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Legal Implications of the G-8 Huntington's Disease Genetic Marker

Cheryl L. Becker

LEGAL IMPLICATIONS OF THE G-8 HUNTINGTON'S DISEASE GENETIC MARKER*

The genetic marker is a scientific marker that has never been considered from a legal perspective. Yet, it is foreseeable that once the marker is widely utilized, many legal issues will arise. This Note addresses these issues, and presents some possible solutions, in order to prepare for the successful implementation of this innovative and much needed scientific procedure.

IN 1983, a team of researchers discovered a genetic marker[1] which is said to be "linked" to the gene causing Huntington's disease.[2] Although they did not discover the actual disease-causing gene itself, the finding holds profound implications for those individuals at risk of inheriting this deadly disorder. Researchers anticipate that once preliminary sample testing using the marker is completed, a presymptomatic testing program will be established whereby those individuals at risk for developing the disease will be allowed to undergo testing for the presence of the marker.[3] Presence of the marker indicates the presence of the Huntington's disease gene, and, unfortunately, *all* carriers of the gene *will* develop Huntington's disease.[4] Thus, the uncertainty of individuals at risk for developing the disease, with respect to whether they have actually inherited this deadly gene, will end for those individuals who choose to undergo the testing. Of course, the availability and use of the marker in presymptomatic testing raises significant legal issues not only for those eligible for the

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1. A genetic marker is a stretch of DNA which indicates the presence of another stretch of DNA, such as a disease-causing gene. *See infra* notes 15-28 and accompanying text.

2. Wexler, Conneally, Housman & Gusella, *A DNA Polymorphism for Huntington's Disease Marks the Future*, 42 ARCHIVES OF NEUROLOGY 20, 20 (1985) [hereinafter Wexler].

3. N. WEXLER, P. CONNEALLY & J. GUSELLA, HUNTINGTON'S DISEASE "DISCOVERY" FACT SHEET 3 (May 1, 1984) [hereinafter FACT SHEET]; Craufurd & Harris, *Ethics of Predictive Testing for Huntington's Chorea: The Need for More Information*, 293 BRIT. MED. J. 249, 249 (1986) [hereinafter Craufurd].

4. Kolata, *Huntington's Disease Gene Located*, 222 SCI. 913, 913 (1983).

testing, but also for society at large.

This Note will first present the scientific theory and technology underlying the use of genetic markers.[5] It will then describe the condition known as Huntington's disease.[6] This section will be followed by a description of the genetic marker which has recently been found in connection with Huntington's disease, and a description of the problems in applying the genetic marker test to at-risk individuals.[7] Finally, this Note will examine the legal implications which this marker raises. Specifically, the Note will discuss the legal issues of: negligence, infliction of emotional distress, confidentiality, employment discrimination, insurance discrimination, and equal access to medical procedures, all within the context of the Huntington's disease genetic marker.[8]

I. THE TECHNOLOGY AND THEORY UNDERLYING GENETIC MARKERS

Before one can comprehend the basis of genetic markers, one must have some understanding of fundamental genetic principles. It is, therefore, best to begin with a simple discussion of our genetic make-up. Almost all cells present in the body contain twenty-three pairs of chromosomes.[9] One chromosome of each pair is inherited from one's mother, and the other, from one's father.[10] These chromosomes consist of genes, and genes carry the sequences which determine which proteins our bodies make.[11] Genes, themselves, consist of deoxyribonucleic acid (DNA).[12] DNA is composed of four different bases, and the combinations of these bases determine our characteristics and our genetic make-up.[13] Moreover, each gene is located in a particular position on each chromosome in every individual, so that a given gene present on chromosome number one in individual A will also be present on

5. *See infra* notes 9-28 and accompanying text.
6. *See infra* notes 29-53 and accompanying text.
7. *See infra* notes 54-85 and accompanying text.
8. *See infra* notes 86-218 and accompanying text.
9. FACT SHEET, *supra* note 3, at 6.
10. *Id.*
11. *Id.*
12. *Id.* at 7.
13. *Id.* at 6-7 (The DNA molecule is structured in the form of a double helix resembling a twisted ladder. The rungs of this ladder consist of pairs of the following bases: adenine, thymine, cytosine, and guanine.).

chromosome number one in individual B.[14] Now that the basic genetic principles have been presented, we can consider genetic markers.

Scientists have based their genetic marker research on a basic property of genes. This property is that genes which are close together on a chromosome tend to be inherited together.[15] Thus, if one is able to locate a specific sequence or stretch of DNA, and there is scientific evidence that this stretch is located near another stretch of DNA, for example, a gene causing a specific disease, one can assume that a patient who possesses the located DNA sequence has also inherited the disease-causing gene.[16] Thus, the goal of genetic marker research is to find a stretch of DNA which signals the presence of the disease-causing gene, or in other words, is "linked" to that gene.[17] This linked stretch of DNA is called a genetic marker because it marks the presence of the disease-causing gene.[18]

In order to fully appreciate the value of the Huntington's disease marker, discussed in Section III of this Note,[19] several fundamental principles relating to markers must be understood. Basically, a stretch of DNA from a healthy individual contains certain base sequences. These base sequences are recognized by particular enzymes which have the ability to cut the DNA at these base-sequence sites.[20] These enzymes are referred to as "restriction endonucleases."[21] If a mutation occurs in one of the base sequences, however, as in the case of an individual possessing a genetic disorder, the enzyme will no longer recognize the mutated site and, therefore, will not cleave the DNA at this site.[22] For example, a stretch without a mutation may be cleaved at two or more sites

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14. *Id.*

15. *Id.* at 8; Merz, *Markers for Disease Genes Open New Era in Diagnostic Screening*, 254 J. A.M.A. 3153, 3154 (1985). Inheritance involves the transfer of genetic determinants from parent to child. WEBSTER'S NEW COLLEGIATE DICTIONARY 588 (8th ed. 1981).

16. *See* FACT SHEET, *supra* note 3, at 8.

17. *See* Merz, *supra* note 15, at 3154; Gusella, Wexler, Conneally, Naylor, Anderson, Tanzi, Watkins, Ottina, Wallace, Saleaguchi, Young, Shoulson, Bonilla & Martin, *A Polymorphic DNA Marker Genetically Linked to Huntington's Disease*, 306 NATURE 234, 234 (1983) [hereinafter Gusella].

18. FACT SHEET, *supra* note 3, at 8-9.

19. *See infra* notes 54-66 and accompanying text.

20. Merz, *supra* note 15, at 3153.

21. *Id.*

22. *Id.* Additionally, a mutation may cause a cleavage at a site which would not otherwise appear in the DNA of a healthy individual. Lewis, *Genetic Marker Testing: Are We Ready for It?*, ISSUES SCI. & TECH., Fall 1987, at 77.

while one with a mutation may be cleaved at only one site. Thus, different sized fragments will result.[23] These different sized fragments are termed "haplotypes," and the entire stretch of DNA itself is termed a "restriction fragment-length polymorphism" or RFLP.[24] This RFLP *is the genetic marker*[25] and may contain several different haplotypes.[26] The purpose of genetic marker research is "to find the RFLP haplotype that signals the presence of the gene responsible for a given defect."[27]

As mentioned previously, a genetic marker has recently been found in connection with Huntington's disease.[28] This marker has profound implications for those individuals at risk of inheriting the disease. To fully understand the implications of this marker, one

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23. Merz, *supra* note 15, at 3153.

24. *Id.*

25. Gusella, *supra* note 17, at 234.

26. Merz, *supra* note 15, at 3153.

27. *Id.* at 3154. A haplotype is discovered by use of something called a "probe." A probe is a piece of DNA which has been obtained by cutting a DNA molecule with a restriction endonuclease. The fragment obtained is then radiolabeled and added to a sample of DNA fragments obtained from a patient possessing the disease. This probe will then hybridize, or stick to, any complementary fragment (RFLP) that has the opposite base sequence. If this occurs, one has discovered a probe which interacts with the RFLP linked to the disease-producing gene. In a presymptomatic individual, the adherence would obviously indicate the presence of the disease-causing gene, since the RFLP acts as a genetic marker for this gene. Moreover, this one probe would also detect a different RFLP haplotype since all haplotypes of a certain RFLP possess some common base sequences. This is quite important in that two families having a history of a certain disease may have different haplotypes. The probe would identify the presence of the RFLP, or genetic marker, and, therefore, the presence of the disease-causing gene in those individuals of both families possessing a different haplotype. However, for this method to work, a certain haplotype must be inherited by all of the members of a family who possess the disease-causing gene. This is true since in order to perform the test with accuracy, not only must the at-risk individual's DNA be tested, but the DNA of other family members known to have the disease must also be tested. The specific haplotype must be traced through the family, and can be, since haplotypes are inherited.

Of course, there are problems with this technique in that it is not accurate one-hundred percent of the time. The possibility of inaccuracy is caused by an event called "recombination" which may cause the genetic marker and the disease-causing gene to become separated such that each would end up on two different chromosomes. Thus, upon the performance of the test, the genetic marker present in an individual possessing the disease-producing gene would not be detected. The test results would, therefore, lead such an individual to believe that she had not inherited the deadly gene, when in actuality, she had. The individual might make various personal decisions other than those she would have made if the test results had come out the other way. Moreover, the farther the genetic marker is from the disease-causing gene, the more likely it is that a recombination event will occur. Thus, scientists try to isolate a RFLP or genetic marker which is extremely close to the disease-causing gene such that the recombination rate is found to occur less than two percent of the time. Merz, *supra* note 15, at 3153-54.

28. *See supra* note 2 and accompanying text.

must first understand the nature of Huntington's disease.

II. HUNTINGTON'S DISEASE[29]

A. Clinical Manifestations

Huntington's disease, also referred to as Huntington's chorea, is a lethal genetic disorder.[30] Its symptoms appear in individuals between the ages of thirty-five and fifty.[31] In the United States, at any given time, five to ten people in 100,000 possess the symptoms of Huntington's disease.[32] However, 100,000 more individuals are potentially at risk of developing the disease. These individuals have a history of Huntington's disease in their families, yet they do not presently manifest the symptoms of the disease.[33] Basically, the disease is characterized as a "progressive neurodegenerative disorder."[34] In other words, most of its symptoms are the result of an abnormally early death of the neurons in the brain.[35] Neurons are the cells which allow for the transmission of nervous impulses.[36] They allow the body to receive and carry-out messages sent by the brain.[37]

The symptom of the disease which is most recognized is termed "chorea."[38] Chorea consists of spasmodic, involuntary movements of the arms, legs, and facial muscles.[39] Psychological and intellectual symptoms are also present, including: "memory loss, mood shifts, personality changes, and chronic depression."[40] Many patients experience these symptoms years before they manifest any physical symptoms.[41] Thus, a patient suffering from de-

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29. For a general discussion of Huntington's chorea, see M. HAYDEN, HUNTINGTON'S CHOREA (1981) and Martin & Gusella, *Huntington's Disease*, 315 SEMINARS MED. BETH ISRAEL HOSP., BOSTON 1267 (1986).

30. Rosenfeld, *At Risk for Huntington's Disease: Who Should Know What and When?*, HASTINGS CENTER REP., June 1984, at 5.

31. *Id.*

32. Gusella, *supra* note 17, at 234.

33. Rosenfeld, *supra* note 30, at 5.

34. Gusella, *supra* note 17, at 234.

35. *Id.*

36. H. CURTIS, BIOLOGY 578 (3d ed. 1979).

37. *Id.*

38. Gusella, Tanzi, Anderson, Hobbs, Gibbons, Raschtchian, Gilliam, Wallace, Wexler & Conneally, *DNA Markers for Nervous System Diseases*, 225 SCI. 1320, 1321 (1984) [hereinafter Gusella].

39. WEBSTER'S NEW COLLEGIATE DICTIONARY 195 (8th ed. 1981).

40. Gusella, *supra* note 38, at 1321.

41. Martin, *Huntington's Disease: New Aprroaches to an Old Problem*, 34 NEUROLOGY 1059, 1059 (1984).

pression as a result of Huntington's disease, is often diagnosed as having schizophrenia until the physical symptoms of Huntington's disease appear.[42] As the disease takes its course, these physical symptoms progress to the point where the patient has difficulty standing, speaking, swallowing, and walking.[43]

The disease lasts approximately fifteen to twenty years until the patient has degenerated to the point where he is "totally physically disabled and is unable to communicate."[44] The patient will eventually die from a complication of the disorder such as heart disease resulting from the abnormal bodily movements, or secondary pneumonia resulting from aspiration into the lungs.[45] Death may also result from a subdural hematoma, due to head trauma,[46] or from choking.[47] The disease takes a slow painful course which affects individuals physically, psychologically, and intellectually.

B. The Genetics of Huntington's Disease

Huntington's disease is acquired by the inheritance of one Huntington's disease gene, present on chromosome 4,[48] from a parent affected with the disorder.[49] Since the inheritance of only one disease-gene is sufficient to produce the disorder,[50] an individual carrying the gene will ultimately be a victim of the disease.[51] Since an at-risk individual can either inherit the chromosome carrying the disease-gene from the affected parent or inherit the normal chromosome of the pair from this parent, the child of an affected parent has a fifty percent chance of inheriting the disease.[52] This percentage is quite significant if you are an individual at risk

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42. *Id.*

43. *Id.* at 1060.

44. Gusella, *supra* note 38, at 1321.

45. *Id.*

46. Folstein, Phillips, Myers, Chase, Abbott, Franz, Waber & Kazazian, *Huntington's Disease: Two Families With Differing Clinical Features Show Linkage to the G-8 Probe*, 229 SCI. 776, 776 (1985).

47. Martin, *supra* note 41, at 1060.

48. Gusella, *supra* note 17, at 234-35.

49. Rosenfeld, *supra* note 30, at 5.

50. *Id.* The development of Huntington's disease appears to be due to the inheritance of a dominant mendelian gene. Consequently, the child of a parent who has Huntington's disease, and of a parent who does not, has a 50% chance of inheriting the disease. *See* Kolata, *supra* note 4, at 913. This type of genetic transmission is referred to as autosomal dominant inheritance. Gusella, *supra* note 17, at 234.

51. Rosenfeld, *supra* note 30, at 5.

52. Kolata, *supra* note 4, at 913. This assumption is based on a situation in which the affected parent has at least one healthy chromosome of the pair.

of developing the disease. Moreover, until the advent of the marker, described in section III, these individuals have had to wait until middle-age, when the symptoms of the disease appear, to determine if they would actually develop the disease.[53] Consequently, those individuals at risk of developing the disease lead lives filled with extreme uncertainty and anguish.

III. THE GENETIC MARKER FOR HUNTINGTON'S DISEASE

In 1983, Dr. James Gusella, a researcher at Massachusetts General Hospital, and several colleagues including Dr. Nancy Wexler and Dr. P. Michael Conneally, discovered a genetic marker which is linked to the gene causing Huntington's disease.[54] Their initial search for a marker began with the study of two extended families.[55] The first study involved an examination of a forty-member American family having a high incidence of Huntington's disease.[56] The DNA of the family members was exposed to several probes[57] in the hope that one of them would detect a RFLP linked to Huntington's disease, and on the thirteenth try, a probe succeeded.[58] The marker it detected, referred to as G-8, consisted of 17,800 bases.[59] It was also found to fragment into four different haplotypes (A,B,C, and D) when digested with a bacterial-restriction enzyme.[60] These haplotypes exist because "the marker is not sufficiently close to the gene so that one haplotype invariably segregates with the presence of" the Huntington's disease gene.[61] Only the A haplotype was found to exist in the American family members possessing the symptoms of Huntington's disease.[62]

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53. Rosenfeld, *supra* note 30, at 5; Craufurd, *supra* note 3, at 249.

54. Gusella, *supra* note 17, at 234-35.

55. Merz, *supra* note 15, at 3154. Another marker has recently been discovered which improves the accuracy of the test to 99%. This marker is closer to the location of the Huntington's gene than is the G-8 marker. Boston Globe, Nov. 13, 1987, at 8, col. 6. For a discussion of this marker, referred to as D4543, see Gilliam, Bucan, MacDonald, Zimmer, Haines, Cheng, Pohl, Meyers, Whaley, Allitto, Faryniarz, Wasmuth, Frischauf, Conneally, Lehrach, and Gusella, *A DNA Segment Encoding Two Genes Very Tightly Linked to Huntington's Disease*, 238 SCI. 950 (1987).

56. Merz, *supra* note 15, at 3154.

57. *Id.*

58. *Id.* For a general discussion of probes, see *supra* note 27.

59. Merz, *supra* note 15, at 3154.

60. Wexler, *supra* note 2, at 20.

61. *Id.*

62. Merz, *supra* note 15, at 3154.

The second family studied consisted of more than 3,000 descendants of a woman from a village near Lake Maracaibo, Venezuela, who had Huntington's disease.[63] Since many of the family members still lived in this area, Dr. Wexler was able to collect blood samples from 570 of the family members and send them back to the United States, where the DNA in the samples was tested for the presence of the G-8 marker.[64] The marker was also present in these individuals, although the C haplotype rather than the A haplotype was present.[65] Although this latter study seemed quite conclusive, several problems still exist which make researchers, such as Dr. Gusella, hesitant to apply the test to all presymptomatic individuals who, on the basis of their family histories, are at risk of developing Huntington's disease.[66]

IV. Difficulties With the Utilization of the G-8 Marker for Testing Purposes

The problems associated with using the marker for widescale testing are quite varied in nature. To begin with, it cannot confidently be assumed that chromosome 4 always carries the gene for Huntington's disease.[67] It is possible that a Huntington's disease gene exists on another chromosome in which case the present system, using the G-8 marker, would not yield accurate test results.[68] It is felt that in order to resolve this issue, referred to as "heterogeneity," approximately twenty large families need to be tested for the presence of the marker.[69]

Another problem involves the manner in which the test is performed.[70] Since the test does not detect the actual disease-causing gene, blood must be obtained from several individuals of different generations of the patient's family in order to establish a "marker pattern."[71] All individuals in a family who have Huntington's

63. *Id.* A pedigree dating back to the 1800's was developed tracing all 3,000 descendants to an individual who had died from Huntington's disease. To date, this is the largest known number of Huntington's disease patients in one family. Gusella, *supra* note 17, at 235.

64. Merz, *supra* note 15, at 3154.

65. *Id.*

66. Wexler, *supra* note 2, at 20. *See also* Gusella, *supra* note 17, at 238.

67. Wexler, *supra* note 2, at 20.

68. *Id. See also* Gusella, *Probes in Huntington's Chorea*, 320 NATURE 21, 21 (1986).

69. Wexler, *supra* note 2, at 20.

70. FACT SHEET, *supra* note 3, at 3.

71. *Id.* at 9.

should possess the same pattern.[72] Unfortunately, however, the test will not work with respect to *all* families or *all* family members.[73]

There is also the problem of recombination.[74] Approximately a five percent chance exists that recombination may take place between the marker and the Huntington's disease gene.[75] If this should occur, an individual having the gene may be misdiagnosed,[76] presumably because the marker would not be detected during the testing. Obviously, the best test would be one that could actually detect the Huntington's disease gene *itself*, rather than detecting a genetic marker linked to the gene.[77]

According to Dr. Wexler and her colleagues, "the ability to test asymptomatic individuals for the presence of a lethal, late-onset gene is unique in medical history."[78] Individuals who have absolutely no symptoms of the disease will be allowed to escape the uncertainty of an "unknown" future.[79] The fear which they have sustained their entire lives, because of the knowledge that they have a fifty percent chance of developing the disease, will be eliminated by a positive or negative result.[80] The question then becomes, "What about those who obtain a positive result?" The decision to undergo the test creates a chance of non-carrier status, but it also creates a chance of a certain death due to Huntington's disease.[81] Perhaps Dr. Wexler and her colleagues stated the effect of undergoing the test most accurately by acknowledging:

> As there is nothing that can be done for the illness, an at-risk person wishing to be tested for the sake of knowledge and planning alone gambles for very high stakes: salvation and delivery from a lifetime of anxiety and ambiguity or a virtual death sentence to be rendered by a quixotic, but inescapable,

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72. *Id.*

73. *Id.* at 3.

74. For an explanation of "recombination," see *supra* note 27.

75. Craufurd, *supra* note 3, at 250. *See also* Merz, *supra* note 15, at 3154. Research is currently being performed to find markers on both sides of the Huntington's gene for the purpose of localizing the gene. These flanking markers, as well as any other additional markers, would bring the test beyond its present state in terms of the information yielded. Wexler, *supra* note 2, at 20-21.

76. Craufurd, *supra* note 3, at 250.

77. FACT SHEET, *supra* note 3, at 3. *See also* Merz, *supra* note 15, at 3159.

78. Wexler, *supra* note 2, at 21.

79. Craufurd, *supra* note 3, at 249.

80. *Id.* at 250.

81. Wexler, *supra* note 2, at 22.

executioner.[82]

In addition, it is thought that those individuals receiving a positive test result run a high risk of committing suicide.[83] In fact, it has been stated that in the United States, the "risk of death . . . due to suicide" in Huntington's victims is a great deal higher than that of the United States population as a whole.[84] This is a significant factor which must be considered when deciding how and perhaps whether to apply the presymptomatic test. Furthermore, those individuals who are diagnosed as positive for the gene will definitely be in need of psychological support.[85] First and foremost, they must be made to understand that they can lead normal, productive lives for many years to come, and that they are not alone. Post-testing support groups could be established in which those individuals who have tested positive for the Huntington's gene could discuss their emotions and thoughts regarding their test results. If these individuals are not provided with mandatory counseling, there is no doubt that the suicide trend discussed above will continue, in spite of the fact that one is still dealing with presymptomatic individuals.

Many emotional issues arise as a result of this newfound testing; yet, many legal issues arise as well. Section V of this Note will respond to several of these legal issues and raise several others of which society must be made aware.

V. LEGAL ISSUES WHICH ARISE WITH RESPECT TO THE G-8 MARKER

At the present time, the marker is not available for widespread use; yet, once the testing takes on large-scale proportions, various legal issues will have to be addressed. Scientists have not yet concerned themselves with these questions.[86] They are busy

82. *Id.*

83. *Id.*

84. Craufurd, *supra* note 3, at 250.

85. Bird, *Presymptomatic Testing for Huntington's Disease*, 253 J. A.M.A. 3286, 3287 (1985).

86. The organizations which were contacted in an attempt to gather legal information relating to the G-8 marker include: The National Science Foundation; The Huntington's Disease Society of America (Maryland chapter and the national headquarters in New York); The National Biomedical Research Foundation; The National Clearing House for Human Genetic Diseases; The National Institutes of Health; The National Research Council-Commission on Life Sciences; The Offices of Senators Gore, Simon, and Childs; and The American Association for the Advancement of Science.

trying to locate new markers, and if possible, to locate the Huntington's gene itself. This is quite understandable, as it is not the responsibility of scientists to answer legal questions. Yet, absolutely *no* legal material exists on the subject due to the "recentness" of the testing procedure. Therefore, these questions must be answered *now* by the legal profession so that when individuals do look to the law for guidance, they will not be faced with uncertainty and frustration.

This Note will address the legal areas of: negligence, infliction of emotional distress, confidentiality, employment discrimination, insurance discrimination, and equal access to medical procedures, as they relate to the marker testing. This list is not exhaustive of the legal issues which may arise with respect to the testing procedure; yet, these issues seem to be the ones which are most readily apparent when one thinks about the problems which could arise once the test is put into widescale use.

A. Negligence

1. Testing

One of the first questions which must be addressed, with respect to the widescale use of the marker in testing, involves the problem of who will be liable for errors made at any stage of the testing procedure. One of the most signficant purposes of the testing is to enable at-risk individuals to determine whether they will actually develop the disease, so that they may decide in their childbearing years whether or not to have children. Someone who is told that she carries the Huntington's gene will be less likely to have children and risk passing the gene on to them, than will someone who is told that she most likely does not possess the gene. A problem arises, however, if a mistake is made in the lab. What if an individual is given the wrong results and bases his or her decision to have children on this mistake? Who will be held liable? Similarly, what if an at-risk couple decides to conceive a child and then tests the child in-utero for the presence of the gene? If a lab error is made, who will be liable when it is discovered after birth that the child does in fact possess the Huntington's gene? What if the parents would have aborted the child had the initial test been performed correctly?

There are several aspects to each of these questions, but it is best to begin with the basics. In these situations, one would be dealing with the tort of negligence. In order to establish this tort,

one must establish the presence of three elements.[87] First, one must find the presence of a *duty*.[88] Duty is the standard of care which the physician must use with respect to his patient.[89] Second, one must find *conduct* on the part of the physician which has *violated* this duty or standard of care owed to the patient.[90] Finally, a *causal connection* must be found between the physician's conduct and the injury the patient is alleging.[91] Once the court has found the presence of these three elements, the tort of negligence has been established.

Several negligence cases exist involving the birth of unwanted, defective children (as opposed to healthy children) due to testing errors.[92] Although these cases do not involve Huntington's disease, they do involve a genetic defect which could have been discovered prenatally if the particular testing procedure had been performed correctly. The claims brought in these cases are usually of two types: wrongful birth and wrongful life. The wrongful birth claim is brought by the parents of the child in order to recover damages which they sustained due to the birth of the child.[93] The wrongful life claim "is a cause of action on behalf of a defective child asserting that he would have been better off had he never been born, thus characterizing the fact of his existence as 'wrongful.' "[94] These terms are best understood upon an analysis of applicable case law.

A Virginia case dealing with a wrongful birth claim based on

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87. Waltz, *The Liability of Physicians and Associated Personnel for Malpractice in Genetic Screening*, in GENETICS AND THE LAW 141 (1976).

88. *Id.*

89. *Id.*

90. *Id.*

91. *Id.* at 142.

92. *See* Gildner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692 (E.D. Pa. 1978)(amniocentesis test was performed on expectant mother in order to determine whether fetus had Tay-Sachs disease, and parents were given incorrect test results, in reliance upon which they continued with the pregnancy); Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980) (child born with Tay-Sachs as a result of error made with respect to tests performed on parents); Aliquijay v. St. Luke's-Roosevelt Hosp. Center, 63 N.Y.2d 978, 483 N.E.2d 244, 483 N.Y.S.2d 944 (1984)(child born with Down's syndrome after parents given incorrect amniocentesis test results); Naccash v. Burger, 223 Va. 406, 290 S.E.2d 825 (1982)(patient's blood vial mishandled and patient consequently given inaccurate results regarding Tay-Sachs carrier status, resulting in birth of a Tay-Sachs child).

93. W. KEETON, D. DOBBS, R. KEETON & D. OWEN, PROSSER & KEETON ON THE LAW OF TORTS 371 (5th ed. 1984).

94. Note, *Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling*, 87 YALE L.J. 1488, 1500 (1978).

a lab error is *Naccash v. Burger*.[95] The plaintiffs in the case, the Burgers, were of Jewish, Eastern-European descent and were therefore possible carriers of the Tay-Sachs trait.[96] Consequently, when Mrs. Burger was three and a half months pregnant, she and her husband attempted to undergo blood testing for the presence of the Tay-Sachs gene.[97] The standard testing procedure used to detect Tay-Sachs depends on the status of the parents. If both parents are found to be carriers, the fetus is then tested by use of amniocentesis to see whether the child actually has the disease.[98] A child of two carrier parents has a twenty-five percent chance of inheriting the disease.[99]

The parents in this case were told by a lab technician working for the physician that Mrs. Burger did not have to be tested unless Mr. Burger tested positive for the trait.[100] The result of the test was negative, and the Burgers continued the pregnancy and gave birth to a baby girl.[101] Several months later it was discovered that the child had Tay-Sachs disease, and she died soon thereafter.[102] The parents were then retested and shown to be carriers.[103] It was subsequently discovered that Mr. Burger's blood vial had been mixed up with another patient's vial, thus accounting for the error.[104] A wrongful birth claim was brought, in which the Burgers claimed that had they known they were carriers, they

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95. 223 Va. 406, 290 S.E.2d 825 (1982).

96. *Id.* at 410, 290 S.E.2d at 827. Tay-Sachs is a genetic disease of the brain and spinal cord which is fatal. It involves a deterioration of the central nervous system to the point where the child experiences blindness, deafness, paralysis, seizures, and mental retardation. Death occurs two to four years after birth. *Id.* at 409-10, 290 S.E.2d at 827. Tay-Sachs disease "primarily affects the Eastern European Jewish population and their progeny." Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 815, 816, 165 Cal. Rptr. 477, 480 (1980).

97. *Naccash*, 223 Va. at 410, 290 S.E.2d at 827.

98. *Id.* Amniocentesis is a surgical procedure whereby a hollow needle is inserted into the abdomen and uterus of a pregnant woman. Amniotic fluid is then withdrawn and tested so that genetic or gender abnormalities of the fetus can be detected. WEBSTER'S NEW COLLEGIATE DICTIONARY 38 (8th ed. 1981).

99. *Naccash*, 223 Va. at 410, 290 S.E.2d at 827. As noted previously, the child of a parent carrying the Huntington's disease gene has a 50% chance of developing the disease. *See supra* note 52 and accompanying text. Moreover, a Tay-Sachs carrier who possesses one disease-gene does *not* develop the disease unlike a Huntington's carrier. *Naccash*, 223 Va. at 410, 290 S.E.2d at 827.

100. *Naccash*, 223 Va. at 410, 290 S.E.2d at 827.

101. *Id.*

102. *Id.*

103. *Id.*

104. *Id.*

would have had the child tested by amniocentesis and would have aborted her had she tested positive for the disease.[105]

The court held that the Burgers had a cause of action since there was: 1) a breach of an established duty, 2) a causal connection between this breach and the resulting injury, and 3) a direct injury to the plaintiffs.[106] More specifically, the court held in relation to the above elements that: 1) there was a "duty of reasonable care" owed to the Burgers, with respect to the handling of the blood sample and with respect to the disclosure of accurate test result information, which had been violated by the vial mix-up; 2) because of the incorrect test result, the pregnancy was continued; and 3) the Burgers were deprived of the opportunity to decide whether to abort the defective child.[107] Consequently, the court determined that the Burgers could "recover damages for expenses incurred in the care and treatment of their afflicted child."[108]

The court also allowed the Burgers to collect damages for emotional distress.[109] The court stated that "[a]s a general rule, such damages are not recoverable unless they result directly from tortiously caused physical injury."[110] It then established that a direct link existed between the false test report, the "deprivation" of the parents' decision whether to continue with the pregnancy, and "the emotional distress the parents suffered following the birth of their fatally defective child."[111]

Once the Huntington's marker testing becomes available for widespread use, the fact pattern of the *Burger* case could arise again. For example, what if a couple decides to undergo testing for the marker before bearing children, and one or both of the parties are given incorrect lab results due to a procedural error? Suppose the child then tests positive for the gene? Alternately, suppose amniocentesis is performed and an incorrect result causes the couple to continue with the pregnancy? A case like *Burger* may provide the answers to these questions. For example, it would appear, based on the *Burger* discussion, that a couple giving birth to a Huntington's child would be able to recover in a wrongful birth action should they claim they would not have had the child

105. *Id.* at 411, 290 S.E.2d at 827-28.
106. *Id.* at 414, 290 S.E.2d at 829-30.
107. *Id.*
108. *Id.* at 414, 290 S.E.2d at 830.
109. *Id.* at 416, 290 S.E.2d at 831.
110. *Id.* at 415, 290 S.E.2d at 830.
111. *Id.* at 416, 290 S.E.2d at 831.

had they been given accurate, positive, test results.

However, a Huntington's infant is in quite a different position than a Tay-Sachs infant. A Huntington's child will not manifest the symptoms of the disease until she is a middle-aged adult.[112] A Tay-Sachs child, however, will experience extreme pain and suffering in those first few months or years until death.[113] This is a distinction the courts could draw upon to disallow claims of wrongful birth in cases involving Huntington's disease. After all, a "healthy" child has been born as opposed to an "unhealthy" one. On the other hand, according to the *Burger* court, if a duty of care can be established, as well as a breach of this duty, and a causal connection between the breach and the injury, then there should be recovery. Yet, it is doubtful whether the parents will have a true claim to care and treatment damages since the Huntington's child will not require any such care or treatment beyond that of a normal child. In addition, one could theorize that the parents will suffer no emotional distress until the child, or in this case, the adult, manifests symptoms. Consequently, emotional distress damages should also be denied. These issues will be addressed further in a later section of this Note.

As mentioned above, wrongful life claims are also raised in the context of lab error cases. For example, in *Curlender v. Bio-Science Laboratories*,[114] a couple, like the Burgers, underwent testing to determine whether they were carriers of the Tay-Sachs gene.[115] Once again, the parents were given incorrect lab results and consequently gave birth to a child with severe disabilities caused by Tay-Sachs disease.[116] The court held that medical laboratories involved in genetic testing owe a duty to parents and their unborn offspring to "use ordinary care" in carrying out the testing so that accurate information can be provided concerning possible defects.[117] The court then went on to find a cause of action and established that damages could be awarded based on the child's mental and physical condition at birth and during her short projected lifespan, as opposed to an award based on a normal lifespan.[118] The court also stated that a "wrongful life" claim does

112. Craufurd, *supra* note 3, at 249.
113. *Naccash*, 223 Va. at 410, 290 S.E.2d at 827.
114. 106 Cal. App. 3d 815, 165 Cal. Rptr. 477 (1980).
115. *Id.* at 816, 165 Cal. Rptr. at 480.
116. *Id.*
117. *Id.* at 828, 165 Cal. Rptr. at 488.
118. *Id.* at 830, 165 Cal. Rptr. at 489.

not involve a right not to be born, but is the right of the injured child "to recover damages for the pain and suffering to be endured during the limited lifespan available to such a child and any special pecuniary loss resulting from the impaired condition."[119]

Once again it is conceivable that a child born with Huntington's disease could bring a wrongful life suit based on a testing error. He could allege that but for the error on the part of the defendant, his birth would never have occurred.[120] Once again, however, there is a problem with damages. Unless the suit is brought when the child has reached adulthood and is experiencing the symptoms of the disease, what is the source of the child's damages? Perhaps punitive damages can be awarded, due to the tort committed by the defendant, as was the case in *Curlender*.[121] Beyond that, however, an award of damages seems quite questionable.

2. Failure to Perform Adequate Testing

In addition to the situation where an actual mistake is made during the testing procedure, another problem arises when the physician fails to perform a test which should be performed because of the patient's medical history or for another vital reason. For example, in *Phillips v. United States*,[122] the plaintiff, who was expecting her first child, indicated on several prenatal questionnaires that her sister had been born with Down's syndrome.[123] Her physician did not inform her of the implications of this history with respect to her unborn child or of the existence of amniocentesis, a testing procedure which can be used prenatally to determine the presence of Down's syndrome in a fetus.[124] The child was then born with Down's syndrome.[125] The mother was then tested and found to carry a chromosome translocation which is sometimes a cause of Down's syndrome in offspring.[126] The plain-

119. *Id.* at 831, 165 Cal. Rptr. at 489.
120. *Id.* at 817, 165 Cal. Rptr. at 481.
121. *Id.* at 831-32, 165 Cal. Rptr. at 490.
122. 566 F. Supp. 1 (D.S.C. 1981).
123. *Id.* at 2-3. Down's syndrome is a genetically based condition caused by an extra chromosome associated with chromosome pair 21. It causes mental retardation and the appearance of other prominent physical abnormalities, such as small rounded ears and retarded growth. *Id.* at 2 n.2.
124. *Id.* at 3.
125. *Id.* at 4.
126. *Id.*

tiff was found to have established a cause of action under the Federal Tort Claims Act since the physician had breached the "applicable medical standard of care."[127]

Several other cases of this nature have come before the courts.[128] Again, this situation could arise with respect to an expectant mother having a family history of Huntington's disease. She could make the physician fully aware of this history and yet never be informed of the availability of the G-8 marker test for prenatal use. If the court finds that the doctor should have been aware of this procedure, the plaintiff would have a cause of action under *Phillips*.

A similar cause of action could arise even if a patient not presently expecting a child went to a physician, due to a concern she might have of passing the gene on to her offspring. If this patient was not informed as to the possibility of the test to determine her carrier/victim status, and thus the probability of passing the gene on to her child, then damages most likely would be awarded.

Another issue related to testing performance, or non-performance, involves the situation where a physician fails to instruct the patient that her offspring may be born with birth defects. Many cases addressing this issue have come before the courts.[129] Most of them involve a child who has been born with serious defects due to the mother's contraction of rubella or German measles.

3. Failure to Instruct

In *Gleitman v. Cosgrove*,[130] one of the earliest cases involving

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127. *Id.* at 13.

128. *See* Call v. Kerizian, 135 Cal. App. 3d 189, 185 Cal. Rptr. 103 (1982)(middle-aged, expectant mother was not given amniocentesis, in violation of her physician's duty to perform such testing on middle-aged women, thus causing her to give birth to a child with Down's syndrome); Becker v. Schwartz, 46 N.Y.2d 401, 386 N.E.2d 807, 413 N.Y.S.2d 895 (1978)(where amniocentesis was not performed on an expectant woman over 35 years of age, thereby causing her to give birth to a child with Down's syndrome); Karlsons v. Guerinot, 57 A.D.2d 73, 394 N.Y.S.2d 933 (N.Y. App. Div. 1977)(thirty-seven year old woman not advised of the availability of amniocentesis, and subsequently gave birth to a Down's syndrome child).

129. *See* Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975)(physician failed to properly diagnose expectant mother's contraction of rubella, and consequently could not advise her of risks of that virus, thereby causing child to be born with severe physical abnormalities); Harbeson v. Parke-Davis, Inc., 98 Wash. 2d 460, 656 P.2d 483 (1983)(parents not informed of risks of mother's use of prescription drug during pregnancy, resulting in birth of children with physical and mental abnormalities).

130. 49 N.J. 22, 227 A.2d 689 (1967).

a wrongful life claim, the defendant's patient was informed that she was pregnant, and as a result of this information, she told the defendant that she had recently had a case of German measles.[131] The defendant told the patient that this illness would have no effect on the unborn child.[132] The child was subsequently born with extreme physical abnormalities.[133] The child, through his mother, then brought a wrongful life claim against the defendant which significantly distressed the court.[134] The court stated, in effect, that the child in bringing the suit was claiming that "but for the negligence of the defendant[], he would not have been born to suffer with an impaired body."[135] With respect to compensatory damages, the court stated that it could not measure "the value of life with impairments against the nonexistence of life itself."[136] Thus, since no "damages cognizable at law" arose from the claim, a wrongful life cause of action was not established.[137]

Most importantly, the court stated:

> It is basic to the human condition to seek life and hold on to it however heavily burdened. If Jeffrey [the child] could have been asked as to whether his life should be snuffed out before his full term of gestation could run its course, our felt intuition of human nature tells us he would almost surely choose life with defects against no life at all . . . . A child need not be perfect to have a worthwhile life.[138]

Although this statement is quite profound, all courts ruling on the subject have not taken this position.[139]

The *Gleitman* position seems to conform to section 920 of the Restatement of Torts or the "benefit rule" which provides:

> Where the defendant's tortious conduct has caused harm to the plaintiff or to his property and in so doing has conferred upon the plaintiff a special benefit to the interest

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131. *Id.* at 24, 227 A.2d at 690.
132. *Id.*
133. *Id.* at 25, 227 A.2d at 690.
134. *Id.* at 28, 227 A.2d at 692.
135. *Id.*
136. *Id.*
137. *Id.* at 29, 227 A.2d at 692.
138. *Id.* at 30, 227 A.2d at 693.
139. *See* Harbeson v. Parke-Davis, Inc., 98 Wash. 2d 460, 481-82, 656 P.2d 483, 496-97 (1983)("impossibility of valuing life and nonexistence" does not prevent wrongful life claim, and although general damages cannot be awarded, special damages can be); Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980) (punitive damages awarded based on wrongful life cause of action).

> which was harmed, the value of the benefit conferred is considered in mitigation of damages, where this is equitable.[140]

In fact, the Restatement was directly applied in *Troppi v. Scarf*,[141] where the court held that the "benefits of the unplanned child may be weighed against all the elements of claimed damage."[142]

Applying the above concepts to the topic at hand, it is quite conceivable that a pregnant woman who has Huntington's disease could be told incorrectly that the disease will in no way affect her unborn child. After the birth of the child, the marker testing could reveal that the child does, in fact, possess the gene. If one were to rely on *Gleitman*, the child would not recover for damages. Yet, the *Gleitman* decision appears to be based on the inability of the court to calculate damages notwithstanding the fact that an actual tort had been committed by the defendant. Perhaps another court would take a different approach to this issue. In the other situations discussed above, recovery was allowed for wrongful life claims based on the court's emphasis upon the defendant's tortious conduct.

However, section 920 of the Restatement would definitely present a problem even in those courts allowing recovery for wrongful life claims. A Huntington's child will be "healthy" for several years to come and will provide his or her parents with great joy and happiness. Such joy and happiness could definitely outweigh the damage caused by the defendant's tortious conduct; thus, why should the parents be allowed any form of recovery? This rationale will definitely be raised in the courts in any type of suit brought by the parents of a Huntington's child or brought by the child herself.

In concluding this section, it seems quite apparent that the courts will look to analogous or related fact situations for solutions, once cases arise involving negligence in Huntington's disease testing. These cases will arise in several contexts. Wrongful birth and wrongful life claims will probably be brought if testing procedures are performed incorrectly or are not performed at all. Moreover, such claims will be brought if a physician fails to inform the

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140. RESTATEMENT (SECOND) OF TORTS § 920 (1979)(as quoted in Troppi v. Scarf, 31 Mich. App. 240, 254, 187 N.W.2d 511, 517-18 (1971)).

141. 31 Mich. App. 240, 187 N.W.2d 511 (1971).

142. *Id.* at 255, 187 N.W.2d at 518.

patient of the risk of passing the disease onto the next generation. Although the courts, based on the *Gleitman* decision, have gone in both directions, it appears that most will allow some form of recovery once a cause of action has been established. Each decision, however, will have to be made on a case by case basis with the aid of this related precedent.

B. Infliction of Emotional Distress

Another issue which must be addressed is whether a third party should be able to recover for the emotional pain he has experienced due to the harm inflicted on the Huntington's victim. For example, if a child is born with Huntington's disease due to negligent conduct on the part of a physician, should the parents be able to collect damages for the emotional distress *they* have suffered as a result of the harm done to their child? Moreover, when a wife has tested negative for Huntington's disease due to a lab error, should her husband be allowed to collect damages for the pain he has suffered while his wife is deteriorating due to the progression of the disease? These questions will arise once the marker testing becomes widespread. It is best to answer these questions now by looking to legal precedent.

In *Howard v. Lecher*,[143] the plaintiffs, parents of a daughter who had been born with Tay-Sachs disease and had died from the disease shortly thereafter, alleged that their physician, who knew of their East-European background, should have known and advised them of the availability of tests used to detect their carrier status as well as the status of their unborn child.[144] They alleged that if they had known that the child had Tay-Sachs disease, they would have terminated the pregnancy.[145] The plaintiffs claimed further that they had suffered mental and emotional distress due to their daughter's illness and consequent death.[146]

The court held that the law in New York at the time required a plaintiff to establish the existence of a duty owed to him by the defendant in order to recover for emotional distress.[147] Moreover, the plaintiff had to be "directly injured" as a result of

143. 53 A.D.2d 420, 386 N.Y.S.2d 460 (N.Y. App. Div. 1976), *aff'd*, 42 N.Y.2d 109, 366 N.E.2d 64, 397 N.Y.S.2d 363 (1977).

144. *Id.* at 422, 386 N.Y.S.2d at 461.

145. *Id.*

146. *Id.* at 421, 386 N.Y.S.2d at 460.

147. *Id.* at 423, 386 N.Y.S.2d at 460.

a violation of this duty.[148] The court also stated that since the child was the individual who was directly injured by the defendant's conduct, the parents could not recover for emotional distress due to their indirect harm.[149] The court then stated:

> [I]t is virtually impossible to evaluate as compensatory damages the anguish to the parents of rearing either a malformed child, or a child born with a fatal disease, as against the denial to them of the benefits of parenthood. Damages which are uncertain, contingent or speculative in their nature, cannot be made the basis of a recovery. . . . [A]llowance of recovery would place an unreasonable burden upon physicians and obstetricians. It would either open the way for fraudulent claims or enter a field that has no sensible or just stopping point.[150]

This line of reasoning seems quite harsh, and was overruled less than a year later in *Karlsons v. Guerinot*.[151] In this case, the plaintiffs gave birth to a mongoloid child after the defendants, knowing of the mother's medical history, failed to inform the parents of the risks of bearing a deformed child or of the availability of amniocentesis which could have detected the child's condition.[152] The parents insisted that if they had known of the child's affliction, they would have terminated the pregnancy.[153] The plaintiffs thus sought emotional and mental damages for the pain they suffered as a result of their child's condition.[154]

The court held that the defendants owed a duty to the child's mother, and that this duty had been breached, thereby denying her the choice to terminate the pregnancy.[155] The child was born and this consequently caused mental distress.[156] With respect to the *Howard v. Lecher* decision, the court specifically stated:

> We cannot agree with the conclusion . . . in *Howard* that the injury from which the parents' alleged emotional harm stemmed was suffered solely by the child and, therefore, resulted in only indirect harm to the parents. Rather, the

148. *Id.*
149. *Id.* at 422, 386 N.Y.S.2d at 461.
150. *Id.* at 424-25, 386 N.Y.S.2d at 462-63.
151. 57 A.D.2d 73, 394 N.Y.S.2d 933 (N.Y. App. Div. 1977).
152. *Id.* at 75, 394 N.Y.S.2d at 934. *See also supra* note 128.
153. *Karlsons*, 57 A.D.2d at 75, 394 N.Y.S.2d at 934.
154. *Id.*
155. *Id.* at 78, 394 N.Y.S.2d at 936.
156. *Id.*

> pain, suffering and mental anguish suffered by the plaintiffs as a result of the birth of a mongoloid child is the type of direct injury flowing from defendant's alleged breach of duty to the parents . . . .[157]

Thus, the parents were awarded damages based on the difference between the value of the emotional damages suffered and the benefits arising from having the child.[158] The court felt that difficulty in calculating damages should not prevent such an award.[159] This view is quite contrary to that espoused in *Howard*.

Based on the *Karlsons* line of reasoning, therefore, it would appear that parents of a child born with Huntington's disease, due to a failure on the part of a physician to inform the parents of available marker testing, would be able to collect damages for emotional distress.[160] However, there is an obstacle to recovery in that the child will not be affected physically or mentally until adulthood, unlike a child born with Tay-Sachs disease or Down's syndrome.[161] Consequently, the parents will not experience pain or suffering for many years, except with respect to the knowledge that their child will develop the disease.

A spouse, on the other hand, would probably be allowed to recover damages if his partner's physician, knowing the family history of the patient, failed to mention that the genetic marker testing was available for the partner. However, the disease will develop, with or without the testing. This is different from the above case where the pain and suffering is due to a birth that would not have taken place absent the physician's tortious conduct. Yet, if the physician has breached his duty, by failing to reveal the marker testing procedure, and this procedure is known by most physicians at the time,[162] and pain and suffering result from the spouse's uncertainty regarding the cause of the Huntington's symptoms once they begin to manifest themselves, perhaps the spouse could recover for this emotional distress. This argument, however, is lacking in strength and is quite tenuous.

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157. *Id.*

158. *Id.* at 79, 394 N.Y.S.2d at 937.

159. *Id.* at 78-79, 394 N.Y.S.2d at 937.

160. Specifically, all of the elements which allowed for recovery in *Karlsons* would have been met. *See supra* notes 155-59 and accompanying text.

161. *See supra* notes 96 and 123.

162. W. KEETON, D. DOBBS, R. KEETON, & D. OWEN, PROSSER AND KEETON ON THE LAW OF TORTS 185-87 (5th ed. 1984).

C. Confidentiality

In addition to raising legal issues concerning negligence and the infliction of emotional distress, the marker testing also raises questions concerning confidentiality. For example, once a patient undergoes testing, who will have access to the test results? Will spouses, children, or parents of the patient have a right of access to the patient's test results by law?

To answer these questions it is best to start with the historical standard in the medical profession, which states that confidentiality must be maintained between the physician and the patient.[163] Moreover, it is also thought that all genetic counselors, whether or not they are physicians, must be held to this same standard.[164] When this standard is violated, several theories exist by which the defendant may be held liable. These theories include breach of contract, defamation, and invasion of privacy.[165] In addition, there are licensing, testing, and confidentiality statutes which protect the confidential information.[166]

"[T]he rule of confidentiality forbids unconsented disclosure of medical information to family members as well as to strangers . . . ."[167] It has been suggested, however, that although a patient does not legally have a duty to inform his relatives of his condition, the counselor may have a "moral obligation" to reveal the confidential information.[168] By doing so, the counselor could prevent the passing of a serious genetic disorder to future offspring.[169] Furthermore, if the harm to be prevented is serious enough, liability could result from non-disclosure.[170]

It has been stated that:

> A professional's ethical duty of confidentiality to an immediate patient or client can be overridden only if several conditions are satisfied: (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that the harm will occur if the informa-

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163. Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 618, 674 (1979).

164. *Id.* at 675.

165. Note, *Confidentiality of Genetic Information*, 30 UCLA L. REV. 1283, 1297-301 (1983).

166. *Id.* at 1302-04.

167. Capron, *supra* note 163, at 676.

168. *Id.* at 677.

169. *Id.*

170. *Id.*

> tion is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.[171]

Moreover, it has been suggested that disclosure should be made to relatives when the condition diagnosed is extremely serious but readily treatable in family members if discovered early enough.[172] This is true, for example, with respect to the diagnosis of multiple polyposis of the colon which is a precursor to cancer of the colon.[173]

When dealing with an autosomal recessive disorder such as Tay-Sachs or sickle cell anemia, a positive screening disclosing a carrier of the gene will more than likely cause other family members to undergo screening before bearing children.[174] Moreover, since the siblings of the carrier only have a fifty percent chance of carrying the gene, their risk factor only becomes "relevant" if their spouses carry the gene since two defective genes are necessary to produce the disease in the offspring.[175]

However, this is not the case with Huntington's disease, where a *carrier* of the gene will ultimately be a victim of the disease.[176] If one sibling tests positive, perhaps the results should be disclosed so that other siblings can undergo testing before bearing children, as there is a fifty percent chance that each sibling has the gene and, therefore, the disease.[177] The carrier or noncarrier status of the sibling's spouse will not eliminate the chance of the couple's future offspring inheriting the disease-gene if the sibling carries the gene. Thus, in "dominant gene disorders," such as Huntington's, "sex-chromosome linked conditions and chromosome translocations," there is a greater "risk" involved if disclosure is not made.[178]

A case which discusses the issue of disclosure to a relative is

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171. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 44 (1983) [hereinafter PRESIDENT'S COMMISSION].

172. Capron, *supra* note 163, at 678.

173. PRESIDENT'S COMMISSION, *supra* note 171, at 43.

174. Capron, *supra* note 163, at 678.

175. *Id.*

176. Rosenfeld, *supra* note 30, at 5.

177. Kolata, *supra* note 4, at 913.

178. Capron, *supra* note 163, at 678.

MacDonald v. Clinger.[179] The plaintiff, MacDonald, was seeing a psychiatrist, the defendant, and revealed intimate facts to the defendant which were later revealed to the plaintiff's wife without the plaintiff's consent.[180] The court held that "[t]he relationship of the parties here was one of trust and confidence out of which sprang a duty not to disclose. Defendant's breach was not merely a broken contractual promise but a violation of a fiduciary responsibilty to the plaintiff implicit in and essential to the doctor-patient relationship."[181] In addition, however, the court stated that disclosure is permissible where "there is a danger to the patient, the spouse or another person."[182] Thus, this case leads one to believe that a physician would be liable for disclosing the results of a genetic marker test to the spouse of the at-risk individual except in an instance where the patient is likely to commit suicide.

In addition to the exceptions noted above, there are other instances when close relatives should be informed of the patient's test results. For example, every child has a right to know if his parent has tested positive for the marker. There are several reasons for this line of thinking. First and foremost, if the parent has tested positive then the child has a fifty percent chance of developing the disease.[183] In all likelihood, the child will want to be tested before making his own childbearing decisions. In addition, if a child knows of his or her parent's impending disease, then arrangements can be made to provide for the parent when he can no longer provide for himself. Financial resources can be set aside for the future. Any disease takes a devastating toll on a family, financially as well as emotionally; however, part of the burden can be circumvented if plans are formulated well in advance of the problems to come.

A spouse should also be informed as to his partner's test results for the financial and childbearing reasons stated above. If a spouse tests positive, the other spouse must decide whether he or she wants to subject a child to a fifty percent chance of inheriting the disease-causing gene. The decision whether to bear a child must be made by both parties, and any relevant information involved in this decision should not be held in secrecy by either the

179. 84 A.D.2d 482, 446 N.Y.S.2d 801 (N.Y. App. Div. 1982).
180. *Id.* at 482, 446 N.Y.S.2d at 802.
181. *Id.* at 487, 446 N.Y.S.2d at 805.
182. *Id.* at 488, 446 N.Y.S.2d at 805.
183. Kolata, *supra* note 4, at 913.

genetic counselor or the disease victim. A disclosure by one of the two parties must take place.

With respect to the sibling disclosure issue, it is this author's opinion that a disclosure of test results should not be made mandatory. If an individual is truly concerned about whether or not she is carrying the gene, based on a family history of the disease, then the individual should be allowed to undergo the testing. This individual should not be allowed access to test results from other family members. The familial line must be drawn somewhere, and it should be drawn right outside of the parent-child and spousal relationships.

Confidentiality is certainly one of the most pressing issues involved in the marker testing, and at present, only those individuals who are undergoing the sample testing are given their results.[184] Once testing becomes widespread, however, individuals will want to be informed of their relatives' test results. Solutions, therefore, must be found now, and the above factors must be taken into consideration. In addition, these questions must be answered with respect to disclosing test results to employers.

D. Employment Discrimination

Should an employer, present or potential, have access to the results of the G-8 marker testing? If so, can he use the results to discriminate against a Huntington's victim? It has been stated that disclosure of genetic testing results should only be allowed if the patient has given express consent to such disclosure.[185] It has also been suggested that no justification exists for the disclosure of genetic screening test results to an employer.[186] Yet, in 1981, six large Fortune 500 corporations in the United States were testing their employees for the presence of genes which made them specifically vulnerable to certain chemicals, thereby seemingly indi-

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184. Conversation with Christopher Chambers, Assistant to the Director of Patient Services of the national headquarters of the Huntington's Disease Society of America located in New York, New York (Sept. 1987); Conversation with Philip Cohen of the national headquarters of the Huntington's Disease Society of America located in New York, New York (Oct. 1988) [hereinafter Chambers & Cohen].

185. PRESIDENT'S COMMISSION, *supra* note 171, at 42.

186. Waltz & Thigpen, *Genetic Screening and Counseling: The Legal and Ethical Issues*, 68 NW. U.L. REV. 696, 748 (1973) [hereinafter Waltz]. *See generally* Canter, *Employment Discrimination Implications of Genetic Screening in the Workplace Under Title VII and the Rehabilitation Act*, 10 AM. J.L. MED. 323 (1985); Note, *Genetic Testing in Employment: Employee Threat?*, 15 SUFFOLK U.L. REV. 1187 (1981).

cating that positive test results would be used to dismiss present employees and as an excuse not to hire future employees.[187] In 1982, almost five dozen other Fortune 500 companies said they would implement the same testing within five years.[188] Other instances of this type of discrimination also exist. For example, in the early 1970's, black employees working for the airlines were given ground positions only, out of fear that if these individuals worked in planes, and the planes suddenly depressurized, a "sickling crisis might occur."[189] In addition, prior to 1981, the Air Force would not allow cadets, who were carriers of sickle-cell anemia, into the academy.[190]

In terms of mass screening programs, in 1972, the Sickle Cell Anemia Control Act was passed which allowed the federal government to make grants to those public and private organizations wishing to establish testing and counseling programs.[191] In fact, in 1977, sixteen states set up screening centers.[192] These screening programs were mandatory in eight states.[193] In addition, in 1985, forty-three states had legislation relating to phenylketonuria (PKU) testing.[194] California also is undertaking a mass screening program for alpha fetoprotein.[195] Although all of these programs are used to screen children, who is to say that the test results will not later be disclosed to employers of these children?

A case involving an actual disclosure of medical information to an employer is *Horne v. Patton*.[196] The plaintiff, Horne, claimed that he informed his physician, the defendant Patton, to

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187. Note, *supra* note 165, at 1308 n.175.

188. Smith, *Genetics, Eugenics, and Public Policy*, 1985 S. ILL. U. L.J. 434, 443 n.54.

189. Note, *supra* note 165, at 1292 n.60. Sickle-cell anemia is a condition caused by the inheritance of two recessive genes in which low oxygen concentrations in the blood cause the hemoglobin to take on the shape of an S. Consequently, the red blood cells do not flow through the capillaries properly, and a "sickling crisis" occurs. The effects of the disease include pain, early death, anemia, as well as other debilitating manifestations. *Id.* at 1287 n.29.

190. Smith, *supra* note 188, at 443 n.54.

191. Waltz, *supra* note 186, at 703.

192. Note, *supra* note 165, at 1293 n.61.

193. *Id.*

194. Smith, *supra* note 188, at 442 n.47. PKU is a condition which produces substantial mental retardation in children and is caused by the presence of a single defective gene. *Id.*

195. Steinbrook, *In California, Voluntary Mass Prenatal Screening*, HASTINGS CTR. REP., Oct. 1986, at 5.

196. 291 Ala. 701, 287 So. 2d 824 (1973).

keep all information acquired during the course of the physician-patient relationship confidential. He further alleged that the defendant ignored the instruction and gave the plaintiff's employer some medical information relating to the plaintiff which subsequently caused the plaintiff to be dismissed.[197] The court held:

> [A] medical doctor is under a general duty not to make extra-judicial disclosures of information acquired in the course of the doctor-patient relationship and that a breach of that duty will give rise to a cause of action. Unauthorized disclosure of intimate details of a patient's health may amount to unwarranted publication of one's private affairs with which the public has no legitimate concern such as to cause outrage, mental suffering, shame or humiliation to a person of ordinary sensibilities. Nor can it be said that an employer is necessarily a person who has a legitimate interest in knowing each and every detail of an employee's health.[198]

The plaintiff received a favorable verdict.[199]

It would appear that, based on the *Horne* case, a physician or genetic counselor who has established a physician-patient relationship with a patient who was tested for the presence of the Huntington's gene would be liable for disclosing the results of the test to an employer. This case also establishes that an employer is not entitled to such information.[200]

In addition to the privacy interest described above, there are other reasons why an employer should not have access to test results. For example, it has been suggested that an employer will probably terminate an employee known to have Huntington's rather than accomodate his increasing medical needs.[201] This is legal according to modern case law, at least where private employers are involved.[202]

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197. *Id.* at 704-05, 287 So. 2d at 825-26.

198. *Id.* at 709-10, 287 So. 2d at 830-31.

199. *Id.* at 711, 287 So. 2d at 832.

200. *Id.* at 709-10, 287 So. 2d at 830-31.

201. Note, *supra* note 165, at 1308.

202. *See* Munhollon v. Pennsylvania R.R., 180 F. Supp. 669, 673 (N.D. Ohio 1960)(court stated that it is "well established in law . . . that an employer, apart from contract or statute cannot be compelled to refrain from discharging any or all employees"); Fisher v. Church of St. Mary, 497 P.2d 882 (Wyo. 1972)(ten-month teaching contract terminated by school after plaintiff, a teacher, suffered a cerebral hemorrhage but recovered before the expiration date of the contract). *Cf.* Consolidated Rail Corp. v. Darrone, 465 U.S. 624, 626 (1984)(court discusses § 504 of the Rehabilitation Act of 1973 found at

An employer also has no guarantees regarding an employee's future health status. Any employee may develop cancer or Alzheimer's disease in the future. Why should a disease whose appearance will manifest itself with "certainty" be treated any differently? It is, of course, important that an individual who has tested positive for the disease should not be permitted to take advantage of his employer's lack of knowledge. Once symptoms begin to appear which affect the individual's performance at work, that individual should resign, if necessary, to preserve the safety of his fellow workers as well as his own safety, particularly if he is involved in mechanical labor. However, this individual must not be denied an employment opportunity thirty years before the manifestation of symptoms occurs. All of these reasons support the view that an employer should not have access to the G-8 marker test results.

E. Insurance Discrimination

The same problems which have been referred to above, with respect to employment discrimination, also arise in the context of insurance discrimination. If an insurer is told that the potential insured has tested positive for the presence of the marker, one of two things could happen. The insurer could either charge the insured extremely high premiums or refuse coverage to the applicant.[203] This is a dangerous situation in that those who have tested positive will need to utilize health care services to a more substantial degree than those who have not inherited the disease.

Although it has been stated that there is absolutely no valid reason for an insurance company to receive genetic testing results without the consent of the applicant, due to possible discrimination,[204] instances of such discrimination based on disclosure do exist. For example, in the 1970's, carriers of sickle-cell anemia were charged higher premiums than other insured parties in spite of the fact that the insurance companies did not base the increased pre-

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29 U.S.C. § 504 which states that "[n]o otherwise qualified individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal Financial Assistance"); Kelley v. Bechtel Power Corp., 633 F. Supp. 927 (S.D. Fla. 1986)(plaintiff unlawfully terminated under the Florida Human Relations Act of 1977 due to the handicap of epilepsy).

203. Note, *supra* note 165, at 1308.

204. *Id.* at 1310.

miums on mortality tables.[205] Insurers of Huntington's patients probably will not behave any differently.

However, as asked previously, how does insuring an individual who will definitely acquire Huntington's disease, based on the results of the G-8 testing procedure, differ from insuring someone who has a family history of a particular disorder but for which there is no diagnostic test? This latter individual may develop cancer, Alzheimer's disease, Parkinson's disease, or any other condition thirty years from the time of the initiation of the coverage based on a known or unknown genetic predisposition. An insurer takes a risk any time he insures an individual. Why should he be allowed to discriminate against a person who has tested positive for the marker simply because medical technology has allowed for the discovery of information which cannot be discovered with respect to other potentially lethal conditions? Access could cause discrimination, and thus should not be allowed.

F. Equal Access to the Testing Procedure

Another issue raised by the marker testing involves the availability of access to the procedure. At the present time, only five testing centers are available for use, and they are found in the following states: Maryland, Massachusetts, New York, Michigan, and Minnesota.[206] Moreover, one must actually live within a 150 mile radius of one of the centers in order to be tested (with the exception of the Minnesota center) due to the fact that one must obtain genetic counseling during and after the performance of this two to four month procedure.[207] Yet, serious concerns arise with respect to other individuals who do not reside in these states and who cannot afford to uproot themselves in order to receive the testing. Are they being discriminated against due to their economic status?

The same type of discrimination exists with respect to the program established in California to detect the presence of alpha fetoprotein prenatally.[208] The program requires obstetricians and those individuals involved in prenatal health care to administer the test to all expectant mothers who are searching for prenatal care

205. *Id.* at 1292 n.60.
206. Chambers & Cohen, *supra* note 184.
207. *Id.*
208. *See* Steinbrook, *supra* note 195.

before their twentieth week of pregnancy.[209] The "success or failure" of the program is going to determine whether the testing will be established nationally.[210]

What about the women in other states who have physicians who are not required to offer the test? Are they not being discriminated against as far as testing is concerned? Why should they not receive information regarding the test which their California counterparts are receiving, especially when a fetus' health is at stake?

A case which is somewhat related to the issue at hand is *NAACP v. Wilmington Medical Center, Inc.*[211] The defendant in the case, Wilmington Medical Center, wanted to move the "major tertiary care components" of its inner city hospital to a nearby suburb.[212] The plaintiffs, several organizations and individuals representing the interests of minority and handicapped individuals, contended that such a move would constitute discrimination under Title VI of the Civil Rights Act of 1964 and under Section 504 of the Rehabilitation Act of 1973. The plaintiffs argued that a disproportionate impact would be felt by minorities as well as elderly and handicapped individuals of the inner city, with respect to the quality as well as the amount of health care available.[213]

The Secretary of Health, Education and Welfare found that these statutes had, in fact, been violated. As a remedy, the Secretary established a contract of assurances which called for the defendant to remove the disproportionate impact of the relocation, and thereby conform to the statutes.[214] The court held that the Secretary's decision to adopt the contract of assurances was reasonable, and thus the contract would create compliance with the statutes in question.[215] Consequently, the court found for the defendant on this latter issue.[216]

Based on this case, therefore, it would appear that if those individuals who are not capable of gaining access to the marker testing centers could prove discrimination on a statutory basis, then some form of remedy would be appropriate. Compliance with

209. *Id.* at 5.
210. *Id.*
211. 453 F. Supp. 280 (D. Del. 1978).
212. *Id.* at 285.
213. *Id.* at 284.
214. *Id.* at 330.
215. *Id.*
216. *Id.*

the statute would have to be achieved. It is important to note, however, that at the present time only two centers have been established, so that the accuracy of the testing procedure can be verified, and individuals can be monitored in proper facilities.[217] Researchers must make sure that the test is truly accurate and that all variables can be controlled before they allow widescale administration of the test. A larger number of testing centers will become available in the near future,[218] provided the sample testing goes well. Should this occur, however, equal access must be assured to all at-risk individuals. Monetary factors and state of residency must not play a role in such access. If individuals cannot afford to move to a testing center location, then government funds must be provided. Discrimination with regard to the testing must not occur at any level. If the government does not become involved, the test will basically be available only to those who are well off financially. Such a situation would be intolerable.

CONCLUSION

The G-8 marker test is truly a medical miracle. Now individuals who are at risk of inheriting Huntington's disease can determine, with a fairly high rate of accuracy, whether they actually carry the Huntington's gene and will thus become victims of the disease. This procedure, however, raises serious legal questions. Negligence cases involving testing errors, testing non-performance, and physician failure to instruct as to the possibility of inheritance by offspring, will definitely arise in the future. In addition, the test raises questions concerning infliction of emotional distress, confidentiality, employment and insurance discrimination, as well as equal access to testing centers. Although the courts will handle these cases on an individual basis, there appears to be a high rate of recovery for plaintiffs, with respect to all of these areas, in related factual situations. It must be remembered, however, that the courts have not dealt directly with Huntington's cases which have arisen as a result of the testing procedure. This is due to the fact that the test only recently became available purely for sample testing purposes. Moreover, at the present time, legal information has not been written on this subject to guide the courts. Hopefully, this Note will serve as a guide to courts, attor-

217. Chambers & Cohen, *supra* note 184.
218. FACT SHEET, *supra* note 3, at 5.

neys, or to anyone who is seeking information on the legal implications of the G-8 marker test.

CHERYL L. BECKER