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Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks

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ARTICLE

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I. INTRODUCTION

In 1989, the Congress launched a $3 billion scientific endeavor to uncover the specific links between genes and disease. Labeled by proponents as science's "moon shot" and detractors as the "Manhattan project of science," the Human Genome Project will map (that is, determine the location of) and sequence (analyze the constituent parts of) each of the 50,000 to 100,000 genes in each human cell.[1] The Human Genome Project's ultimate goal is to facilitate the development of genetic diagnostic tests and genetic treatment modalities for the nearly 5000 diseases[2] that have a genetic basis. The tests will determine the presence of genes signalling current and future diseases that may affect the patient. They will also enable couples to determine whether their conceptus suffers from a serious genetic disease, thus providing information that the couple can use to decide whether to continue or terminate the pregnancy.[3]

The Human Genome Project will produce an explosion of information. People will be able to learn of their risks of developing a particular genetic disease, of bearing a child affected with a genetic disorder, and of the possibility that they may develop a particular illness after exposure to environmental stimuli. Information about genetic risks and the availability of genetic diagnostic and treatment services may be crucial to a person making major life decisions, such as where to live, what type of job to take, what type of insurance to purchase, and even whether to bear a child. As the volume of such genetic information grows, questions will arise regarding who has the duty to convey genetic information and under what circumstances.

With the limited forms of genetic information traditionally available, health care professionals have generally been regard-

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1. *See* Victor A. McKusick, *Mapping and Sequencing the Human Genome*, 320 NEW ENG. J. MED. 910, 910-13 (1989).

2. *See, e.g.*, VICTOR A. MCKUSICK, MENDELIAN INHERITANCE IN MAN at xvii (9th ed. 1990).

3. Understanding the genetic bases of diseases may lead to the development of new gene therapies. In September 1990, researchers at the National Institute of Health performed the first gene therapy on humans. *See* Barbara J. Culliton, *Gene Therapy Begins*, 249 SCIENCE 1372, 1372 (1990). The protocol involved gene transplants into children with severe combined immune deficiency caused by the lack of the enzyme adenosine deaminase (ADA). *Id.*

ed as the appropriate sources of information. The legal principles supporting the duty of health care professionals to provide genetic information can be found in cases recognizing causes of action for wrongful life and wrongful birth,[4] finding a duty to warn a patient of newly-discovered risks from previously rendered services,[5] and allowing breaches of confidentiality to protect third parties.[6]

The sheer magnitude and diversity of genetic information that the Human Genome Project will produce raises questions about whether health care professionals are necessarily the most appropriate source of such disclosures. Future genetic testing will provide information to an asymptomatic individual that he or she may suffer a genetic disease later in life[7] or will be susceptible to a disorder if he or she is exposed to a particular environmental stimulus.[8] Yet an asymptomatic individual, who has not yet developed any sign of a genetic defect, may not contact a health care professional. Therefore, placing the duty to warn on health care professionals will not assure that such a person will be informed. Even when a person does seek health care services, the range of identifiable genetic defects may be so extensive that it may be unreasonable to expect the health care provider to provide information for each possible defect.[9]

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4. Refer to notes 10-58 *infra* and accompanying text.

5. Refer to notes 116-44 *infra* and accompanying text.

6. Refer to notes 145-80 *infra* and accompanying text.

7. For example, a person can now find out if he or she will later suffer from Huntington's disease. *See* James Gusella et al., *A Polymorphic DNA Marker Genetically Linked to Huntington's Disease*, 306 NATURE 234, 237-38 (1983) (stating that researchers have identified a DNA marker genetically linked to the Huntington's disease locus).

8. One such disorder would be porphyria, which can be precipitated by exposure to barbituates. *See* Arno Motulsky, *The Significance of Genetic Disease*, *in* ETHICAL ISSUES IN HUMAN GENETICS: GENETICS COUNSELING AND THE USE OF GENETIC KNOWLEDGE 59, 64 (Bruce Hilton et al. eds., 1973).

There are at least 50 other genetic defects that enhance an individual's susceptibility to the toxic or carcinogenic effects of environmental agents. EDWARD J. CALABRESE, ECOGENETICS: GENETIC VARIATION IN SUSCEPTIBILITY TO ENVIRONMENTAL AGENTS 323-28 (1989). For example, a single gene appears responsible for enhancing an individual's risk of developing emphysema; smoking or exposure to grain dust exacerbates that risk. *See* S. Eriksson et al., *Effects of Smoking and Intermediate Alpha$_1$-Antitrypsin Deficiency (PiMZ) on Lung Function*, 67 EUR. J. RESPIRATORY DISEASE 279, 283 (1985) (concluding that genetic factors, such as alpha$_1$-antitrypsin deficiency, and smoking combine cumulatively to increase lung disfunction); S.L. Horn et al., *Pulmonary Function in PiM and MZ Grainworkers*, 89 CHEST 795, 796-98 (1986) (stating that grain dust exposure produces disfunctions similar to those produced by smoking). *See generally* CALABRESE, *supra*, at 323-28 (identifying various genetic factors that affect one's susceptibility to environmental agents).

9. Physicians can diagnose at least 448 conditions through amniocentesis. DAVID D. WEAVER, CATALOG OF PRENATALLY DIAGNOSED CONDITIONS at xviii (1990).

This Article explores the legal precedents that may be used to impose a duty to disclose genetic risks upon health care professionals. It also addresses the critical questions that future courts will face regarding health care professionals' liability for failing to provide genetic information. These questions include: Which patients are sufficiently at risk to warrant disclosure? Which genetic tests are sufficiently predictive to be offered? Is there a duty to recontact patients or former patients as previously-rendered genetic tests take on new meaning? Is there a duty to inform third parties, such as a spouse or relative, about a patient's genetic risks? This Article suggests that the range of available genetic information—and the number of people interested in that information—may be so great that health care providers may not be the appropriate source. Other societal mechanisms may be necessary to insure that people can obtain sufficient genetic information in order to make important life choices.

II. WRONGFUL BIRTH AND WRONGFUL LIFE CASES

The legal issues surrounding the dissemination of genetic information first reached the courts in the wrongful birth and wrongful life cases. Various courts have held that physicians and geneticists have a duty to disclose information to prospective parents concerning both the genetic risks to their potential offspring and the diagnostic procedures available to ascertain those risks so that they might choose whether to refrain from conceiving or to abort a fetus with a serious disorder.

A. The History of Wrongful Birth and Wrongful Life Cases

Courts initially resisted recognizing a cause of action for wrongful birth.[10] The early cases befuddled the courts because, unlike traditional malpractice cases, nothing that the health care provider could have done would have prevented the harm to the child.[11] The logic behind these early suits was that if the parents of the affected child had received proper counseling or diagnosis, they could have decided not to conceive or to seek an abortion. Early case law dealing with wrongful birth actions rejected the notion that the failure to warn the parents of a fetus' risk of serious defect was action-

10. Refer to note 28 *infra* and accompanying text.

11. *See, e.g.*, Procanik v. Cillo, 478 A.2d 755, 760 (N.J. 1984) (plaintiffs did not assert that the physician's negligence caused the child's congenital rubella syndrome or that the child ever had a chance to live a normal life).

able because the physician was not the proximate cause of the defect.[12] However, liability for a missed diagnosis in other areas of medicine was, and still is, common even though, in such cases, the physician did not cause the illness.[13]

Another reason that courts were reluctant to recognize the wrongful birth cause of action was that the post-conception remedy available—abortion—was illegal.[14] This reasoning is no longer valid after *Roe v. Wade*,[15] which upheld a woman's constitutional right to undergo an abortion during the first two trimesters of pregnancy. As one court noted, "[t]he value of genetic testing programs . . . is based on the opportunity of parents to abort afflicted fetuses, within appropriate time limitations."[16]

Wrongful birth cases are now widely recognized.[17] An ac-

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12. *See* Gleitman v. Cosgrove, 227 A.2d 689, 692-93 (N.J. 1967) (holding that no causal link existed between a fetus' injury resulting from its mother's exposure to German measles and the doctor's failure to warn the parents of the risk of such an injury).

13. *See* Alexander M. Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 619, 628 (1979) (discussing the application of traditional malpractice rules in the context of genetic counseling). Dissenting from a Georgia Supreme Court opinion that rejected a cause of action for wrongful birth, Judge Smith made a similar point:

> The majority would keep this issue from a jury because the "impairment [was] inherited from her parents and an impairment which was already in existence when the parents first came into contact with the physician." If a patient comes to the doctor with an inflamed appendix, or gall or kidney stones, and the doctor fails to properly diagnose the condition, we do not absolve the doctor of all future damages because the condition was genetic and because it was in existence when the patient walked into the office. That would be absurd. With a proper diagnosis no injury would have occurred.

Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 564 (Ga. 1990) (Smith, J., dissenting).

14. *See Gleitman*, 227 A.2d at 693-94 (refusing to recognize plaintiffs' claim that they were denied the opportunity to abort their fetus on the basis that such conduct is prohibited by law); Dumer v. St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975) (stating that the issue of availability of an abortion required a legal opinion, which the doctor was not required to give). *But see* Jacobs v. Theimer, 519 S.W.2d 846, 848 (Tex. 1975) (refusing to excuse a physician's failure to properly render a diagnosis, despite the illegality of eugenic abortions).

15. 410 U.S. 113 (1973).

16. Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692, 695 (E.D. Pa. 1978).

17. *See, e.g.*, Gallagher v. Duke Univ., 852 F.2d 773, 774 (4th Cir. 1988); Robak v. United States, 658 F.2d 471, 477 (7th Cir. 1981); Haymon v. Wilkerson, 535 A.2d 880, 882 (D.C. 1987); Moores v. Lucas, 405 So. 2d 1022, 1026 (Fla. Dist. Ct. App. 1981); Blake v. Cruz, 698 P.2d 315, 319 (Idaho 1984); Siemieniec v. Lutheran Gen. Hosp., 512 N.E.2d 691, 706 (Ill. 1987); Pietre v. Opelousas Gen. Hosp., 517 So. 2d 1019, 1028 (La. Ct. App. 1987), *aff'd in part, rev'd in part*, 530 So. 2d 1151 (La. 1988); Proffitt v. Bartolo, 412 N.W.2d 232, 242 (Mich. Ct. App. 1987); Smith v. Cote, 513 A.2d 341, 355 (N.H. 1986); Procanik v. Cillo, 478 A.2d 755, 762 (N.J. 1984); Schroeder v. Perkel, 432 A.2d 834, 840 (N.J. 1981); Becker v. Schwartz, 386 N.E.2d

tion exists when physicians fail to warn prospective parents that they are at risk of conceiving or giving birth to a child with a serious genetic disorder.[18] This potential liability includes instances in which a reasonable physician should have known of the risk because the couple's previous child had a genetic disorder[19] or because of the woman's advanced age.[20] Liability can also arise if the health care provider fails to advise prospective parents of known risks due to one or both parents belonging to a particular ethnic or racial group.[21] Finally, courts find physicians liable for failing to discuss the availability of genetic services when specific risk assessment services are available.[22] Thus, physicians may be liable for failing to inform a couple about the availability of carrier status testing (to determine whether the parents' genes harbor a defect which, if passed to the child, could cause a genetic disorder)[23] or prenatal diagnosis[24] (to determine if the fetus is

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807, 814 (N.Y. 1978); Speck v. Finegold, 439 A.2d 110, 113 (Pa. 1981); Jacobs v. Theimer, 519 S.W.2d 846, 847-48 (Tex. 1975); Naccash v. Burger, 290 S.E.2d 825, 830 (Va. 1982); Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 493 (Wash. 1983) (en banc); James G. v. Caserta, 332 S.E.2d 872, 882 (W. Va. 1985); Dumer v. St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975). Only a few states refuse to recognize the cause of action. *See, e.g.*, Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 564 (Ga. 1990); Wilson v. Kuenzi, 751 S.W.2d 741, 746 (Mo.), *cert. denied*, 488 U.S. 893 (1988); Azzolino v. Dingfelder, 337 S.E.2d 528, 537 (N.C. 1985), *cert denied*, 475 U.S. 835 (1986).

18. *See, e.g.*, Nelson v. Krusen, 678 S.W.2d 918, 919 (Tex. 1984) (erroneously interpreting as negative a woman's carrier status test for Duchenne muscular dystrophy); Naccash v. Burger, 290 S.E.2d 825, 829-30 (Va. 1982) (allowing a wrongful birth cause of action when a doctor erroneously informed a father that he was not a carrier of Tay-Sachs). Liability does not only exist in cases in which a physician erroneously informs a couple that their fetus is unaffected. At least one case exists in which a physician erroneously diagnosed a fetus as having a neurological disorder and the pregnant woman consequently aborted a normal fetus. *See* Martinez v. Long Island Jewish Hillside Medical Ctr., 512 N.E.2d 538, 538 (N.Y. 1987) (mem.).

19. For example, in Schroeder v. Perkel, 432 A.2d 834 (N.J. 1981), a physician failed to diagnose a couple's first child as having cystic fibrosis. *Id.* at 840. The couple later gave birth to another child who also had the disease. The physician was held liable for failing to properly diagnose the first child's disorder in time to afford the couple the opportunity to choose whether to conceive the second child. *Id.*

20. *See, e.g.*, Becker v. Schwartz, 386 N.E.2d 807, 814 (N.Y. 1978) (noting the effect of a mother's age on the development of a fetus).

21. *See* Naccash v. Burger, 290 S.E.2d 825, 837 (Va. 1982) (allowing recovery for a physician's failure to use a blood test to determine the risk that an eastern-European Jewish couple had of passing Tay-Sachs disease to their children).

22. *See* Haymon v. Wilkerson, 535 A.2d 880, 881 (D.C. 1987) (finding liability when a couple followed a physician's advice discouraging genetic testing of their fetus and the fetus was subsequently diagnosed as having Down's syndrome).

23. *See, e.g.*, Goldberg v. Ruskin, 471 N.E.2d 530, 540 (Ill. App. Ct. 1984) (finding liability for a doctor's failure to inform prospective parents of their likelihood of conceiving a Tay-Sachs afflicted child), *aff'd*, 499 N.E.2d 406 (Ill. 1986); *Naccash*, 290 S.E.2d at 837.

24. Physicians most commonly undertake prenatal diagnosis through amniocente-

currently affected or will develop the genetic disorder).[25]

In addition to the wrongful birth suits that parents can bring when a physician does not accurately advise them of the possibilities of genetic defects in their children, parents can also bring wrongful life suits on behalf of the children. In a wrongful life action,

> [t]he child does not allege that the physician's negligence caused the child's deformity. Rather, the claim is that the physician's negligence—his failure to adequately inform the parents of the risk—has caused the *birth of* the deformed child. The child argues that *but for* the inadequate advice, it would not have been born to experience the pain and suffering attributable to the deformity.[26]

The controversy surrounding this cause of action stems from

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sis or chorionic villi sampling. Physicians employing amniocentesis insert a needle into the mother's uterus in order to remove a small amount of amniotic fluid. This procedure, which is usually performed between the 16th and 19th weeks of pregnancy, allows physicians to determine the sex, chromosomal defects, and numerous genetic defects of the fetus. *See, e.g.*, OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, HUMAN GENE THERAPY—BACKGROUND PAPER 64-65 (1984); NICHD Nat'l Registry for Amniocentesis Study Group, *Midtrimester Amniocentesis for Prenatal Diagnosis—Safety and Accuracy*, 236 JAMA 1471, 1471 (1976); Nancy E. Simpson et al., *Prenatal Diagnosis of Genetic Disease in Canada: Report of a Collaborative Study*, 115 CAN. MED. ASS'N J. 739, 745 (1976).

Physicians can use chorionic villi sampling (CVS) to detect and diagnose prenatal chromosomal and genetic defects as early as eight weeks into pregnancy. Doctors take samples from the villi, which attach the fetal placenta to the uterus. The subsequent analysis of the tissue takes approximately one week. For discussions of the application of CVS, see generally B. Brambati et al., *Chorionic Villi Sampling: General Methodological and Clinical Approach*, *in* FIRST TRIMESTER FETAL DIAGNOSIS 6 (M. Fraccaro et al. eds., 1984); Mark I. Evans, *Chorionic Villus Sampling Detects More than 100 Fetal Abnormalities*, 84 MICH. MED. 456 (1985); W.A. Hogge et al., *Prenatal Diagnosis by Chorionic Villi Sampling: Lessons of the First 600 Cases*, 5 PRENATAL DIAGNOSIS 393 (1985); L.G. Jackson et al., *Letters to the Editor: Safety of Chorionic Villus Biopsy*, LANCET, Mar. 1986, at 674; Laird Jackson, *Prenatal Genetic Diagnosis by Chorionic Villus Sampling (CVS)*, 9 SEMINARS PERINATOLOGY 209 (1985); P.D. Knott et al., *Effect of Chorionic Villus Sampling and Early Pregnancy Counselling on Uptake of Prenatal Diagnosis*, 293 BRIT. MED. J. 479 (1986); H. Nguyen The & G. Pescia, *Chorionic Villi Sampling: The Lausanne Study*, *in* 15 CONTRIBUTIONS TO GYNECOLOGY AND OBSTETRICS 11 (G. Pescia & H. Nguyen The eds., 1986); Renate Oehme et al., *DNA-Diagnosis of Sickle Cell Anemia from Chorionic Villi: Possible Influence of Maternal Cell Contamination*, 73 HUMAN GENETICS 186 (1986).

25. *See, e.g.*, Phillips v. United States, 566 F. Supp. 1, 13 (D.C.S.C. 1981) (holding a physician liable for failure to test a fetus when a defective genetic trait was known to exist in the family); Becker v. Schwartz, 386 N.E.2d 807, 808-09 (N.Y. 1978) (holding a physician liable for failure to inform an older mother of the availability of genetic testing); James G. v. Caserta, 332 S.E.2d 872, 878-79 (W. Va. 1985) (holding a physician liable for failure to inform parents of the availability of genetic testing where the parents would have aborted a genetically afflicted fetus).

26. Thomas D. Rogers, *Wrongful Life and Wrongful Birth: Medical Malpractice in Genetic Counseling and Prenatal Testing*, 33 S.C. L. REV. 713, 713 (1982).

the nature of the claim: the allegation that one would be better off in a state of non-existence than in a state of impaired existence. While certain jurisdictions have recognized the validity of wrongful life actions,[27] others have refused to grapple with the philosophical and ethical implications of such an allegation.[28]

Wrongful life and wrongful birth causes of action present similar fact situations in jurisdictions that recognize wrongful life as a cause of action. For example, courts have recognized a wrongful life cause of action when doctors failed to advise prospective parents of genetic risks[29] or provided erroneous information.[30] Courts have also recognized this cause of action in non-genetic circumstances in which parents were not advised of other fetal risks.[31]

In both wrongful birth and wrongful life cases, the current

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27. California, New Jersey, and Washington have recognized a cause of action for wrongful life. *See* Turpin v. Sortini, 643 P.2d 954, 965 (Cal. 1982); Procanik v. Cillo, 478 A.2d 755, 762 (N.J. 1984); Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 496-97 (Wash. 1983). In Illinois, a court allowed a wrongful life cause of action but limited damages to extraordinary expenses. Siemieniec v. Lutheran Gen. Hosp., 480 N.E.2d 1227, 1232 (Ill. App. Ct. 1985). A subsequent Illinois Supreme Court case dealing with third parties denied the award of general damages in a wrongful life case and distinguished that case from *Siemieniec*: "Here compensation is sought for general damages only . . . and thus we do not consider here the separate question whether a child may recover medical or other expenses . . . ." *Goldberg*, 499 N.E.2d at 407. *See generally* Joseph S. Kashi, *The Case of the Unwanted Blessing: Wrongful Life*, 31 U. MIAMI L. REV. 1409, 1410-19 (1977) (presenting an analytical framework for leading wrongful life cases); Maxine A. Sonnenburg, Note, *A Preference for Nonexistence: Wrongful Life and a Proposed Tort of Genetic Malpractice*, 55 S. CAL. L. REV. 477, 484-93 (1982) (analyzing leading wrongful life cases and suggesting a structural analysis for genetic torts).

28. *See, e.g.*, Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692, 695 (E.D. Pa. 1978); Lininger v. Eisenbaum, 764 P.2d 1202, 1212 (Colo. 1988); Blake v. Cruz, 698 P.2d 315, 332 (Idaho 1984); Dorlin v. Providence Hosp., 325 N.W.2d 600, 601 (Mich. Ct. App. 1982); Eisbrenner v. Stanley, 308 N.W.2d 209, 213 (Mich. Ct. App. 1981); Azzolino v. Dingfelder, 337 S.E.2d 528, 532-33 (N.C. 1985), *cert. denied*, 479 U.S. 835 (1986); Schroeder v. Perkel, 432 A.2d 834, 840 (N.J. 1981); Berman v. Allen, 404 A.2d 8, 12 (N.J. 1972); Gleitman v. Cosgrove, 227 A.2d 689, 692 (N.J. 1967); Alquijay v. St. Luke's-Roosevelt Hosp. Ctr., 473 N.E.2d 244, 245 (N.Y. 1984); Becker v. Schwartz, 386 N.E.2d 807, 812 (N.Y. 1978); Ellis v. Sherman, 478 A.2d 1339, 1342 (Pa. Super. Ct. 1984), *aff'd*, 515 A.2d 1327 (Pa. 1986); Rubin v. Hamot Medical Ctr., 478 A.2d 869, 872 (Pa. Super. Ct. 1984), *appeal granted*, 498 A.2d 868 (Pa. 1985); Nelson v. Krusen, 678 S.W.2d 918, 928 (Tex. 1984); James G. v. Caserta, 332 S.E.2d 872, 881 (W. Va. 1985); Dumer v. St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975); Beardsley v. Wierdsma, 650 P.2d 288, 289-90 (Wyo. 1982).

29. *See, e.g.*, Turpin v. Sortini, 643 P.2d 954, 965 (Cal. 1982) (bringing claim against a health care provider for failure to advise parent of a hereditary hearing defect).

30. Curlender v. Bio-Science Lab., 165 Cal. Rptr. 477, 479-80 (Ct. App. 1980) (bringing suit against a laboratory for negligently conducting genetic tests).

31. *See, e.g.*, Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 486 (Wash. 1983) (finding liability for the failure to inform an epileptic mother of the potential effects that medication could have on her fetus).

trend with respect to damages is to allow the recovery of only the additional costs of treatment and special resources for the child, not the entire cost of rearing the child. In fact, Maine has codified that approach: "Damages for the birth of an unhealthy child born as the result of professional negligence shall be limited to damages associated with the disease, defect or handicap suffered by the child."[32]

B. The Future of Wrongful Birth and Wrongful Life Cases

The cases imposing liability on physicians have thus far involved serious, generally untreatable disorders which affect children at birth or shortly thereafter, such as Tay-Sachs disease.[33] Modern tests, however, are increasingly able to diagnose less serious disorders,[34] serious disorders that are treatable after birth,[35] and latent disorders which do not appear until much later in life.[36] Putting aside the ethical issues involved when couples seek abortions when the fetus is not imminently and irreparably at risk,[37] questions arise regarding the liability of health care providers for failing to warn parents of these risks and for failing to inform prospective parents about the genetic services available to ascertain such risks.

Existing wrongful birth and wrongful life cases provide guidance when answering questions concerning physician liability. Courts consider the severity of the disorder as a factor in assessing the health care professional's liability for failing to provide information about genetic risks. For example, in *Turpin v. Sortini*,[38] a wrongful birth case, the California Supreme Court asserted, "[i]n this case, in which the plaintiff's only af-

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32. ME. REV. STAT. ANN. tit. 24, § 2931(3) (West Supp. 1989).

33. Tay-Sachs disease is a recessive genetic disorder occurring most commonly in families of eastern-European Jewish origin. Children with Tay-Sachs exhibit early progressive and profound retardation, blindness, and paralysis with characteristic cherry red spots on the retina. LAWYERS' MEDICAL CYCLOPEDIA § 4.10 (3d ed. 1981). Affected children usually die by age three or four. *Id.*

34. An example of a genetic condition that is not regarded as a serious disorder is polydactyly, whereby the affected person has more than five digits on one hand and one foot. MCKUSICK, *supra* note 2, at 764-66.

35. An example is phenylketonuria (PKU), a genetic disorder that results in mental retardation unless affected children are given a special diet. RICHARD E. BEHRMAN, NELSON TEXTBOOK OF PEDIATRICS 307-09 (Robert E. Kliegman et al. eds., 14th ed. 1992).

36. One example is Huntington's disease. *See* Gusella et al., *supra* note 7, at 234.

37. *See* Marc Lappé, *The Limits of Genetic Inquiry*, HASTINGS CENTER REP., Aug. 1987, at 5, 9 (discussing the ethical issues inherent in aborting a fetus with PKU rather than treating the condition after birth).

38. 643 P.2d 954 (Cal. 1982).

fliction is deafness, it seems quite unlikely that a jury would ever conclude that life with such a condition is worse than not being born at all. Other wrongful life cases, however, have involved children with much more serious, debilitating and painful conditions . . . ."[39] Using the reasoning presented in *Turpin*, a slight disadvantage such as short stature would probably not be sufficient to find liability.[40]

Moreover, even if courts allowed a wrongful birth or wrongful life case for a child born with a non-serious disorder, the courts might limit damages. In some cases, courts have reasoned that because parents of an affected child experience love as well as anguish,[41] the benefits of having the child should offset any damage award.[42] Such analyses may lead courts to subtract from damage awards an amount equal to the perceived benefit of the child to the parents. Thus, the less seriously affected the child, the more the courts may value his or her benefit to the parents, based on factors such as future earning capacity.

An additional related issue will arise if the Supreme Court severely restricts a woman's right to have an abortion. If the Court reverses its position that the federal constitutional right to privacy covers a woman's decision to terminate a pregnan-

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39. *Id.* at 962-63.

40. *Cf.* Zepeda v. Zepeda, 190 N.E.2d 849, 859 (Ill. App. Ct. 1963) (refusing to allow an illegitimate son to sue his father for wrongful life). The *Zepeda* court recognized a wrongful act, the defendant's fraudulent inducement of plaintiff's mother into a sexual relationship based on promises of marriage, *id.* at 852, and a resultant injury, the plaintiff's illegitimacy, *id.* at 855. The court refused to recognize a cause of action because it felt that it was the legislature's job to redress such a far-reaching tort. The court noted:

> Encouragement would extend to all others born into the world under conditions they might regard as adverse. One might seek damages for being born of a certain color, another because of race; one for being born with a hereditary disease, another for inheriting unfortunate family characteristics; one for being born into a large and destitute family, another because a parent has an unsavory reputation.

Id. at 858.

41. *See* Becker v. Schwartz, 386 N.E.2d 807, 814 (N.Y. 1978) (mitigating the parents' wrongful birth claim with the benefits of parenthood).

42. However, some disagree with this approach.

> More importantly we would not even consider the theory that the joy of parenthood should offset the damages. Would anyone in their right mind suggest that where a healthy fetus is injured during delivery the joy of parenthood should offset the damages? There is no more joy in an abnormal fetus come to full term than a normal fetus permanently injured at delivery. Both are heartbreaking conditions that demand far more psychological and financial resources than those blessed with normal children can imagine.

Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 565 (Ga. 1990) (Smith, J., dissenting).

cy,[43] state legislatures will be free to enact restrictions on abortions. Evidence exists that states will continue to allow abortions for fetuses affected with serious disorders even if they enact restrictive abortion laws. Polls show that seventy-four percent of Americans surveyed approve of abortion in such circumstances.[44] Even prior to *Roe v. Wade*,[45] model abortion laws promulgated by legal[46] and medical[47] groups allowed abortions of fetuses with serious genetic defects.[48] Along those lines, the Maryland legislature recently enacted a restrictive abortion law, but specifically allowed abortion when "[t]here is substantial risk of the birth of the child with grave and permanent physical deformity or mental retardation."[49]

Although state laws would likely still allow abortions for genetic reasons following a reversal of *Roe v. Wade*, such abortions might be restricted, as they are under the new Maryland law, to instances of particularly serious disorders such as Tay-Sachs. State legislatures could ban abortions when the disorder is not rapidly life-threatening, such as when a prenatal test indicates a late onset disorder like Huntington's disease, or when a disorder can be treated after birth, such as phenylketonuria. In those states, courts would be unlikely to allow abortions—or, hence, damages in wrongful life and birth cases—with respect to non-life-threatening disorders.

In addition to the possibility that state legislatures may restrict abortion in the future, some legislatures have already begun to restrict wrongful birth and wrongful life actions.[50] Groups that oppose abortion have successfully lobbied for the enactment of statutes prohibiting wrongful birth or wrongful life suits[51] on the basis that prenatal diagnosis encourages

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43. Roe v. Wade, 410 U.S. 113 (1973).

44. *See Arguing Abortion*, 21 NAT'L J. 1264, 1264 (1989) (favoring abortion where pregnancy results from rape, where the woman's life is endangered, or where the fetus has a serious defect or is likely to develop such a defect).

45. 410 U.S. 113 (1973).

46. Rowland L. Young, *No Fault Divorce Act and "Non-Arrest" Custody Bill Are Opposed by the House of Delegates in New Orleans*, 58 A.B.A. J. 379, 380 (1972) (Uniform Abortion Act approved in February 1972 by the ABA House of Delegates).

47. AMERICAN MEDICAL ASS'N, PROCEEDINGS OF THE AMA HOUSE OF DELEGATES 40-51 (June 1967) (permitting abortions if there is "documented medical evidence" that the child "may be born with incapacitating physical deformity or mental deficiency").

48. *See Roe*, 410 U.S. at 141-46 (discussing existing and proposed abortion laws prior to *Roe*).

49. MD. HEALTH-GEN. CODE ANN. § 20-208(a)(3) (Supp. 1990).

50. *See, e.g.*, MINN. STAT. ANN. § 145.424(2) (West 1989) (eliminating wrongful life and birth claims).

51. Refer to note 54 *infra* and accompanying text.

abortion. Whether their factual assumption is correct remains unclear. Dr. Aubrey Milunsky argues that "[p]renatal diagnosis is a life-giving not a life-taking technology."[52] Fewer than three percent of women undergoing amniocentesis discover that they have an affected fetus and face the decision whether to have an abortion.[53] If prenatal diagnosis were not available to reassure women that they were not carrying an affected fetus, the fear of having an affected child, particularly among those already raising a child with a serious disorder, might lead to a greater number of abortions than does prenatal diagnosis.

Currently, at least four states have statutes that prohibit parents from bringing wrongful birth suits against health care practitioners and institutions.[54] Under the Supreme Court's existing precedents involving abortion, such statutes could be challenged as violating the couple's right to privacy. Specifically, one could argue that by eliminating an incentive for physicians to give parents-to-be information necessary to make procreative decisions, such statutes infringe on a couple's most intimate decisions. In *Lifchez v. Hartigan*,[55] one federal district court was persuaded by a similar argument and held that the couple's constitutional right to privacy included the right to obtain information in order to decide whether to terminate a pregnancy.[56] The court explained that "[t]he cluster of constitutional choices that includes the right to abort a fetus within the first trimester must also include the right to submit to a procedure designed to give information about that fetus which can then lead to a decision to abort."[57] In *Lifchez*, the court

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52. Aubrey Milunsky, *Prenatal Diagnosis: New Tools, New Problems, in* GENETICS AND THE LAW III 335, 335 (Aubrey Milunsky & George J. Annas eds., 1985).

53. *Id.*

54. MINN. STAT. ANN. § 145.424(1)-(2) (West 1989); MO. ANN. STAT. § 188.130-1 (Vernon Supp. 1990); 42 PA. CONS. STAT. ANN. § 8305 (Purdon Supp. 1991); S.D. CODIFIED LAWS ANN. § 21-55-2 (1987). Four more states prohibit wrongful life suits. *See* IDAHO CODE § 5-334 (Supp. 1985); IND. CODE ANN. § 34-1-1-11 (Burns Supp. 1989); N.D. CENT. CODE § 32-03-43 (1991); UTAH CODE ANN. § 78-11-24 (1987).

55. 735 F. Supp. 1361 (N.D. Ill.), *aff'd without opinion sub. nom.* Scholber v. Lifchez, 914 F.2d 260 (7th Cir. 1990), *cert denied*, 111 S. Ct. 787 (1991).

56. *Id.* at 1377.

57. *Id.* A different result might be reached if the Supreme Court departs from its earlier decisions and finds that the federal right to privacy does not protect abortion decisions. At such a time, courts would uphold statutes that prohibit wrongful life and wrongful birth suits unless they violated a state constitutional right to privacy or did not further a rational governmental purpose.

State constitutional provisions protect certain privacy rights that the federal Constitution fails to protect such as an indigent woman's right to have an abortion at government expense. *See* Committee to Defend Reprod. Rights v. Myers, 625 P.2d 779, 784-89 (Cal. 1981); Moe v. Secretary of Admin. & Fin., 417 N.E.2d 387, 402 (Mass. 1981); Right to Choose v. Byrne, 450 A.2d 925, 941 (N.J. 1982).

struck down a state statute that banned fetal research because it interfered with couples' rights to undergo experimental prenatal diagnostic technologies to ascertain their fetus' risk of having a genetic disorder.[58] Similar logic might be used to strike down statutes banning wrongful birth actions.

III. LIABILITY FOR FAILURE TO ADVISE OF RISKS AND FAILURE TO OFFER GENETIC SERVICES IN A NON-REPRODUCTIVE CONTEXT

To date, most genetic risk assessments occur in the context of reproductive decisionmaking. The most common situations involve healthy potential parents who are at risk of having children affected with a serious single gene recessive disorder[59] or a chromosomal abnormality.[60] New tests are becoming available to inform people not about risks to their potential offspring but about future risks to themselves.[61] These tests includes those for late-onset diseases, such as Huntington's disease,[62] or for disorders that will develop only if the people come into contact with certain environmental stimuli.[63] The range of such disorders seems unlimited—from early coronary disease[64] to cancer,[65] diabetes,[66] and asthma.[67] All of us

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58. *Lifchez*, 735 F. Supp. at 1376.

59. In the case of a recessive disorder, the person who has one faulty gene is not affected by the disease. However, if that person conceives a child with another person who has one faulty gene, the couple has a 25% chance of having an affected child—that is, a child with two faulty genes. LORI B. ANDREWS, NEW CONCEPTIONS: A CONSUMER'S GUIDE TO THE NEWEST INFERTILITY TREATMENTS—INCLUDING IN VITRO FERTILIZATION, ARTIFICIAL INSEMINATION, AND SURROGATE MOTHERHOOD 54 (1985).

60. With the chromosomal abnormality known as Down's syndrome, the individual has an extra chromosome 21. *Id.* at 53. Approximately 1 in 200 infants are born with a chromosomal abnormality. *Id.* That number is greater—3 per 200—among infants of mothers over age 35. *Id.* Testing the parents generally does not indicate whether the child will be affected, so the primary test used in conjunction with the reproductive decisions are amniocentesis and chorionic villi sampling. *Id.*

61. Much research attention has been focused on the association between HLA factors and susceptibility to various diseases. *See, e.g.*, L.P. Ryder and A. Svejgaard, *Genetics of HLA Disease Association*, 15 ANN. REV. GENETICS 169, 177 (1981).

62. *See generally* Gusella et al., *supra* note 7 (identifying a genetic marker linked to the Huntington's disease locus).

63. Refer to note 8 *supra*.

64. *See* Jerry E. Bishop, *All in the Genes: New Medical Strategy Against Heart Disease Probes Inherited Flaws*, WALL ST. J., Apr. 13, 1990, at A1.

65. *See* Natalie Angier, *Some Genetic Pieces are Falling into Place in Breast Cancer Puzzle*, N.Y. TIMES, Dec. 25, 1990, at A38; *see also* Scott E. Kern et al., *Allelic Loss in Colorectal Carcinoma*, 261 JAMA 3099, 3099 (1989).

66. *See* J.A. Todd et al., *Identification of Susceptibility Loci for Insulin-Dependent Diabetes Mellitus by Trans-Racial Gene Mapping*, 338 NATURE 587, 587 (1989). *See generally* A. Cziezel et al., *The Load of Genetic and Partially Genetic*

may be able to learn something about our future illness profile through genetic testing. In some cases, such information might aid us in preventing illness. In others, the information may help us prepare financially and emotionally for future health problems. Consequently, the duty to inform of genetic risks and genetic services will affect physicians in all fields of medical practice.

Malpractice suits in this area are inevitable because physicians are unprepared for the onslaught of genetic information. Medical schools do not emphasize the teaching of genetics,[68] and many practicing physicians have an inadequate grasp of genetics.[69] General practitioners, in particular, may find themselves facing liability for the failure to provide genetic information.

Hundreds or even thousands of genetic risks may become predictable as a result of the Human Genome Project. It may be unreasonable to assume that physicians will be able to warn each patient of all the potential risks and tests available to determine those risks. Courts have already begun to limit the types of genetic risks that physicians must disclose. The characteristics that place a patient at a higher risk of having a particular genetic defect than the general population are key in determining whether the genetic test available for assessing a particular risk is sufficiently discriminating.

A. Determining Which Patients Are Sufficiently at Risk

The requirement that a patient be in a sufficiently high

Diseases in Man II. Some Selected Common Multifactorial Diseases: Estimates of Population Prevalence and of Detriment in Terms of Years Lost and Impaired Life, 196 MUTATION RESEARCH 259 (1988) (incorporating diabetes into a study of genetic diseases).

67. *See generally* Cziezel et al., *supra* note 66 (incorporating asthma into a study of genetic diseases).

68. NEIL A. HOLTZMAN, PROCEED WITH CAUTION: PREDICTING GENETIC RISKS IN THE RECOMBINANT DNA ERA 160 (1989).

69. *Id.* at 160-161 (noting that physicians' continuing education programs seldom address genetics). In addition, the infertility specialists who screen potential sperm donors for genetic suitability sometimes have erroneous notions about which donors are at risk for passing on a genetic defect. A Congressional study of infertility specialists by the Office of Technology Assessment found that approximately half of physicians who conduct donor insemination on a regular basis utilize genetic screening. OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, ARTIFICIAL INSEMINATION: PRACTICE IN THE UNITED STATES—SUMMARY OF A 1987 SURVEY 33 (1988). The OTA found that "a majority of physicians would reject healthy donors with family histories of X-linked disorders that are not transmissible unless the donor himself has the condition;" examples of such disorders are hemophilia or Duchenne muscular dystrophy. *Id.* at 38.

risk group for geneticists to have a duty to offer a particular test was recognized in *Munro v. Regents of the University of California.*[70] When Mrs. Munro became pregnant, the Munros consulted geneticist Dr. Barbara Crandall of U.C.L.A. Medical Center, who asked them about their ethnic background. Mrs. Munro responded that her mother was English and Canadian, and Mr. Munro responded that his mother was " 'some peculiar kind of French.' "[71] Because the incidence of Tay-Sachs disease is extremely low except among people of Ashkenazi (Eastern European) Jewish background, Dr. Crandall did not order Tay-Sachs testing as part of the amniocentesis of the fetus.[72] At the time, however, Dr. Crandall knew that there was also a small community in French Canada with a higher prevalence of Tay-Sachs disease than the general population.[73]

When the results of the prenatal testing came back, a U.C.L.A. Medical Center employee called Mrs. Munro and told her that she was carrying a healthy baby boy.[74] Mrs. Munro gave birth, and the child subsequently developed Tay-Sachs disease.[75] The Munros sued, claiming that they should have been told that they had been excluded from Tay-Sachs screening because they were not Jewish and that they would have availed themselves of the Tay-Sachs tests if it had been offered.[76] They contended that the "defendants had a duty to disclose material information to enable [them] to make an informed decision whether to take the Tay-Sachs test."[77]

The court took an excessively narrow view of health care providers' disclosure duties, stating that they had "no duty to disclose where no diagnostic testing or treatment is recommended."[78] Under such an analysis, the failure to offer testing or treatment would never be actionable, even if the patient were clearly harmed.[79]

The *Munro* court was obviously sympathetic to physicians, quoting an earlier case which held that requiring physicians to

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70. 263 Cal. Rptr. 878, 882 (Ct. App. 1989).
71. *Id.* at 880.
72. *Id.*
73. *Id.*
74. *Id.*
75. *Id.*
76. *Id.* at 881.
77. *Id.* at 883.
78. *Id.* at 884 (citing Scalere v. Stenson, 260 Cal. Rptr. 152 (Ct. App. 1989), a case that did not involve genetic testing).
79. Such an approach eviscerates much of malpractice law, seemingly allowing doctors not to offer even those diagnostic tests and treatments that are needed for the patient's own immediate health benefit.

advise patients of the risks and benefits of non-treatment "would impose significant new burdens on already harried doctors without awarding demonstrable benefits to their patients."[80] Such reasoning, however, appears misguided. Recognizing a duty to inform, even if no diagnostic or treatment technology is proposed, would not create any *new* burden on physicians. The duty to advise appropriate patients of the availability of genetic testing already serves as the basis for finding liability in wrongful birth cases. For example, liability may be imposed on a physician who does not tell a woman older than thirty-five that amniocentesis is available to determine whether her fetus suffers from chromosomal abnormalities that are more common in children born to older women.[81] Moreover, a previous California case that the *Munro* court did not cite held that there is a duty to warn of genetic risks even when no testing or treatment is contemplated.[82]

Limiting disclosure duties only to situations in which the health care provider recommends a diagnostic or treatment intervention seems particularly inappropriate in cases involving geneticists. While most medical encounters involve ill patients who seek interventions to make them feel better, those people who seek genetic counseling are specifically seeking information about genetic risks. It is ludicrous not to find liability on the part of a geneticist who does not provide such information to sufficiently at-risk couples. For example, it would be unjust if Dr. Crandall could not have been found liable had she failed to recommend a Tay-Sachs test to future parents of Ashkenazi Jewish ancestry.

The defendants' own expert in the *Munro* case did not advocate the creation of such a broad exclusion from liability. He suggested instead that liability for not offering testing was warranted for at-risk couples.[83] At one point in the court's decision, however, the court intimates that its ruling was narrow. In particular, the court suggested that it would not create "a duty to give plaintiffs information regarding a genetic test defendants did not recommend because it was not indicated by any facts which plaintiffs told to defendants, or even any fact of which plaintiffs were aware."[84]

A concurring judge specifically offered a sounder rule for

80. *Munro*, 263 Cal. Rptr. at 884.
81. Refer to note 20 *supra*.
82. Turpin v. Sortini, 643 P.2d 954, 965 (Cal. 1982).
83. *Munro*, 263 Cal. Rptr. at 882.
84. *Id.* at 885.

genetics cases by indicating that regardless of whether a physician's proposed course is to test, a duty to disclose that amount of information is needed so that parents may make an informed choice.[85] However in this case, because the Munros were not of Ashkenazi Jewish background and no reason existed to suspect that Mr. Munro's relatives of French heritage were from the small at-risk French Canadian community, Dr. Crandall had no duty to disclose the risks and benefits of testing for Tay-Sachs.[86]

B. Determining Which Tests are Sufficiently Predictive

In addition to the question of who should be advised of genetic risks and offered testing, the question of what type of testing physicians should offer must be considered. The early forms of genetic testing with which courts dealt in wrongful life and wrongful birth cases could assess with virtual certainty whether a particular disorder affected the fetus. Chromosomal analyses (karyotyping) undertaken on amniotic fluid has a high probability of diagnosing Down's syndrome,[87] and the enzyme test for Tay-Sachs can detect almost all cases of that disorder.[88] However, some of the newer tests do not have the same predictive power.[89]

As scientists learn more about the human genome, they may find that a variety of defects in a gene may each cause the same disorder. Therefore, a test that does not pinpoint all of those defects will not reliably predict the occurrence of the disorder. An example of this problem is the test developed to determine carrier status for cystic fibrosis, the most common lethal single gene defect affecting Caucasians.[90]

One in twenty-five Caucasians carries this gene.[91] If two carriers have a child together, they have a twenty-five percent chance that their child will suffer from cystic fibrosis, a disorder which can result in obstructive lung disease and pancreatic

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85. *Id.* at 886 (Johnson, J., concurring) (citing Truman v. Thomas, 611 P.2d 902 (Cal. 1980)).

86. *Id.* at 887.

87. *See* Atlanta Obstetrics & Gynecology Group, 398 S.E.2d 557, 558 n.1 (Ga. 1990).

88. *See* Simons v. West Covina Medical Clinic, 260 Cal. Rptr. 772, 775-76 (Ct. App. 1989).

89. For example, the initial test for cystic fibrosis could detect only 57% of all carriers. Refer to notes 93-94 *infra* and accompanying text.

90. Thomas F. Boat et al., *Cystic Fibrosis, in* THE METABOLIC BASIS OF INHERITED DISEASE 2649, 2649 (Charles R. Scrivner et al. eds., 6th ed. 1989).

91. Benjamin A. Wilfond & Norman Frost, *The Cystic Fibrosis Gene: Medical & Social Implications for Heterozygote Detection*, 263 JAMA 2777, 2777 (1990).

insufficiency.[92] The initial test found a defect identified as Delta F508.[93] That defect does not cause all cystic fibrosis, however, and the test could only accurately detect fifty-seven percent of the carriers of cystic fibrosis.[94] When faced with the policy question of whether geneticists should begin offering cystic fibrosis testing to all Caucasian couples, the American Society of Human Genetics (ASHG) and a National Institutes of Health Workshop recommended against it on the grounds that the test did not have sufficient predictive power.[95] Instead, the ASHG recommended that cystic fibrosis carrier status testing be offered to couples who had a close relative affected with cystic fibrosis; for example, an existing affected child.[96]

Initially, many individuals were concerned about the ambiguous results many couples would receive. When the test indicated that one spouse had the Delta F508 locus, but the other spouse did not, the couple could still give birth to a child with cystic fibrosis. This unfortunate occurrence could still happen because the spouse who tested negative on the Delta F508 test might actually have a different mutation that would give rise to a child affected with cystic fibrosis when paired with the other spouse's Delta F508 mutation. Since early testing, researchers have found 125 other additional mutations of the cystic fibrosis gene.[97] If the geneticist tests the couple for between four and seven mutations, the predictive ability of the tests increases to eighty-five percent.[98]

In assessing whether health care providers should be liable for failure to offer a particular genetic test, courts will undoubtedly have to consider the predictive ability of the test. This issue arose in *Simmons v. West Covina Medical Clinic*.[99] This case involved wrongful birth and wrongful life allegations against a physician who did not offer to test the blood of a pregnant woman to determine the fetus' level of

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92. Boat et al., *supra* note 90, at 2649.

93. Wanda K. Lemna et al., *Mutation Analysis for Heterozygote Detection and the Prenatal Diagnosis of Cystic Fibrosis*, 322 NEW ENG. J. MED. 291, 291 (1990).

94. *Id.*

95. C. Thomas Caskey et al., *The American Society of Human Genetics Statement on Cystic Fibrosis Screening*, AM. J. HUM. GENETICS 393, 393 (1990); *Statement From the National Institutes of Health Workshop on Population Screening for the Cystic Fibrosis Gene*, 323 NEW ENG. J. MED. 70, 71 (1990).

96. Caskey, *supra* note 95, at 393.

97. Arthur L. Beaudet, *Invited Editorial: Carrier Screening for Cystic Fibrosis*, 47 AM. J. HUM. GENETICS 603, 603 (1990).

98. *Id.*

99. 260 Cal. Rptr. 772, 775 (Ct. App. 1989) (stating that the alpha-fetoprotein test has a predictive ability of 20%).

alpha-fetoprotein.[100] A high level of alpha-fetoprotein in the mother's blood indicates that the fetus may have a neural tube defect.[101] This test finds seventy-nine percent of the fetuses affected by spina bifida[102] and eighty-eight percent of the fetuses affected by anencephaly.[103] Numerous false positives (finding a high level of these proteins in unaffected fetuses) occur,[104] so women who have a high level of the protein in their blood must undergo subsequent tests, such as ultrasound and amniocentesis, in order to determine whether their fetus is actually affected.

After the alpha-fetoprotein test was introduced to detect neural tube defects, clinicians learned that a low level of this protein in the women's blood indicates that the fetus might have Down's syndrome.[105] Although the test detected only twenty percent of all cases,[106] it did provide the potential for detecting some cases that would not otherwise be found. Since amniocentesis involves risks,[107] health care professionals usually only offer it to women age thirty-five or older because the chances of these women bearing children with Down's syndrome are higher. Thus, for a woman under age thirty-five, the test for maternal serum alpha-fetoprotein, which is recommended for all pregnant women, may be the only means of detecting Down's syndrome.

In *Simmons*, the defendants failed to offer the test to Mrs. Simmons, and she subsequently gave birth to a child with Down's syndrome.[108] A California health department regula-

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100. *Id.* at 773-74.

101. ANDREWS, *supra* note 59, at 68 (stating that neural tube defects can cause anencephaly or spina bifida).

102. Lewis Nelson et al., *Maternal Serum Alpha-Fetoprotein, in* ULTRASOUND APPLIED TO OBSTETRICS AND GYNECOLOGY 252, 253 (Rudy E. Sabbagha ed., 2d ed. 1987).

103. *Id.*

104. *See id.* (pointing out that 7.2% of normal fetuses will generate false positives); ANDREWS, *supra* note 59, at 68 (explaining that the level of alpha-fetoprotein may be high even though the woman is not carrying an affected fetus). A pregnant woman may exhibit a high level of alpha-fetoprotein because she is carrying twins or because the pregnancy is farther along than previously thought. *Id.*

105. Simmons v. West Covina Medical Ctr., 260 Cal. Rptr. 772, 774 (Ct. App. 1989).

106. *Id.* at 776.

107. As many as 1 in 2,000 fetuses miscarry following amniocentesis. S. Elias & J.L. Simpson, *Amniocentesis, in* GENETIC DISORDERS AND THE FETUS: DIAGNOSIS, PREVENTION, AND TREATMENT 31, 48 (Aubrey Milunsky ed., 1986). With chorionic villi sampling, there is a fetal loss rate of two to three percent. OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, HUMAN GENE THERAPY—BACKGROUND PAPER, app. at 65 (1989).

108. *Simmons*, 260 Cal. Rptr. at 773.

tion in effect at the time required physicians to advise all pregnant women of the existence of the test.[109] The defendants admitted that they negligently failed to offer the test to her, but argued that their conduct did not proximately cause the birth of the child because the test provided only a twenty percent probability of detecting that particular disorder.[110] The court held that, "A mere 20 percent chance does not establish a 'reasonably probable causal connection' between defendants' negligent failure to provide the AFP test and plaintiffs' injuries. A less than 50-50 possibility that defendants' omission caused the harm does not meet the requisite reasonable medical probability test of proximate cause."[111] The court's logic, however, is at odds with cases that hold physicians liable for causing a patient to lose an opportunity, even in instances where the chance of survival of recovery is fifty percent or less.[112] A dissenting judge in *Simmons* cited to the lost opportunity cases and pointed out that

> California, like other states, affords considerable protection to a woman's right to make an informed decision whether to continue with a pregnancy . . . Hence, a breach of duty that deprives a woman of information which may be necessary to such a decision, or the reasonable *opportunity* to make that decision, results in liability.[113]

In looking at the predictive ability of particular tests, courts need to understand that the field of genetics, in general, deals with the prediction of low risks. For example, all states have newborn screening programs which screen every infant for phenylketonuria,[114] even though the chance that the disorder will actually affect any particular child is 1 in 12,000 to 15,000.[115] Similarly, when tests indicate that both members of a couple are carriers of a single gene recessive disorder, the

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109. *Id.* at 774.

110. *Id.*

111. *Id.* at 776 (citations omitted).

112. *See generally* Joseph H. King, *Causation, Valuation, and Chance in Personal Injury Torts Involving Preexisting Conditions and Future Consequences*, 90 YALE L.J. 1353 (1981) (discussing recovery for the loss of an opportunity in the contexts of preexisting conditions and future consequences).

113. *Simmons*, 260 Cal. Rptr. at 780 (Spencer, J., dissenting) (citations omitted). The dissenter urged that the matter should have gone to the jury once the evidence demonstrated that the defendants' negligence increased the risk of harm. *Id.*

114. Louis J. Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 844 (1990).

115. Delbert A. Fisher et al., *Problems and Pitfalls of Newborn Screening Programs Based on the Experience in California and New England*, *in* LEGAL LIABILITY AND QUALITY ASSURANCE IN NEWBORN SCREENING 24, 24 (Lori B. Andrews ed., 1985).

couple has only a twenty-five percent chance of having an affected child. Courts should reject arguments suggesting that no duty exists to inform future parents of the existence of the test because the underlying risk of the disorder is low, even if the courts accept arguments that liability should not be found because a particular test has a low chance of discovering a genetic disorder.

IV. THE DURATION OF THE DUTY TO WARN OF GENETIC RISKS

If health care professionals are to serve as the primary sources of genetic information in reproductive and nonreproductive settings, questions will arise about whether their duties extend beyond an initial interchange with the patient. The current rapid evolution of genetic diagnostic testing and the possible relation of established tests to new tests make it likely that existing information about a patient will subsequently take on new meaning. This process will be heightened as the Human Genome Project progresses, and courts will be called upon to assess whether health care professionals have a duty to recontact patients to inform them of the newly-discovered meaning of previously-rendered tests.

The evolution of genetic tests may create the following scenario. A physician may use a diagnostic test on a patient to learn the level of a certain gene product, such as an enzyme. At the time the test is employed, the physician is aware that a high level of the product indicates carrier status for a serious autosomal recessive disorder. The physician provides the test to hundreds of patients, duly noting the results in their records and informing those patients with a high level that they are carriers and that, if they mate with another carrier, they have a twenty-five percent chance of giving birth to an affected child. By following such protocol, the physician will discharge his or her current responsibility.

But what happens when a month, a year, or a decade later it is learned that a low level of the gene product signals carrier status for a different, although equally fatal, disorder? The physician's files now contain information about other individuals who might give birth to a child with a fatal disorder. Does he or she have a duty to contact those individuals and disclose that fact?

A similar question may arise with respect to other types of genetic diagnostic techniques. Health care professionals have used certain tests to determine if a person was a carrier of a particular autosomal recessive disorder. The traditional learning

was that a carrier was not herself at health risk but that if she mated with another carrier, she might give birth to an affected child. In recent years, however, research has indicated that carriers of single-gene recessive disorders might have a predisposition toward developing other types of health problems. For example, carriers of homocystinuria are at higher-than-average risk for developing cardiovascular disease.[116] Again, physicians and genetic counselors may be responsible for recontacting patients and former patients who had been identified as carriers in order to advise them of this newly discovered health risk.

If the individual is still a patient of the professional, it is reasonable to expect the professional to disclose the new or now-relevant information. That responsibility seems more attenuated when the individual is no longer a patient. The practitioner might claim that he should have no duty to recontact a former patient in these situations because physicians do not have a duty to recontact patients with other types of disorders when new information becomes available to aid their condition. For example, physicians are not thought to have a responsibility to contact a patient with high blood pressure when a new medication becomes available. However, the genetic scenarios discussed above are distinguishable. The issue is not whether the physician has a duty to advise a patient of a potential new service, but rather whether the practitioner has a duty to advise the patient of the new implications of a previously rendered service—i.e., the diagnostic test which now has new significance.

A system for recontacting patients has already been advocated. Herbert Lubs suggested a genetic data bank containing information on patients in order "to offer benefits of research to affected families, without the usual five to ten year delay."[117] The computerized registry would be used for yearly contacts to update information on people with certain genetic disorders and to provide information to them about new treatments.[118]

No direct legal precedents can be found for this situation. The closest analogy is the logic of cases creating duties to disclose subsequently-discovered risks of treatment. If a court were to require a health care practitioner to recontact a patient to provide him or her with updated genetic information, the court

116. LORI B. ANDREWS, MEDICAL GENETICS: A LEGAL FRONTIER 116 (1987).

117. Herbert A. Lubs, *Privacy and Genetic Information*, *in* ETHICAL ISSUES IN HUMAN GENETICS: GENETIC COUNSELING AND THE USE OF GENETIC KNOWLEDGE, *supra* note 8, at 267, 275.

118. *Id.* at 273.

would probably rely on these cases. Physicians have had a long-standing duty to warn patients about the risks inherent in the use of a proposed medication or other treatment as part of the duty of obtaining "informed consent." In recent years, the duty of the physician to the patient has expanded[119] so that courts have imposed liability for failure to inform the patient of risks ascertained after the use of the medication or the pursuit of the treatment.[120]

The earliest expression of a duty to recontact is found in *Schwartz v. United States*,[121] a 1964 case brought under the Federal Tort Claims Act. Schwartz, while in the U.S. Navy, had umbrathor,[122] a dye, inserted into his sinuses in order to allow physicians to take an x-ray.[123] Years later, he brought suit when he learned that the radiopaque dye had irritated one of his sinuses, resulting in a tumor.[124]

The court held for Schwartz.[125] The court noted that grave warnings of the potentially hazardous nature of the dye had appeared as early as the 1930s and had been confirmed in the 1940s.[126] Noting that the government doctors should have been aware of the dangers long before the 1956 discovery of Schwartz's condition, the court reasoned that the government had a duty to review the records of all patients treated with umbrathor and to warn those patients of the danger facing them.[127] Thus, "even if [Schwartz] had never returned to a Government physician after his discharge from military service, there was a duty resting on the Government to follow up those cases in which umbrathor had been installed."[128]

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119. *See generally* David A. Berg & Harold L. Hirsh, *Malpractice and the Physician's Duty to Recall*, 86 CASE & COM. 24 (1981) (discussing the possible extension of a physician's duty of care to a "duty to recall," thus requiring physicians to warn previously treated patients of newly discovered dangers).

120. Barbara E. Calfee, Note, *What You Don't Know Will Hurt You: Physicians' Duty to Warn Patients About Newly Discovered Dangers in Previously Initiated Treatment*, 31 CLEV. ST. L. REV. 649, 660-64 (1982).

121. 230 F. Supp. 536 (E.D. Pa. 1964).

122. Umbrathor is a trade name for a form of thorium dioxide. *Id.* at 537 n.1.

123. *Id.*

124. *Id.* at 539-40. Schwartz did not argue that the government was negligent in inserting the dye originally, because under the *Feres* doctrine, the government would not have been liable "for injuries to servicemen where the injuries [arose] out of or [were] in the course of activity incident to service." Feres v. United States, 340 U.S. 135, 146 (1950). However, since Schwartz was able to show a *separate* act of negligence on the part of the government, occurring solely *after* discharge, he could recover. *Schwartz*, 230 F. Supp. at 540.

125. *Schwartz*, 230 F. Supp. at 542.

126. *Id.* at 540.

127. *Id.* at 540-41.

128. *Id.* at 540. The court also noted that the clinic physicians had not even

More recent cases have held that physicians have a duty to recontact patients in whom they had inserted a Dalkon Shield IUD and to warn them of subsequently-discovered risks.[129] The logic of such cases, as explained in *Tresemer v. Barke*,[130] is that "a 'defendant owes a duty of care to all persons who are *foreseeably* endangered by his conduct, with respect to all risks which make the conduct unreasonably dangerous.'"[131] The *Tresemer* court was particularly swayed by the fact that the best and perhaps only way for patients to receive warnings was through health care providers.[132] The court noted that a manufacturer's duty to warn of the possible hazards inherent in its prescription drugs is discharged by warning the doctor because the doctor is in the best position to locate the consumer-patient.[133]

The post-treatment duty to disclose is related to other legal doctrines. For example, it may be viewed as a corollary of the informed consent doctrine. In *Taber v. Riordan*,[134] a case in which a patient suffered a non-negligently inflicted complication from surgery, the court pointed out that "[t]he duty to inform of possible complications before an operation or course of treatment can be analogized to the duty to inform the patient afterwards of complications that have arisen."[135]

The post-treatment duty to disclose can also be seen as part of the physician's duty not to abandon the patient. A person who engages a physician for diagnosis and treatment implicitly engages the physician to attend throughout the illness or until services are no longer needed.[136] The physician who unilaterally ends the relationship while the patient still needs

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taken "the ordinary steps of obtaining and employing the past medical records of its patients." *Id.*

129. *E.g.*, Tresemer v. Barke, 150 Cal. Rptr. 384, 394 (Ct. App. 1978). A similar fact situation occurred in Reyes v. Anka Research, Ltd., 443 N.Y.S.2d 595 (Sup. Ct. 1981). Although the IUD in that case had been inserted at least six years before the suit was brought, the physician could not bar the patient's action on the grounds that the statute of limitations had run. *Id.* at 597. Rather, the court found that the physician's failure to recontact the patient to disclose that the device should be removed was a "continuing omission" and that the statute of limitations did not begin to run until the patient learned that the device had been recalled. *Id.*

130. 150 Cal. Rptr. 384 (Ct. App. 1978).

131. *Id.* at 393-94 (quoting Rodriguez v. Bethlehem Steel Corp., 525 P.2d 669, 680 (Cal. 1974)).

132. *See id.*

133. *See id.*

134. 403 N.E.2d 1349 (Ill. App. Ct. 1980).

135. *Id.* at 1353.

136. *See* Ricks v. Budge, 64 P.2d 208, 211-12 (Utah 1937) (stating that a physician's employment continues as long as the patient requires attention, absent a contrary agreement).

treatment abandons the patient.[137] Physicians are liable for all damages caused by such an unilateral termination.[138] One commentator has noted that "[t]he failure of a doctor to update his patients . . . is tantamount to abandonment."[139] While a physician can generally end a physician-patient relationship if services are no longer needed, a physician cannot claim services are no longer needed when the physician has information that the patient needs.

A practitioner who does not provide subsequent genetic information might argue that his or her activities have not harmed the patient. In contrast to the physician who treats the patient with a drug or device that later turns out to be harmful, the physician has not "caused" a potential harm to the patient. Unlike the physicians in *Schwartz, Tresemer,* or *Mink v. University of Chicago,*[140] the practitioner with new genetic information undertook no intervention which later became regarded as dangerous. In all of those cases, the treating physicians would presumably have acted differently were they to treat the same patient in the light of current medical knowledge.

With respect to the genetic information case, the practitioner would not have acted differently. She would have performed the same test. However, she would have provided additional information at the time of the test. This situation raises the classic tort issue of the difference between commission and omission. Yet, in the genetics context, courts have been willing to hold practitioners liable for omitting to provide information—such as failure to inform older pregnant women about the availability of amniocentesis.[141] Since the stock in trade of a genetics practitioner is information, courts may be especially likely to find liability for failure to disclose genetic information.

When a duty to recontact has been found, it has not mattered that the contact with the patient was fleeting[142] or that much time had passed since the physician rendered the services.[143] As one article on physician's disclosure duties notes,

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137. *See id.* at 212.

138. *See id.*

139. *Calfee, supra* note 120, at 660.

140. 460 F. Supp. 713, 715, 719-22 (N.D. Ill. 1978). In *Mink,* the plaintiff was given DES as part of a medical experiment. *Id.* This drug was later considered to be extremely hazardous. *Id.*

141. *See, e.g.,* Becker v. Schwartz, 386 N.E.2d 807 (N.Y. 1978).

142. *See Tresemer,* 150 Cal. Rptr. at 389 (noting that the patient had visited the physician only once).

143. *Mink,* 460 F. Supp. at 715 (pointing out that approximately two decades passed between the contact with the patient and the subsequent duty to disclose).

"the lapse of time following medical treatment must not soften the physician's perception of this obligation. When a patient may be harmed because of prior treatment or when new information of critical importance is available concerning past care, a physician has a duty to reasonably notify those affected individuals."[144] Relying on cases involving the duty to recontact, courts may hold that professionals who undertake genetic diagnostic procedures, even if they had only a fleeting contact years earlier, have a duty to update patients about subsequently discovered meanings of those tests.

V. DO THIRD PARTIES HAVE A RIGHT TO KNOW ABOUT A PATIENT'S GENETIC RISKS?

Another important question that courts will face is to whom the duty to inform about genetic risks applies. Courts may confront suits alleging that the physician of an at-risk patient should have warned the patient's relatives, since they may also be at risk, or should have warned the patient's spouse about the risk of having an affected child. If health care providers are to serve as our primary source of genetic information, a claim could be made that they have a duty to provide risk information to spouses and relatives, even if the patient objects.

The major precedents against such liability are the legal rules that protect the confidentiality of information that physicians gain in the course of a doctor-patient relationship.[145] Courts now recognize causes of action against health care providers and health care institutions for breaches of confidentiality based on breach of contract,[146] violation of privacy,[147]

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144. Theodore R. LeBlang & Jane L. King, *Tort Liability for Nondisclosure: The Physician's Legal Obligations to Disclose Patient Illness and Injury*, 89 DICK. L. REV. 1, 30 (1984).

145. In some instances, the goal of protecting confidentiality conflicts with the goal of protecting public health. One dramatic example of this conflict occurred recently in France, where researchers studying five centuries of records from the village of Brittany uncovered a pattern of blindness caused by hereditary juvenile glaucoma among descendants of a 15th century couple. *See* Alexander Dorozynski, *Privacy Rules Blindside French Glaucoma Effort*, 252 SCIENCE 369, 369 (1991). The researchers identified at least 30,000 living individuals who were descendants of that couple and thus at risk for blindness. *Id.* In fact, half of the reported juvenile glaucoma cases in France involved descendants of that couple. *Id.* The researchers intended to contact the physicians of the at risk individuals and warn them because with early diagnosis and treatment the glaucoma could be arrested and blindness averted. *Id.* However, a French privacy law prevented them from doing so. *Id.* Many were concerned that circulating the names of individuals who were potentially at risk might lead to discrimination in employment and insurance. *Id.* at 370.

146. *See* Horne v. Patton, 287 So. 2d 824, 831-32 (Ala. 1973); *see also* MacDonald v. Clinger, 446 N.Y.S.2d 801, 803-04 (App. Div. 1982) (discussing the contractual na-

malpractice,[148] and breach of fiduciary duty.[149] Courts may also recognize a cause of action based on interference with contractual relations[150] or infliction of emotional distress.[151] Indeed, as one court pointed out, "[t]he promise of secrecy is as much an express warranty [on the part of the health care provider] as the advertisement of a commercial entrepreneur."[152]

The assurance of confidentiality is meant to encourage the free flow of information between patient and physician so that the patient's sickness may be adequately treated. A physician can serve the patient's interests only in an atmosphere of total frankness and candor.[153] In fact, the New York legislature

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ture of the physician-patient relationship). On contractual grounds, "a physician, who enters into an agreement with a patient to provide medical attention, impliedly covenants to keep in confidence all disclosures made by the patient concerning the patient's physical or mental condition as well as all matters discovered by the physician in the course of examination or treatment." *Id.* at 804.

147. *See Horne*, 287 So. 2d at 830-31 (recognizing a right of privacy to protect persons from unauthorized disclosure of medical records); Bazemore v. Savannah Hosp., 155 S.E. 194, 195 (Ga. 1930) (finding a cause of action for invasion of privacy based on a doctor's publication of a picture of the plaintiffs' dead son); *see also* Scott Newman, Note, *Privacy in Personal Medical Information: A Diagnosis*, 33 U. FLA. L. REV. 394, 403 & n.60 (1981) (pointing out that almost all states recognize a tort for invasion of privacy). Only courts in Rhode Island, Nebraska, and Wisconsin have not established the tort of invasion of privacy. *Id.* at 403 n.60. However, two of these states now recognize the tort by statute. *See* R.I. GEN. LAWS § 9-1-28.1 (1985); WIS. STAT. ANN. § 895.50 (1985-86) (West 1983 & Supp. 1991).

148. *See MacDonald*, 446 N.Y.S.2d at 805-06 (Simons, J., concurring) (indicating that the basis for the plaintiff's cause of action was malpractice). In Hammer v. Polsky, 233 N.Y.S.2d 110 (N.Y. 1962), a physician testified that his patient's husband was a paranoid schizophrenic. *Id.* at 111-12. The court seemed to indicate that a malpractice cause of action for disclosure might have arisen had there been a doctor-patient relationship between the physician and the husband. *See id.* at 112. However, the court dismissed the complaint, with leave to amend, on the ground that the plaintiff failed to allege a doctor-patient relationship. *Id.*

149. *See Horne*, 287 So. 2d at 827-30 (recognizing a confidential relationship between doctor and patient, which imposes a fiduciary duty on the doctor and may give rise to a cause of action for unauthorized disclosures); *MacDonald*, 446 N.Y.S.2d at 805 (holding that a psychiatrist's disclosure of confidential information was "a violation of fiduciary responsibility to [the] plaintiff implicit in and essential to the doctor-patient relation[ship]").

150. *See* Charles J. Roedersheimer, Note, *Action for Breach of Medical Secrecy Outside the Courtroom*, 36 U. CIN. L. REV. 103, 117-19 (1967) (asserting that interference with the physician-patient relationship which causes a disclosure of confidential information could give rise to a cause of action for interference with contractual relations). The elements of the cause of action are set forth in Fowler V. Harper, *Interferences With Contractual Relations*, 47 NW. U.L. REV. 873 (1953).

151. *See* W. PAGE KEETON ET AL., PROSSER & KEETON ON THE LAW OF TORTS § 12 (5th ed. 1984) (outlining the cause of action for infliction of mental distress).

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

153. Research has indicated that people who are told by an interviewer that their answers will not be kept confidential provide less intimate information. Kathryn M. Woods & J. Regis McNamara, *Confidentiality: Its Effect on Interviewee Behavior*, 11

passed the first statute recognizing the need to protect medical confidentiality in 1828 to facilitate the seeking of care.[154] That law recognized a physician-patient privilege.[155] Because the only health care measure for communicable disease was quarantine, public knowledge of one's disorder could lead to social stigma and financial harm.[156] The New York legislature reasoned that without confidentiality, people would avoid seeking medical treatment.[157]

The need to protect the confidentiality of medical records containing genetic information is particularly strong. Unlike an infectious disease, a genetic disorder is generally immutable. Thus, an inappropriate disclosure may haunt the individual throughout his or her life. The revelation of genetic information can cause serious financial, emotional, and perhaps even physical harm to the patient. An employer might decide to fire an employee based on the evidence that the employee will suffer from a late-onset disorder. An insurance company might decide not to provide coverage to that person based on the same information.

A major exception to confidentiality, however, should be noted. A physician may, in certain instances, breach confidentiality in order to protect third parties from harm, such as when the patient might transmit a contagious disease[158] or commit violence against an identifiable individual.[159] In a landmark California case, the court found that a psychiatrist had a duty

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PROF. PSYCHOL. 714, 719 (1980).

154. N.Y. CIV. PRAC. L. & R. 4504 (McKinney Supp. 1992).

155. Robinson v. Lane, 480 P.2d 620, 622 (Okla. 1971). The 1828 statute provided:

> No person duly authorized to practice physic or surgery, shall be allowed to disclose any information which he may have acquired in attending any patient, in a professional character, and which information was necessary to enable him to prescribe for such patient as a physician or to do any act for him as a surgeon.

N.Y. CIV. PRAC. L. & R. 4504 (McKinney Supp. 1992).

156. *See* Sandra G. Nye, *Privilege, in* CONFIDENTIALITY OF HEALTH RECORDS, 17, 24 (1982).

157. *See id.*

158. *See* Davis v. Rodman, 227 S.W. 612, 614 (Ark. 1921); Skillings v. Allen, 173 N.W. 663, 664 (Minn. 1919). For a more recent case regarding a duty to warn third parties of communicable diseases, see Gammill v. United States, 727 F.2d 950 (10th Cir. 1984). The *Gammill* court cited *Davis v. Rodman* and held that a "physician may be found liable for failing to warn a patient's family, treating attendants, or other persons likely to be exposed to the patient, of the nature of the disease and the danger of exposure." *Id.* at 954 (emphasis omitted).

159. *See* Tarasoff v. Regents of Univ. of Cal., 551 P.2d 334, 348-49 (Cal. 1976) (holding that California laws regulating the disclosure of confidential information did not prevent a psychotherapist from warning the plaintiff's daughter that a mentally ill patient had threatened to kill her).

to warn the potential victim that his patient planned to kill her.[160]

One can make an argument that health care professionals working in the medical genetics field have disclosure obligations similar to those of the physician whose patient suffers from an infectious disease or a psychotherapist whose patient is a potentially violent. Because of the inheritable nature of genetic diseases, a health professional who, through research, counseling, examination, testing, or treatment, gains knowledge about an individual's genetic status invariably has information valuable not only to the patient, but also to his or her spouse or relatives.

When a married individual is diagnosed as having a genetic defect, the spouse may claim that the health care provider has a duty to share that information to facilitate reproductive decisionmaking.[161] A few cases have allowed physicians to disclose medical information about an individual in order to protect a spouse or potential spouse.[162] Cases allowing disclosure of communicable diseases lay the foundation for this approach.[163] In situations such as disclosure of information about venereal disease or AIDS, some individuals make the argument that sacrificing confidentiality and notifying spouses and lovers is not only necessary for public health and welfare

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160. *See id.* at 340 (holding that a therapist incurs an obligation to use reasonable care to protect an intended victim when it is determined that his or her patient presents a serious danger of violence to another).

161. The individual generally asks that physicians inform his or her spouse of the genetic defect as well. *See* Motulsky, *supra* note 8, at 69-70 (statement of Jerome Lejeune). However, in rare instances, an individual may or may not want personal genetic information disclosed to his or her spouse.

162. *See, e.g.*, Curry v. Corn, 277 N.Y.S.2d 470, 471 (N.Y. 1966) (holding that "during marriage each has the right to know the existence of any disease which may have bearing on the marital relation"); Berry v. Moensch, 331 P.2d 814, 817-18 (Utah 1958) (allowing a doctor to disclose confidential information to protect the health of a potential spouse). The husband's status as head and master of the marital community is an additional rationale that earlier courts gave for disclosure of women's health to their husbands. *See, e.g.*, Tooley v. Provident Life & Accident Ins. Co., 154 So. 2d 617, 618 (La. Ct. App. 1963) (stating that "the husband, during the marriage, has a right to a full report from his wife's doctor" because "[h]e is head and master of the community and responsible for its debts" (cited with approval in *Curry*, 277 N.Y.S.2d at 471-72)). However, one court recently pronounced that this rationale is "outmoded." *See* MacDonald v. Clinger, 446 N.Y.S.2d 801 (App. Div. 1982). The court held that a psychiatrist's disclosure to his patient's wife provided a basis for an action for breach of fiduciary duty. *See id.* at 804-05. The court recognized, however, that there might be circumstances in which disclosure to a spouse by a psychiatrist is justified; for instance, if a danger to the patient, spouse, or other person exists. *Id.* at 805.

163. *See* Simonsen v. Swenson, 177 N.W. 831, 832 (Neb. 1920) (holding that physicians are privileged to make disclosure of confidential information to protect the public from highly contagious and infectious diseases).

but also is essential as a warning to endangered third parties in a special relationship.[164]

Since genetic disorders are not communicable, one can argue that no legitimate reason exists for disclosing them to a spouse. However, the spouse may have a great interest in the genetic information in order to protect any potential children from risk. Consider the case of a doctor who learns that a young man will later suffer from Huntington's disease. The wife would appear to have at least some claim to that information because if she and her husband have children, those children have a fifty percent chance of inheriting the disease. Similarly, each spouse would seem to have a claim to the information that the other was a carrier of a single gene recessive defect. Because of the importance of reproductive decisions, such information is of crucial importance to the individual.

Another instance in which genetic risk information arises in the marriage context is through prenatal screening. A fetus may be found to have an autosomal recessive disorder, which occurs only if both parents carry the defective gene. If, in the course of prenatal diagnosis, it is learned that the mother is a carrier of the gene but her husband is not, the health care professional has knowledge that the husband is not the father of the child. One could claim that the health care professional has a duty to advise the husband of his genetic status, informing him that his future children will not be at risk for that particular disorder.

On the other hand, one can strongly argue that spouses should not be entitled to genetic risk information about a patient, even if it is relevant to their future reproductive plans.[165] The right of reproductive decisionmaking is the right

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164. The notion of warning third parties was taken to an extreme in Berry v. Moench, 334 P.2d 814 (Utah 1958), when the court allowed an overly wide latitude of disclosure. In *Berry*, a physician gave information about a patient he had treated seven years earlier to the doctor providing services to the family of the patient's fiancee. *See id.* at 816. The information included the patient's alleged trouble in school, trouble with the authorities, and trouble handling finances. *See id.* The patient provided evidence that the information was false. *See id.* at 819. The court, reversing a judgment for the physician and sending the case back for trial, nevertheless held that concern for the fiance's well-being "was a sufficient interest to protect," even if the disclosure ultimately proved false, and that the extent of the physician's privilege should be determined by "consider[ing] the likelihood and the extent of benefit to the recipient, if the matter is true, as compared with the likelihood of injury and the extent thereof to the subject, if it prove false, or improper to reveal." *Id.* at 818.

165. The man whose non-paternity is shown through prenatal screening might argue that, in addition to its relevance to his future childbearing plans, the information has an immediate financial implication because he might not wish to support

of the individual.[166] The Supreme Court has held that a woman can have an abortion without her husband's consent even if doing so would interfere with her husband's reproductive plans.[167] More recently, the Supreme Court held that a husband was not even entitled to notice that his wife intends to abort.[168] The court expressed concerns that the husband might react to the disclosure with violence, threats to withhold economic support, or psychological coercion.[169] The lower court in that case underscored "the value placed by our society on the right of each individual to privacy concerning personal health information."[170]

Although cases indicate that one may breach confidentiality to prevent harm to third parties, the harm that these cases envisioned generally has been substantial and imminent.[171] The spouse's claim of future harm due that may result from the possibility of later conceiving a child with a genetic disorder would not be a sufficient reason to breach confidentiality.[172] In addition, with respect to information that suggests adultery, confidentiality may better protect the interests of potential offspring since women may refuse genetic testing or amniocentesis

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the child. However, state paternity statutes provide that a child born during a marriage is the husband's child and require him to support the child, even if it could be shown that he was not the child's father. The logic behind such cases is that there is a societal interest in the integrity of the family.

166. *See* Eisenstadt v. Baird, 405 U.S. 438, 453 (1972) (stating that "[i]f the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear a child").

167. Planned Parenthood v. Danforth, 428 U.S. 52, 69 (1976).

168. Planned Parenthood v. Casey, Nos. 91-744, 91-902, 1992 WL 142546, at *31 (U.S. June 29, 1992).

169. *Id.* at *28-*30.

170. Planned Parenthood v. Casey, 947 F.2d 682, 712 (3d Cir. 1991) (citing United States v. Westinghouse Elec. Corp., 638 F.2d 570, 577 (3d Cir. 1980) and Whalen v. Roe, 429 U.S. 589, 599-600 (1977)), *aff'd*, Nos. 91-744, 91-902, 1992 WL 142546 (U.S. June 29, 1992).

171. *See, e.g.*, Tarasoff v. Regents of Univ. of Cal., 551 P.2d 334, 339-40 (Cal. 1976) (mental patient intended to kill another patient); Simonsen v. Swenson, 177 N.W. 831, 832 (Neb. 1920) (allowing a physician to disclose confidential information about contagious diseases to third parties). Courts have used a similar standard in constitutional cases regarding the justifiable infringement of fundamental rights to protect the public. *See, e.g.*, New York Times Co. v. United States, 403 U.S. 713, 730 (1971) (Stewart, J., concurring) (declining to enjoin publication of the *Pentagon Papers* because disclosure would not "result in *direct, immediate,* and *irreparable damage* to our Nation and its people") (emphasis added).

172. In addition, disclosure of genetic information to a spouse, even in cases where the information may be relevant to the spouse's childbearing plans, might severely damage the marital relationship. In one case, a young man decided not to marry his fiancee when he learned that her father had Huntington's disease, which she might have inherited and might pass on to their children. AUBREY MILUNSKY, KNOW YOUR GENES 53 (1977).

if they fear that their husbands' non-paternity will be disclosed.

Relatives of the patient have a more convincing claim. They can argue that the information about genetic risks or the availability of genetic testing may be relevant to the relative's own future health care.[173] One case in point is porphyria, a genetic disorder that can be precipitated with exposure to barbiturates.[174] When a patient is diagnosed as having porphyria, warning his or her relatives against taking such drugs can prevent harm to them.[175] The strongest case for a warning exists when there is a high likelihood that the relative has the genetic defect, the defect presents a serious risk to the relative and his or her children, and presumably the disclosure is necessary to prevent serious harm. Yet even in that more compelling situation, the health care provider is not in a professional relationship with the relative, and previous cases regarding a duty to provide genetic information or the post-treatment duty to recontact have all involved a health care provider in a professional relationship with the person to be informed.[176] Although the infectious disease cases provide a precedent for warning strangers about potential risks,[177] genetic diseases are dissimilar from infectious diseases.

As a legal policy, it is less appropriate to require health care practitioners to disclose a patient's genetic defect to a relative than to disclose a patient's infectious disease or violent tendencies. In the latter case, the patient could potentially harm the relative. In the former case, that of genetic defect, the patient will not cause harm to the relative. The only argument that the health care professional could make for contacting the relative is that through diagnosis of the patient, the

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173. If a patient is the carrier of the gene for a serious autosomal recessive disorder, his or her relatives might also argue that the ignorance that they, too, are at risk of having children with that disorder would harm them. However, the remoteness of the risk to future offspring may not warrant a breach of confidentiality. Refer to text accompanying notes 153-70 *supra*.

174. Motulsky, *supra* note 8, at 59, 64.

175. *See id.*

176. *See, e.g.*, Tresemer v. Barke, 150 Cal. Rptr. 384 (Ct. App. 1978); Goldberg v. Ruskin, 471 N.E.2d 530 (Ill. App. Ct. 1984), *aff'd*, 499 N.E.2d 406 (Ill. 1986).

177. *E.g.*, Simonsen v. Swenson, 177 N.W. 831, 832 (Neb. 1920) (allowing a physician to disclose confidential information about contagious diseases to third parties); McIntosh v. Milano, 403 A.2d 500, 508-09 (N.J. Super. Ct. 1979) (stating that a physician has a duty to warn third persons against possible exposure to contagious diseases). *See generally* Tracey A. Bateman, Annotation, *Liability of Doctor or Other Health Practitioner to Third Party Contracting Contagious Disease from Doctor's Patient*, 3 A.L.R. 5TH 370 (1992) (collecting and analyzing cases in which courts have considered the liability of a physician to a third party who contracts a contagious disease from the doctor's patient).

health care professional has reason to believe that the relative is at higher risk than the general population of being affected by a genetic disorder. However, the practitioner has similar knowledge about a variety of third parties, such as the risk that pregnant women over forty will give birth to a child with a chromosomal defect. If the practitioner has a duty to tell a relative with whom he or she does not have a professional relationship about the enhanced risk to that relative, a practitioner should also have an obligation to tell any other stranger about the enhanced risk that stranger faces. The logic might similarly require a reader of this article, who now knows of the increased risk of Down's syndrome to women over thirty-five, to warn the forty year-old-pregnant woman sitting next to him or her on an airplane about the risks and existence of amniocentesis.

Even if the disclosure duty were limited to relatives, it would be time-consuming and expensive. Since research is increasingly revealing that many common disorders have a genetic basis, physicians in general practice or in specialties other than genetics might also have a duty to inform relatives. For example, if a young man has coronary artery disease, he might have a duty to warn his siblings that they may also be at risk. Consider that in one clinician's estimate, there are an average of three at-risk family members for each patient[178] and that because family members may be scattered around the country, the burdens of identifying and tracking down relatives may be great. Such a duty would seem to be excessive, and thus it might be appropriate to limit practitioners' disclosure duties to the patient alone.

This approach is consistent with the particularly illuminating analogy used to illustrate the physician's obligations of confidentiality. The doctor-patient relationship has been compared to that of a trustee-principal relationship, with the confidential information making up the trust.[179] Consider the implications of that analogy for the disclosure of genetic information to potentially affected relatives against the wishes of the patient. The rationale for such disclosures is that they are necessary to benefit the relatives. However, in a standard financial trust, the trustee is not viewed as having any right to give money to relatives of the principal—even if those relatives are

178. Motulsky, *supra* note 8, at 66 (statement of Cedric O. Carter) (citing work of Dr. Alan Emery, Professor of Human Genetics in Edinburgh).

179. *See* Hammonds v. Aetna Casualty & Sur. Co., 243 F. Supp. 793, 803 (N.D. Ohio 1965) (comparing the confidential information given to a physician with the *res* of a trust and comparing the doctor-patient relationship to a trustee-principal relationship).

in need—unless the principal so consents.[180]

Moreover, in some instances, the relative may not wish to partake of the genetic knowledge, particularly if it reveals a risk of a serious, untreatable disorder. With respect to Huntington's disease, for example, only a small proportion of potentially affected individuals seek testing; therefore, one cannot assume that all relatives want to know their genetic status. For those who do not, merely offering to provide information to a relative could be problematic because, even if the person whom the physician contacted refuses the information, he or she will know by the contact itself that there is a potential genetic risk.

VI. CONCLUSION: ALTERNATIVES TO THE HEALTH CARE PROFESSIONAL'S DUTY

The explosion of genetic information and genetic services that will become available as work progresses on the Human Genome Project may tax the disclosure capacities of health care professionals. Geneticist Dr. Michael Kaback, a defense witness in *Munro v. Regents of University of California*,[181] stated: "Since it is medically impossible to screen all patients for all known genetic abnormalities, the standard of care requires that specific screening tests be performed only on those patients who meet specific profile characteristics that warrant such tests."[182] Yet this statement is true only if the current manner of delivering genetic information remains unchanged.

The sheer magnitude of genetic information to be generated by the Human Genome Project is an argument in favor of the development of alternative methods of handling that information. In terms of scientific research, much of the initial funding will be applied to the development of more efficient technologies for mapping and sequencing the genome,[183] including computer technologies to handle the vast information that is generated.[184] The recognition that new methods will be necessary for studying the human genome should give rise to a corresponding recognition that new methods will be necessary to explain the

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180. *See* RESTATEMENT (SECOND) OF TRUSTS § 164 (1959) (stating that a trustee's power is defined by the terms of the trust and that necessary to fulfill the trustee's fiduciary duty to the beneficiary).

181. 263 Cal. Rptr. 878 (Ct. App. 1989).

182. *Id.* at 882.

183. *See* OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, MAPPING OUR GENES: GENOME PROJECTS: HOW BIG, HOW FAST? 46-48 (1988) (discussing the technological advances in genome mapping and sequencing).

184. *See id.* app. at 189 (describing various computer databases that serve the needs of researchers in genome mapping and sequencing).

study's results to people.

In the *Munro* case, the physician did not have time to question the Munros about every aspect of their family background that might have provided a hint of potentially relevant genetic services. In particular, she did not have time to ask, "Were any of your ancestors French Canadians?" It must have seemed to be a pointless question, given that few couples who had not already volunteered that information would suddenly remember it. The difficulty of asking relevant questions and providing sufficient disclosures will grow as more information becomes available. Perhaps, as with the Human Genome Project itself, health care professionals will have to use new technologies, such as computer programs, to handle the information, especially in the context of reproduction. Computer programs could also facilitate recontacting patients in order to update them on the new significance of previously-rendered tests.

Currently, many pregnant women have multiple prenatal visits, often involving routine check-ups. Beyond the hour-or-so visit with the genetic counselor, many opportunities exist for the physician to convey genetic information. Moreover, pregnant women often spend more time in the waiting room than in the visit with the health care professional. Instead of reading outdated magazines, these women could read materials concerning genetic risks and fill out questionnaires that might be useful in ascertaining those risks.[185] Just as computer programs will be developed to aid scientists in accessing the genetic information that they need,[186] other programs could be developed for use by patients and other members of the public in settings such as doctors' waiting rooms. Mr. and Mrs. Munro might have volunteered that they had French Canadian ancestors if they had learned from a brochure or computer program that this information was relevant in determining whether they were appropriate candidates for Tay-Sachs screening. Perhaps in the future, courts will hold health care professionals liable for not having such computer programs in their offices.

In the long run, though, health care professionals may not be the most appropriate source of genetic risk information. People will need genetic information before they know that they need it and before any symptoms appear that would cause

185. The fact that many pregnant women are interested in becoming more informed about issues related to their future children's well-being is obvious from the vast array of similar press books that are sold regarding pregnancy and childrearing.

186. *See* OFFICE OF TECHNOLOGY ASSESSMENT, *supra* note 183, at 189 (describing various computer databases that serve the needs of researchers in genome mapping and sequencing).

them to consult a physician. In addition, the sheer volume of genetic information that may be potentially relevant to an individual—about, for example, cancer and coronary artery disease—will be difficult to convey in the small number of encounters an asymptomatic person normally has with his or her health care providers.

Educating people earlier will be important if they are going to have the opportunity to make informed choices regarding genetic risks in major life decisions such as reproduction, employment, and diet. High school might be an appropriate setting for conveying that information, but most teachers lack sufficient knowledge of the medical and ethical dimensions of testing.[187] Moreover, some individuals may be less open to learning about genetics when such information is presented in a formal educational setting than when encountered in a voluntary setting. Perhaps folding genetics into entertainment[188]—with Saturday morning cartoon characters imparting information about how to judge probabilities or video arcade games with the double helix as their setting—can begin to provide people with the interest to seek out genetic information and the ability to use it.

At the present time, holding health care providers liable for not advising about genetics at least assures that some information on this topic is conveyed. The process can be improved by discussing with patients in advance of testing the possibility that the results will later take on a new significance and by coming to an accord about how such situations should be handled. In the future, however, the health care provider/patient relationship may become an obsolete mechanism for transferring the bulk of genetic information. If we as individuals or as a society are to make the best use of the growing genetic information, we must develop a much greater understanding of the nature of genetics and its potential for figuring into our major life decisions.[189]

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187. *See* HOLTZMAN, *supra* note 68, at 239.

188. Individuals who make such efforts would have to be careful not to advocate eugenics. Recall, for example, the movement in this country earlier this century in which eugenics was popularized, finding its way into popular press articles, religious sermons, and even a song by Princeton undergraduate F. Scott Fitzgerald, "Love or Eugenics." DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY 58 (1985). The movement resulted in the enactment of laws to sterilize people who were thought to carry genetic defects.

189. This is not to say that people should be forced to learn about their individual genetic makeups, but rather that they should have a different degree of understanding sufficient to make an informed decision about whether or not to undergo genetic services.