas and Sherman Elias, Social Policy Research Priorities for the Human Genome Project, in GENE MAPPING at 273 (Oxford University Press 1992) ("It is likely that both employers and insurance companies will want to use large-scale genetic screening of applicants when the technology becomes relatively inexpensive...The challenge is to prevent the products of the Human Genome Project from becoming just another mechanism for discrimination.").
41. ABOUT THE HUMAN GENOME PROJECT, supra note 1.
42. ETHICAL, LEGAL AND SOCIAL IMPLICATIONS (ELSI), supra note 40.
43. See id.
44. See id.
45. See id.
47. See id.
third parties who desire access to this genetic information. Potential third parties are varied and include insurance companies, employers and family members. In the hands of both groups, genetic information could lead to discrimination. The insurance industry could use this information as a tool by which to measure one's life expectancy and propensity for illness in order to set insurance rates. Genetic information, which might affect employment decisions, could also aid employers in determining which employees are predisposed to certain diseases. Of special importance are third parties who are family members that would be placed at risk by this information. While genetic information should be considered medical information, it is both individual and familial in nature. The patient is entitled to keep personal medical information private. However, since it is genetically transferable, it may impact other family members. This creates a conflict between physicians' confidentiality obligations to their patients and the physicians' ethical duty to warn the at-risk relatives.

Well before the emergence of any legal requirements, physicians had an ethical obligation to protect personal information about their patients. Since ancient times, the Hippocratic Oath has directed doctors

49. See id. at 561.
50. See id.
51. See Paul Recer, Gene Map May Create Discrimination, WASH. POST, Feb. 12, 2001, at A5. ("Without adequate safeguards, the genetic revolution could mean one step forward for science and two steps backward for civil rights . . . [m]isuse of genetic information could create a new underclass: the genetically less fortunate.").
52. Burnett, supra note 48, at 561; see also Recer, supra note 51, at A5 ("[Sen. Bill] Frist and Sen. Olympia Snowe are introducing legislation that would prevent insurance companies from requiring genetic testing and ban the use of genetic information to deny coverage or to set rates.").
53. Burnett, supra note 48, at 561; see also Recer, supra note 51, at A5 ("A survey of 2,133 employers this year by the American Management Association found that seven are using genetic testing for either job applicants or employees. . . .").
54. Burnett, supra note 48, at 561.
55. See id.
56. See id.
57. See generally Brownrigg, supra note 5, at 247 (1999) (discussing the Hippocratic Oath's continued importance as a "tenet of medical care today.").
to refrain from divulging information about their patients. This ethical position on physician-patient confidentiality remains intact today.

With respect to medical information, the right of privacy affords protection of personal data and affirmation of confidentiality. As genetic information is considered medical information, it is protected by the legal and ethical principles of confidentiality existing within the physician-patient relationship. Traditionally, confidentiality in the physician-patient relationship was absolute and therefore barred physicians from disclosing any genetic information to their patients’ relatives. Health care providers also had an ethical duty not to breach patient confidentiality. However, as with legal duty, codes of medical ethics provide exceptions to permit physicians to disclose otherwise confidential information. One such exception occurs where a known third party is at risk.

**D. Ethical Considerations**

Today, four ethical alternatives to this strict confidentiality requirement have been proposed as applicable in certain situations. First, the 1983 President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research states that where a patient

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58. See Oath of Hippocrates, reprinted in Barry R. Furrow et al., BIOETHICS: HEALTH CARE LAW AND ETHICS (3d ed. 1997) (“[F]or the benefit of my patients . . . I will not divulge . . . all that should be kept secret.”).

59. Id. (“A physician shall . . . safeguard patient confidences within the constraints of the law.”).

60. ASHG, supra note 6, at 747.

61. See id.

62. See id.

63. See id.

64. See id. at 477 (noting “that the Code of Ethics of the Canadian Medical Association [155(8) CAN. MED. Assoc. J. 1176A (1996)] permits a breach of a patient’s right to confidentiality ‘when the maintenance of confidentiality would result in a significant risk of harm to others.’ In contrast, the Code of Ethics of the American Medical Association [Fundamental Elements of the Patient-Physician Relationship, AMA Current Options 624 (1996)] does not refer to risk of harm but restricts itself to disclosure ‘need[ed] to protect the welfare of the individual or the public interest.’”).

65. See id.

66. See id.
refuses, health care professional disclosure to at-risk family members is permissible when:

(1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability that harm will occur if the information is withheld, and the disclosed information will actually be used to avert harm; (3) the harm that would result to identifiable individuals 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.67

The second proposal came from the American Institute of Medicine Committee's 1994 report on assessing genetic risks. The Committee adopted a position similar to that of the President's Commission.68 While recommending that genetic information remain confidential, the report suggested the possibility of disclosure to relatives in situations where the genetic disorder is highly likely to present itself and is treatable or preventable.69

Another suggested ethical position is a genetic “Miranda warning” that would inform a patient, in advance, of circumstances which could result in disclosure of genetic information to other family members.70 With notice provided before testing, patients would receive forewarning about possible disclosure regardless of their intentions to disclose.71 Consent by the patient constitutes a waiver of the privilege and effectively preserves the provider's ethical obligations. This position offers the advantage of preserving the physician-patient relationship. However, it may also lead to patient reluctance to undergo testing for fear that the results will be

67. See id. at 478 (stating the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, in Screening and Counseling for Genetic Conditions (U.S. Government Printing Office 1983)).

68. See id. (discussing the Institute of Medicine Committee's report on Assessing Genetic Risks, in Assessing Genetic Risks: Implications for Health and Social Policy (National Academy Press 1994) “The committee noted that the strongest case for warning by a health care professional would exist where there is a high likelihood that the relative has the genetic defect, the defect presents a serious risk to the relative and there is reason to believe that the disclosure is necessary to prevent serious harm.”).

69. See id.

70. See id.

71. See id.
reported to anyone, especially family members, who may have a negative reaction to the reported condition.

The fourth proposal suggests that an ethical standard imposing a duty to warn could become obligatory. While currently this duty is merely permissible, an ethical duty may evolve into a professional and legal standard absent any countervailing policy restraints.

It is presumed that most properly informed patients would warn their relatives of potential risks in order to ensure them early monitoring, detection and treatment. At a minimum, health care professionals should feel ethically obliged to inform patients of the implications of their genetic test results and the potential risk to family members. However, under certain conditions, health care professionals ethically should be permitted to breach patient confidentiality and disclose information to at-risk relatives.

II. LEGAL DUTY RECOGNIZING PATIENT CONFIDENTIALITY AND THE PRIVILEGE TO DISCLOSE

The common law policy has been to encourage the free flow of information in the physician-patient relationship. This policy is based on the advantages afforded to all by full disclosure of facts, which may bear upon the diagnosis and treatment of the patient, however embarrassing or harmful to the patient. Courts have generally upheld or recognized the right of a patient to recover damages from a physician for unauthorized disclosure on invasion of privacy grounds. With a few exceptions, courts have also held or recognized that a patient may have a cause of action against the physician for breach of the confidential relationship.

72. See id.
73. See id.
74. See id. at 475.
75. See id. at 474.
77. See id. § 2.
78. See id.
79. See id. §7. In a few jurisdictions, courts take the view that unauthorized disclosure does not constitute breach of the confidential relationship, see e.g., Collins v. Howard, 156 F. Supp. 322 (D. Ga. 1957). However, in a number of jurisdictions, it has been held or recognized that unauthorized disclosure may
Statutes relating to testimonial privileges or licensing requirements may provide a legal obligation for physicians to maintain patient confidentiality.\(^8\) In the 1920 case, *Simonsen v. Swenson*,\(^8\) the Nebraska Supreme Court found a legal duty from a licensing statute that authorized the revocation of medical licenses when a physician "'betray[ed]'... a professional secret to the detriment of a patient.'"\(^8\) This decision was based on the public policy interest in maintaining physician-patient confidentiality.\(^8\) Some jurisdictions have also looked to doctor-patient evidentiary statutes as indications of the underlying public policy justification for allowing patients tort recovery when physicians violate the duty of confidentiality. Recently, two South Carolina cases confirmed the value placed on confidentiality within the physician-patient relationship. The court recognized a cause of action in tort absent any doctor-patient evidentiary privilege.\(^8\) Critical to both decisions was the unique relationship of the doctor-patient relationship.\(^8\)

In the absence of a state statute, courts have applied contract theory to find liability for breach of confidentiality.\(^8\) In the 2000 case of *Doe v. Community Health Plan-Kaiser Corp.*,\(^8\) the court held that a physician's duty not to disclose a patient's confidential personal information "springs from the implied covenant of trust and confidence that is inherent in the physician-patient relationship," the breach of which is actionable as a constitute breach of the confidential relationship, see e.g., *Horne v. Patton*, 287 So. 2d 824 ( Ala. 1973).

80. Id. at 699-700.
81. 177 N.W. 831, 832 (Neb. 1920).
82. Id. (quoting NEB. REV. STAT. § 2721 (1913)).
83. See id.
85. See id.
86. See *Horne v. Patton*, 287 So.2d 824 ( Ala. 1973) (identifying an implied contractual duty preventing the disclosure of patient information as one of several legal justifications for protecting patient confidentiality).
tort. Other courts have found more than a mere contractual relationship between patient and physician. In 1997, the Virginia Supreme Court in Fairfax Hospital v. Curtis found that physicians, without authorization, owe a duty to their patients not to disclose information gained in the course of treatment. In so holding, the court also noted that this duty existed absent either a statutory command to the contrary or serious danger to the patient.

Courts also recognize exceptions to the physician-patient confidential relationship that require disclosure. One such exception to the confidentiality rule rests primarily on the concept of preventing foreseeable harm to identifiable third parties. In Tarasoff v. University of California Board of Regents, the California Supreme Court determined that psychotherapists who learn that their patient is likely to cause serious and foreseeable harm to an identifiable third party, have a duty to warn the endangered individual and take steps to protect that individual from harm.

In addition, courts have created exceptions to the physician-patient confidentiality rule to prevent harm. For example, a doctor may breach

88. Id. at 217.
89. See Sonia M. Suter, Whose Genes Are These Anyway?: Familial Conflicts over Access to Genetic Information, 91 Mich. L. Rev. 1854, 1872 (Tenn. 1993) (discussing the Supreme Court of Oregon's decision in Humphers v. First Interstate Bank, 696 P.2d 527 (Or. 1985), in which the court held the physician to a nonconsensual duty of confidentiality, which "is determined by standards outside the tort claim for its breach.").
90. 492 S.E.2d 642 (Va. 1997).
91. See id. at 644.
92. See id.
94. See Tarasoff v. Regents of University of California, 551 P.2d 334 (Cal. 1976) (en banc) (special relationship between physician and patient supports duty of reasonable care to protect identifiable third party from harm threatened by patient); see also Bradshaw v. Daniel, 854 S.W.2d 865 (1993) (holding that physician had duty to warn patient's wife of her risk of contracting Rocky Mountain Spotted Fever when he should have known patient had such disease); Hoffman v. Blackmon, 241 So. 2d 752 (Fla. Dist. Ct. App. 1970) (finding physician negligent for failing to diagnose tuberculosis in father, and failing to warn family of child's risk of contracting such disease).
95. 555 P.2d 334 (Cal. 1976) (en banc).
96. Tarasoff, 551 P.2d at 340.
confidentiality to protect the public from exposure to contagious disease, or report an incidence of child neglect, an exception recognized in every state. Moreover, when informed that the child may be genetically predisposed to disease, the failure of physicians to notify or arrange for genetic testing of children may be viewed as analogous to neglect. This situation would implicate the need for another privilege exception. However, courts are split on whether to actually extend such an exception to genetically inheritable diseases.

III. PHYSICIAN-PATIENT CONFIDENTIALITY WITH RESPECT TO GENETIC INFORMATION

A. Case Law

Two leading cases demonstrate that courts are not settled on whether to create a new exception to physician-patient confidentiality rules based on disclosure of genetic information to help a patient's family avoid harm. In *Pate v. Threlkel*, the Florida Supreme Court held that a physician does not need to directly inform the patient's children of their genetic predisposition to a disease. Conversely, in *Safer v. Estate of Pack*, the New Jersey Supreme Court rejected the argument that a physician's duty to warn a patient's family members of a genetic disease is satisfied by notifying only the patient. Instead, the court required that a doctor take

97. In Simonsen v. Swenson, 177 N.W. 831, 832 (Neb. 1920) (per curiam), the court found that physicians should not be liable for disclosing information when "necessary to prevent the spread of . . . disease."; see also N.Y. Pub. Health Law 2101 (McKinney 1993); N.Y. COMP. CODES R. & REGS. TIT. 10 2.10 (1997) (allowing exceptions to the confidentiality requirement where patients are diagnosed with communicable diseases). See also Alexander v. Culp, 705 N.E.2d 378 (8th Dist. Cuyahoga County 1997) (holding that a physician is not liable for disclosing confidential information to a non-patient if the communication to the non-patient was necessary for the welfare of the non-patient or the welfare of the public).

98. See James T.R. Jones, *Battered Spouses: Damage Actions Against Non-Reporting Physicians*, 45 DEPAUL L. REV. 191, 212 ("By statute all states require physicians to report known or suspected child abuse to specified authorities.").

99. 661 So.2d 278 (Fla. 1995).

100. *See id.* at 282.


102. *See id.* at 1192.
reasonable steps to ensure that family members are notified of a genetic disease.\textsuperscript{103}

\textit{1. Pate v. Threlkel}

Heidi Pate, the adult daughter of a woman diagnosed with medullary thyroid carcinoma,\textsuperscript{104} a malignant cancer of the thyroid, received the same diagnosis three years after her mother was treated.\textsuperscript{105} Subsequently, Pate filed a complaint against her mother's physicians for failure to warn of the hereditary nature of the cancer.\textsuperscript{106} Not until she learned that she suffered from this disease did Pate discover that her condition was genetically inherited from her mother.\textsuperscript{107} Accordingly, Pate claimed that the doctors should have been aware of the disease's hereditary quality and that the physicians owed her mother a duty to warn her about testing her children for the disease.\textsuperscript{108} This notice would have allowed Pate to monitor for the cancer and take precaution that would have made a cure more probable than not.\textsuperscript{109}

The trial court dismissed the complaint due to lack of privity between Pate and her mother's physicians.\textsuperscript{110} The appellate court agreed with the rationale of the trial court in rejecting the idea that the familial relationship justified extension of the physician's duty to certain family members.\textsuperscript{111} The court did, however, note that a physician's duty may extend to third parties outside the physician-patient relationship when there exists a "foreseeable zone of risk" to the third party.\textsuperscript{112} However, the court reasoned that Ms. Pate was not within this foreseeable zone of

\begin{thebibliography}{}
\bibitem{103} See id.
\bibitem{104} Familial medullary thyroid carcinoma is a genetic disease, one in which specific information carried by the genes causes the disease. Robert F. Gagel, M.D. & Zoila Torres Feldman, R.N., M.S., \textit{Familial Medullary Thyroid Carcinoma - A GUIDE FOR AFFECTED FAMILIES}, at http://endocr06.mda.uth.tmc.edu/educational/mtc.htm (last visited Dec. 18, 2001).
\bibitem{105} See Pate, 661 So.2d at 279.
\bibitem{106} See id.
\bibitem{107} See id.
\bibitem{108} See id.
\bibitem{109} See id.
\bibitem{110} See id. at 279-80.
\bibitem{111} See id.
\bibitem{112} Id.
\end{thebibliography}
risk and therefore no duty towards her existed.113

The Florida Supreme Court reversed the lower courts’ decisions, holding that the physician had a duty to warn Pate’s mother of the cancer’s genetically transferable nature.114 The court recognized that Florida’s statutory definition of duty provided that a claimant has the burden of proving that the alleged actions of the health care provider represented a breach of the prevailing professional standard of care for that provider.115 The court accepted the plaintiff’s allegation that the prevailing standard of care commanded that the patient receive a warning about the genetic inheritability of her disease.116 The court also noted that Pate satisfied the privity requirement because she could be considered an intended third party beneficiary of the prevailing standard of care.117

Further, the court noted that a patient’s children do fall under the requisite zone of foreseeable risk encompassing the physician’s duty to warn.118 Specifically, the court held that the physicians’ duty to warn their patients’ children of their predisposition to a genetically inheritable disease is satisfied by warning only the patient.119 The court reasoned that, based on the advice of their physicians, patients are responsible for warning their children.120 The court stated that if a physician were to warn the third party directly, he would breach his duty of confidentiality to his patient.121 The court also noted that the duty to warn a third party was impractical and burdensome.122

2. Safer v. Estate of Pack

Donna Safer was diagnosed with cancerous polyposis,123 a cancer of the

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113. See id.
114. See id.
115. See id.
116. See id. at 281.
117. See id. at 282.
118. See id.
119. See id.
120. See id.
121. See id.
122. See id. ("To require the physician to seek out and warn various members of the patient’s family would often be difficult or impractical and would place too heavy a burden on the physician.").

123. Defined in Stedman’s, supra note 16, at 1424, as “Several cancerous polyps.”
colon, thirty-four years after her father was treated for the same condition.¹²⁴ Safer and her husband filed a complaint against the estate of her father’s treating physician.¹²⁵ The complaint alleged that the physician knew of the hereditary nature of cancerous polyposis, and was therefore under a duty to warn relatives at risk.¹²⁶ Safer argued that if she had been warned, the worst effects of her disease could have been avoided.¹²⁷

Relying on the appellate court’s decision in Pate, the trial court held that the physician did not have a duty to warn his patient’s child of genetic risk for disease.¹²⁸ The court determined that privity impeded the action due to the lack of a patient-physician relationship between the child and the doctor.¹²⁹ Because there was no risk to public health, the court reasoned that no exception to the privity requirement existed.¹³⁰ The Court found that the duty to warn in this case differed from those involving contagious or infectious disease because the harm already exists within the child instead of being introduced by a patient warned to stay away.¹³¹

The Superior Court of New Jersey reversed the trial court’s decision.¹³² It acknowledged that a physician has a duty to warn the patient as well as members of the patient’s immediate family who may be adversely affected by a failure to warn.¹³³ The court maintained that no significant difference existed between the threat of infection from contagious disease and the threat posed by genetic disease when a physician fails to disclose the condition.¹³⁴ The court also discussed prior case law establishing a cause of action due to increased risk of harm.¹³⁵

Further, the court reasoned that an early warning is beneficial to

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¹²⁴. See Safer, 677 A.2d at 1190.
¹²⁵. See id.
¹²⁶. See id.
¹²⁷. See id.
¹²⁸. See id. at 1191 (noting the trial court’s statement that Pate v. Threlkel, 640 So.2d 183 (Fla. Dist. Ct. App. 1994), was the only case “on point”).
¹²⁹. See Safer, 677 A.2d at 1190.
¹³⁰. See id. at 1190-91.
¹³¹. See id.
¹³². See id. at 1192.
¹³³. See id.
¹³⁴. See id.
¹³⁵. See id. at 1192 (citing Evers v. Dollinger, 471 A.2d 405 (N.J. 1984), recognizing a cause of action for increased risk of harm).
individuals at risk in preventing some of the consequences of the disease. Accordingly, reasonable steps must be taken to inform the parties at risk. However, the court did not define what constitutes "reasonable steps," leaving unresolved the problem of how to limit physician-patient confidentiality in certain circumstances.

The Safer Court broadened the physician's duty to warn to members of the patient's immediate family. In acknowledging this new duty, the court allowed the privity requirement of the physician-patient relationship to be superseded, suggesting a new legal standard for genetic testing. In addition to judicial attempts to balance physicians' duty of confidentiality against the duty to warn, legislators and regulators have also worked to address this quandary.

B. Legislation and Regulations Addressing Disclosure of Genetic Information

Public disclosure of one's genetic information may be harmful to that individual. Possible negative results of disclosure include psychological, social and financial injury as well as stigmatization, discrimination and potential loss or difficulty in obtaining employment or insurance. At least thirty-one states have enacted legislation to protect the privacy of genetic information in an effort to deter related discrimination.

One example of such legislation is Illinois' Genetic Information Privacy Act. The primary objective of this legislation is to promote public health by facilitating voluntary, confidential and nondiscriminatory use of

136. See id.
137. See id.
138. See id. at 1192.
139. See id. at 1192-93.
140. Burnett, supra note 48, at 575.
141. ASHG, supra note 6, at 478.
genetic testing information. Included in the code is a section recognizing exceptions to the otherwise confidential and privileged nature of genetic information. While permitting some exceptions, the statute specifically states that these exemptions create neither an express nor implied duty for the health care provider to notify the subject's spouse or legal guardian of the test results.

So far, no federal legislation has been passed specifically relating to genetic discrimination. However, on February 8, 2000, President Clinton signed an executive order protecting federal employees from discrimination in hiring or promotion actions. In addition, some existing federal anti-discrimination laws may be applicable to genetics.

144. See id. §5.

(2) Despite existing laws, regulations, and professional standards which require or promote voluntary and confidential use of genetic testing information, many members of the public are deterred from seeking genetic testing because of fear that test results will be disclosed without consent or be used in a discriminatory manner.

145. See id. §15 ("Except as otherwise provided in this Act, genetic testing and information derived from genetic testing is confidential and privileged and may be released only to the individual tested and to persons specifically authorized, in writing in accordance with Section 30, by that individual to receive the information.").

146. See id. §30.

(a) No person may disclose or be compelled to disclose the identity of any person upon whom a genetic test is performed or the results of a genetic test . . . except to the following persons:

The subject of the test or the subject's legally authorized representative. This paragraph does not create a duty or obligation under which a health care provider must notify the subject's spouse or legal guardian of the test results, and no such duty or obligation shall be implied. No civil liability or criminal sanction under this Act shall be imposed for any disclosure or nondisclosure of a test result to a spouse by a physician acting in good faith under this paragraph.

147. See Human Genome Project Information, GENETICS, PRIVACY AND LEGISLATION, at http://www.ornl.gov/hgmis/project/about.html (last visited Dec. 18, 2001) (noting that several bills were introduced during the last decade, with the primary public concern being discrimination by insurers and employers).

148. Id.

149. See generally The Americans with Disabilities Act of 1990 ("ADA"), The Health Insurance Portability and Accounting Act of 1996 ("HIPAA"), and
With respect to familial disclosure of genetic testing, The Medical Privacy in the Age of Technologies Act of 1997\textsuperscript{150} permits health care providers to notify a patient's family of genetic disease unless there is an express instruction from the patient that such information remain confidential.\textsuperscript{151} However, this legislation does not require the physician to disclose genetic information to a patient's children without his or her consent.\textsuperscript{152}

Nevertheless, when a physician deems it necessary to inform a patient's relative about the risk of a genetic disorder, an environment must exist in which no detrimental consequences will result from the revelation of this information. Thus, there is a need for set guidelines about how and when disclosure of genetic data should occur.

IV. GUIDELINES FOR DISCLOSURE OF GENETIC INFORMATION TO RELATIVES AT-RISK

Considering ethical and legal obligations, determinations about whether to disclose genetic information must be evaluated according to a number of factors.\textsuperscript{153} While confidentiality should be respected, its scope is not absolute.\textsuperscript{154} Competing interests may impose on physicians a duty to warn relatives of their risk for genetically inherited disease.\textsuperscript{155}

Accordingly, when reasonable efforts have failed to persuade the patient to disclose information about genetically inheritable defects to relatives, disclosure by the health care provider should be permissible if:

"(1) there is a high risk of serious, imminent and foreseeable harm; (2) the at-risk relative(s) is (are) identifiable; (3) the disease is preventable, treatable or early monitoring will reduce the genetic risk; (4)"

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Title VII of the Civil Rights Act of 1964 ("Title VII").

151. See id.
152. See id.
153. See id.
154. See id.
155. See id.
The harm of failing to disclose outweighs the harm of disclosure.\footnote{156}

\textit{A. High Risk of Serious, Imminent and Foreseeable Harm.}

In \textit{Tarasoff}, the California Supreme Court referred to protection of "the threatened victim.\footnote{157} The Court also stated that disclosure was unwarranted "unless such disclosure is necessary to avert danger to others.\footnote{158} An individual refusing to disclose information to an at-risk relative is, in effect, threatening the health of that relative if the danger could be avoided by disclosure of that information.\footnote{159}

The court in \textit{Pate} expanded the physician's duty to warn, noting that a patient's children do fall under the requisite zone of "foreseeable risk.\footnote{160} Thus, the duty to warn may logically extend to physicians who possess knowledge about a patient's refusal to inform relatives about genetic information that is likely to be harmful to them.

\textit{B. The At-Risk Relative(s) Is (Are) Identifiable.}

The \textit{Tarasoff} court found that a duty to warn probably exists if the physician has a special relationship with the person who may cause the harm of the potential victim, the potential victim or person at risk is identifiable, and the harm to the victim is foreseeable and serious.\footnote{161} The court in \textit{Safer} recognized that a physician owes a duty to communicate about risk of disease to the patient as well as to members of the patient's immediate family who may be adversely affected by a failure to warn.\footnote{162} This conclusion differed from the court's determination in \textit{Pate} that directly warning at-risk relatives would be impractical and burdensome for physicians.\footnote{163}

At-risk relatives possess genetic relatedness.\footnote{164} Therefore if these relatives are identifiable and reasonably reachable by the health care

\footnote{156. See id.}
\footnote{157. Tarasoff, 551 P.2d at 347.}
\footnote{158. Id.}
\footnote{159. See Jennifer Miller, \textit{Physician-Patient Confidentiality and Familial Access to Genetic Information}, 2 HEALTH L. J. 141, 149 (1994).}
\footnote{160. Pate, 661 So.2d at 282.}
\footnote{161. Tarasoff, 551 P.2d at 450.}
\footnote{162. Safer, 677 A.2d at 1192.}
\footnote{163. Pate, 661 So.2d at 282.}
\footnote{164. ASHG, \textit{supra} note 6.}
professional, these at-risk relatives deserve to be warned of possible disease.

**C. The Disease Is Preventable, Treatable or Early Monitoring Will Reduce the Genetic Risk.**

While analysis of Tarasoff arguably supports finding a duty to warn at-risk relatives about potential genetic risk, legal scholars have distinguished its applicability in the two situations. These commentaries interpret differences in the nature of the harm. They argue that in cases of threats of violence, it is the patient's actions that cause the harm. With genetic conditions, however, the patient is not placing relatives at risk by carrying the gene mutation since, regardless of the patient's actions, the relatives will either possess or not possess the mutation.

However, this reasoning does not hold when the genetic risk is preventable, treatable, or early monitoring reduces its ill effects. In such cases, warning the at-risk relative is not futile. Instead, providing the relative notice of his or her possible disease can only aid in preventing harm. This provides a responsible and benevolent approach to handling such information.

**D. The Harm of Failing to Disclose Outweighs the Harm of Disclosure.**

In Safer, the New Jersey Supreme Court applied the infectious disease model. The court held that no significant difference existed between the


166. ASHG, *supra* note 6, at 479 (citing Suter, *supra* note 88, and Miller, *supra* note 157, who point out that there are number of similarities between the two cases: a special relationship exists between the physician and the patient, the third party is identifiable, there is no special relationship between the physician and the third party, the information to be disclosed is confidential, and there is an opportunity for the prevention of harm.

167. *Id.*

168. *See id.*

169. Safer, 677 A.2d at 1192.
threat of infection and the threat posed by a genetic disease when a physician fails to disclose the condition. The court also noted that the genetic risks are as foreseeable as infectious ones and that "[t]he individual or group at risk is easily identified, and substantial future harm is easily identified or minimized by a timely and effective warning."71

Disclosure of communicable disease is allowable because society's welfare is protected through warnings about the risk of infection.72 As with disclosure of contagious disease, disclosure of harmful genetic information may serve an overriding public interest. When disclosure will prevent or lessen the harm caused by genetic defect, it should be permissible.

CONCLUSION

The confidentiality requirement of the physician-patient relationship is sacred. Unrestrained use of an individual's genetic information could result in denial of employment, mortgages, pensions, loans and life insurance.73 Thus, the privacy of medical information should be respected. However, certain situations warrant a physician's breach of the confidentiality of his or her patient's medical information. In these cases, physicians may disclose patient information to at-risk third parties in an attempt to warn them of adverse consequences. Such action is justified to prevent harm if the harm in failing to disclose outweighs the harm of disclosure. Factors to consider in this balancing include the relative's likelihood of developing the disease, the severity of the disease, and the ability to prevent or treat the disease. Additionally, the provider should take into account the patient's reaction, considering his or her mental and physical well being. Many of these patients are already under great stress and such a revelation may exacerbate their anxiety. Accordingly, a support mechanism may need to be in place.

New developments in genetic testing allow for increased forewarning of possible harms based on genetic information. Disclosure of this information could possibly prevent harm or help those at-risk of harm. Optimally, physicians need only explain such risks to patients, who in turn will warn their at-risk relatives. However, when patients fail to do so,
courts in some cases are willing to extend a physician's privilege to warn third parties when the matter involves relatives at-risk for genetically inheritable disease.

Finally, as suggested in Tarasoff, the duty to disclose must be narrowly tailored. Thus, more specific guidelines should be drawn as to when certain genetic predispositions may or may not be disclosed. This would allow for some consistency in the medical community and help avoid charges of unnecessary disclosure. However, as the disclosure of any medical information is inconsistent with the medical ethic, we should be careful to carve out only the narrowest exceptions necessary to achieve the desired goal.