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1997

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## Recommended Citation

Richard H. Underwood & Ronald C. Cadle, *Genetics, Genetic Testing, and the Specter of Discrimination: A Discussion Using Hypothetical Cases*, 85 Ky. L.J. 665 (1997).

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# Genetics, Genetic Testing, and the Specter of Discrimination: A Discussion Using Hypothetical Cases\*

BY RICHARD H. UNDERWOOD\*\*  
AND RONALD G. CADLE\*\*\*

## INTRODUCTION

Most lawyers and law teachers have a limited scientific background. They are, for the most part, pre-Copernicans. If a lawyer has any knowledge of genetics it consists of some vague memory from high school biology, having something to do with fruit flies (the pesky *drosophila*) or with brother Mendel's smooth and wrinkled peas. Still, genetic experiments have been with us since the beginning. Consider Chapters 30 and 31 of *Genesis*:<sup>1</sup>

Jacob said unto Laban [Jacob's Father-in-Law and Master], "Send me away, that I may go unto mine own place, and to my country.

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\* A version of this Article was presented during a teaching workshop at the Medical Institute for Law Faculty held June 5-14, 1996, in Cleveland, Ohio. The workshop was sponsored by the Cleveland-Marshall College of Law and the Cleveland Clinic Foundation.

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<sup>1</sup> The principal author is a Sunday school drop-out who was tipped to the story by a secondary source. See LARRY GONICK & MARK WHEELIS, THE CARTOON GUIDE TO GENETICS 9-10 (1991).

. . . [L]et me go; for thou knowest my service which I have done thee.”

And Laban said unto him . . . “tarry.

. . . Appoint me thy wages, and I will give it.”

. . . .

. . . And Jacob said . . . “if thou wilt do this thing for me, I will again feed and keep thy flock.

I will pass through all thy flock to day, removing from thence all the speckled and spotted cattle, and all the brown cattle among the sheep, and the spotted and speckled among the goats: and of such shall be my hire.

. . . [E]very one that is not speckled and spotted among the goats, and brown among the sheep, that shall be counted stolen with me.”

. . . .

. . . [In other words, Laban would get all of the solid color animals. Laban agreed to the deal because he didn't know recessive genes from blue jeans, and assumed that the solid-colored would produce solid-colored as long as there was no interbreeding.] And [in an effort to cheat Jacob once more, Laban] removed that day the he goats that were ringstraked and spotted, and all the she goats that were speckled and spotted, and everyone that had some white in it, and all the brown among the sheep, and gave them into the hand of his sons.

And he set three days' journey betwixt himself and Jacob; and Jacob fed the rest of Laban's flocks.

And Jacob took him rods of green poplar, and of the hazel and chestnut tree; and pilled white strakes in them, and made the white appear which was in the rods.

And he set the rods which he had pilled before the flocks in the gutters in the watering troughs when the flocks came to drink, that they should conceive when they came to drink.

And the flocks conceived before the rods, and brought forth cattle ringstraked, speckled and spotted.

And Jacob did separate the lambs, and set the faces of the flocks toward the ringstraked, and all the brown in the flock of Laban; and he put away his own flocks by themselves, and put them not unto Laban's cattle.

And it came to pass, whensoever the stronger cattle did conceive, that Jacob laid the rods before the eyes of the cattle in the gutters, that they might conceive among the rods.

But when the cattle were feeble, he put them not in: so the feebler were Laban's, and the stronger Jacob's.

And the man increased exceedingly, and had much cattle, and maidservants, and menservants, and camels, and asses.<sup>2</sup>

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<sup>2</sup> *Genesis* 30:25-43 (King James). God had visited Jacob in a dream, and

Now a "genetic revolution" is upon us. Techniques for genetic testing have increased in sophistication, and an international effort to map and sequence human DNA — The Human Genome Project ("HGP")<sup>3</sup> — is now well under way. We are beginning to exploit our new found genetic knowledge.<sup>4</sup> Recognition of the relationship between developments in genetic science, law, and public policy,<sup>5</sup> is creeping into the "literature"<sup>6</sup> and into the law school curriculum.<sup>7</sup> Even the popular *60 Minutes*

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had given him the idea, although Jacob had not actually understood what was going on any more than Laban had.

Martin Pernick suggests that Jacob's notion of what worked was Lamarkian, the thought being that "specific shocks during conception or pregnancy could leave recognizably similar 'marks' or 'impressions' on the offspring." MARTIN S. PERNICK, *THE BLACK STORK: EUGENICS AND THE DEATH OF "DEFECTIVE" BABIES IN AMERICAN MEDICINE AND MOTION PICTURES SINCE 1945*, 43 (1996).

<sup>3</sup> See generally Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313 (1992) (discussing the HGP and its implications).

<sup>4</sup> See Rosemary Orthmann, *Human Genome Testing Progresses; Gene Discoveries Lead to Prospect of Testing*, EMPLOYMENT TESTING — L. & POL'Y REP., Sept. 1995, at 129 (discussing discovery of genes or mutations associated with different categories of Alzheimer's disease, leukemia (ALL1 gene), breast and ovarian cancer (BRCA1 gene), kidney cancer (von Hippel-Landau or VHL gene), and ataxia telangiectasia, a rare and fatal neurological disorder in children (ATM mutated gene)). For a discussion of recent advances in screening techniques that can identify germline carriers of the disease genes for familial adenomatous polyposis ("FAP") and hereditary nonpolyposis colorectal cancer ("HNPCC"), see Susan C. Rossi & Sudhir Srivastava, *National Cancer Institute Workshop on Genetic Screening for Colorectal Cancer*, J. NAT'L CANCER INST., Mar. 20, 1996, at 331, 331-39.

<sup>5</sup> See ADVANCES IN GENETIC INFORMATION: A GUIDE FOR STATE POLICY MAKERS — EMPLOYMENT ISSUES, INSURANCE, CRIMINAL JUSTICE, HEALTH CARE, GENETIC TESTING, CIVIL LIBERTIES (2d ed. 1993). For international perspectives, see Dorothy C. Wertz, *International Perspectives on Ethics and Human Genetics*, 27 SUFFOLK U. L. REV. 1411 (1993).

<sup>6</sup> For an extensive bibliography, see L. Brett Lockwood, *Genetics and the Law*, 39 EMORY L.J. 875 (1990). In the authors' neck of the woods, the local paper ran a five-part, front-page series on the subject of genetic testing. Jim Warren, *Gene Testing: Promise or Peril?*, HERALD-LEADER (Lexington, Ky.), Dec. 26, 1995, at A1.

<sup>7</sup> See, e.g., Barry Furrow et al., *Genetic Screening and Engineering, in HEALTH LAW: CASES, MATERIALS AND PROBLEMS* 1014, 1014-33 (2d ed. 1991); GEORGE SMITH II, *BIOETHICS AND THE LAW: MEDICAL, SOCIO-LEGAL AND PHILOSOPHICAL DIRECTIONS FOR A BRAVE NEW WORLD* (1993).

television "news magazine" recently did a program on the perils of genetic testing.<sup>8</sup> Still, for lawyers and policymakers at least, the material is not all that accessible.

The following Problems were developed by the faculty of the College of Medicine of the University of Kentucky and were used in a panel presentation for medical students.<sup>9</sup> The discussion that follows each hypothetical is far from exhaustive, and is offered as a starting point. Readers desiring more information are directed to the *Selected Bibliography*.<sup>10</sup>

These Problems present a rather thorough survey of the "issues." They give the reader some notion of the state-of-the-art in genetic research and its applications; the Problems also suggest possible implications for confidentiality, tort liability for disclosure, lawsuits for "wrongful birth" and "wrongful life," and so on; and they allude to the newsworthy Americans with Disabilities Act ("ADA").<sup>11</sup> Finally, the Problems may motivate the reader to reflect on other topics, such as euthanasia and eugenics, from another perspective.<sup>12</sup>

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<sup>8</sup> *60 Minutes: Do You Really Want to Know? Pros and Cons of Genetic Testing* (CBS television broadcast, Apr. 21, 1996).

<sup>9</sup> The original Problems were assembled by Ron Cadle and were presented by Jeffrey Davidson (Ph.D. — Department of Microbiology & Immunology, University of Kentucky College of Medicine), R. Steven Brown (Director of the Centers for Health and Environment at The Council of State Governments), Jennifer Morrow (Ph.D. — University of Kentucky College of Medicine), Anjana Pettigrew (M.D. — University of Kentucky College of Medicine), and Richard Underwood (University of Kentucky College of Law). Some of the Problems were based on cases described in *ADVANCES IN GENETIC INFORMATION*, *supra* note 5, published by the Council of State Governments and compiled by R. Steven Brown. Ron Cadle is the "co-author" because the Problems were his creation. He is not responsible for the "answers."

<sup>10</sup> See *infra* pp. 695-96.

<sup>11</sup> Pub. L. No. 101-336, 104 Stat. 328 (1990) (codified at 42 U.S.C. §§ 12101-12213 (1994)). The subject of AIDS provides another obvious opportunity for examining the implications of the ADA. See, e.g., *Abbott v. Bragdon*, 912 F. Supp. 580 (D. Me. 1995) (dentist liable for discrimination under ADA for refusing to treat patient with asymptomatic HIV in office), *aff'd*, No. 96-1643, 1997 WL 85096 (1st Cir. Mar. 5, 1997); *Howe v. Hull*, 874 F. Supp. 779 (N.D. Ohio 1994) (doctor and hospital may be held liable for discrimination under the ADA for refusing to provide medical treatment to a patient infected with HIV). *But cf.* *Simenson v. Hoffman*, No. 95 C 1401, 1995 WL 631804, at \*3-4 (N.D. Ill. 1995) (individual employee physician not liable under ADA for refusing to treat child suffering from neurofibromatosis).

<sup>12</sup> For cautionary tales, Professor Underwood recommends accounts of the

## THE PROBLEMS

*Problem #1*

Jacob and Rachel go to Medical Clinic for cystic fibrosis ("CF") DNA carrier testing. No counseling accompanies the testing. Three weeks later they are told that Rachel is not a carrier, but that Jacob is a carrier. Rachel's brother recently died from complications of CF. The couple had assumed that if either were a carrier, it would have been Rachel. They are relieved because they assume that both parents have to be carriers to produce a child with CF. That assumption is based on what they heard on a television program.

Two years later Jacob and Rachel learn that their two-month-old daughter has CF. They discover that the carrier testing cannot identify all carriers. Ten to fifteen percent of carriers have one of the CF genes that currently cannot be tested for, so that a person whose test results are negative for carrier status cannot be absolutely sure that he or she is a noncarrier. The testing reduces the risk, but the risk cannot be eliminated.<sup>13</sup> Jacob and Rachel contact a lawyer and sue the Clinic for five million dollars.

*Comments*

Here we have the problem of screening without adequate information and counseling. This is common when the patient is involved in mass screening.<sup>14</sup> According to the American Society for Human Genetics

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German infatuation with eugenics set forth in Rita L. Marker et al., *Euthanasia: A Historical Overview*, 2 MD. J. CONTEMP. LEGAL ISSUES 257, 265-75 (1991); HENRY FRIEDLANDER, *THE ORIGINS OF NAZI GENOCIDE: FROM EUTHANASIA TO THE FINAL SOLUTION* (1995); and in the chilling account of the adventures of an American "pioneer" in Martin Pernick's newly-released book, PERNICK, *supra* note 2.

<sup>13</sup> Scientists have discovered that the CF gene is very long, which means that there are more places where its message can be altered by mutation. See James W. Hanson, *Impact of Advances in Genetic Technology on Health Care and Public Policy*, 3 DICK. J. ENVTL. L. & POL'Y 39, 44-45 (1994).

<sup>14</sup> Louis Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 839 (1990) (discussing a hypothetical in which an 18-year-old seeks Tay-Sachs testing in a screening sponsored by her synagogue); see also Orthmann, *supra* note 4, at 129 (discussing problems caused by the shortage of adequately trained counselors who are able to discuss the

("ASHG"), Rachel's brother's history indicates that the couple should be tested. One would ordinarily assume that the couple is entitled to full and accurate disclosure of information.

Now that things have turned out terribly wrong, the couple's lawyer will presumably argue that if they had known that there was some risk, they would have prevented a pregnancy or they would have chosen to abort any pregnancy. Was there negligence? What are the damages? The lawyer may bring a "wrongful birth" or "wrongful life" claim, or both.<sup>15</sup> If the lawyer does not suggest such claims, may he or she be sued for malpractice?

One observer states that she is:

worried that we have a generation of primary care providers who don't necessarily have a very strong background in genetics; who may have difficulty explaining the testing that's available; and may have difficulty sitting down with the family to let them know what the test results mean, and knowing what to do with that information.<sup>16</sup>

The testing laboratories can be another source of unhappy returns. Some labs do not have a very good record for accuracy.<sup>17</sup>

In any event, the ripples are about to break on an adjoining lily pad.

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accuracy and implications of testing, including the employment and insurance implications).

<sup>15</sup> For good discussions, see Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 152-61 (1992) (discussing the history and future of wrongful birth and wrongful life suits); Cheryl L. Becker, Note, *Legal Implications of the G-8 Huntington's Disease Genetic Marker*, 39 CASE W. RES. L. REV. 273, 282-88 (1988-89) (discussing specific negligence suits involving wrongful birth and wrongful life claims). For a wrongful birth suit involving CF, see *Schroeder v. Perkel*, 432 A.2d 834 (N.J. 1981). For an interesting case involving a wrongful life claim, see *Procanik ex rel. Procanik v. Cillo*, 478 A.2d 755, 758 (N.J. 1984).

<sup>16</sup> Elizabeth J. Thomson, *Ethical, Legal and Social Implications of the Human Genome Project*, 3 DICK. J. ENVTL. L. & POL'Y 55, 60 (1994) (parents asserted a malpractice claim against their former attorneys who erroneously informed them that they had no wrongful birth cause of action for their child born with birth defects).

<sup>17</sup> See, e.g., Hanson, *supra* note 13, at 49; see also *Curlender v. Bio-Science Lab.*, 165 Cal. Rptr. 477 (Cal. Ct. App. 1980) (Tay-Sachs disease — "wrongful life" claim against laboratory).

*Problem #2*

Jacob's brother Esau lives in another state. He farms and hunts. He is trained as a police officer and worked as a police officer in nearby Town for a year, but returned to full-time farming with his wife Mahalath. Much of the family income goes to pay for life and health insurance. Esau's insurer learns about the CF status of Jacob's daughter from a "national database." The insurer informs Esau that he and his wife must have carrier testing, at the insurer's expense, or have their coverage terminated. At first the couple is irritated by the insurer's demand, but they decide that testing might set their minds at ease. However, testing reveals that they are both carriers. The insurer then notifies them that their coverage is terminated because of this "pre-existing condition" that had not been reported to the insurer at the time the policy was issued. Esau contacts a lawyer to see if he has any grounds for a lawsuit against the insurer. The lawyer says there is a "strong case" and agrees to pursue it on a contingency fee basis.

*Comments*

The problem is that with genetic tests, you learn something about people [who] are not present. If I do a test on someone in this room, I may discover that they have a genetic condition, but this implies that probably one or both their parents have that same condition or genetic factor [and] that their brothers are at a high risk for that same condition or genetic factor as well as their offspring.<sup>18</sup>

Esau and his wife have private life and health insurance, and their insurer has obtained genetic information from the Medical Information Bureau ("MIB")<sup>19</sup> or a similar outfit indicating that this couple might have a CF child some time in the future. One commentator, Carol Lee,

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<sup>18</sup> Hanson, *supra* note 13, at 51; *see also* Sonia M. Suter, Note, *Whose Genes Are These Anyway?: Familial Conflicts over Access to Genetic Information*, 91 MICH. L. REV. 1854, 1864-69 (1993) (remarking that one person's test results will have an effect on other family members, and providing four hypotheticals illustrating conflicting interests).

<sup>19</sup> "The MIB is an unincorporated trade association whose several hundred members are the largest insurance companies in North America." T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification?*, 60 DEF. COUNS. J. 249, 259 (1993). The MIB maintains a databank of information about insureds that is used by the member companies for risk classification. *Id.*



claims that the MIB “currently does not carry genetic information” and that insurers may not have any incentive to test as long as no other insurers test;<sup>20</sup> but other commentators allude to case studies that suggest that insurers will react on an opportunity basis when they receive information about a specific individual.<sup>21</sup> Here we have actual disease in other family members that may have generated claims.<sup>22</sup> The insurer insists on testing — the alternative is policy cancellation. When the couple receive the bad test results, the company terminates them based on the “pre-existing condition.”

One assumes that the terminated policy is health insurance. It seems unlikely that a life insurer would try to justify termination, even during the contestable period, since there was no misrepresentation. In some states a life insurer might try to rely on a “good-health” clause, but in most states that approach would be a loser — the life insured is not affected by the disease, and, in states that apply a subjective standard, the insured did not know of the condition when the policy was issued.

One also assumes that this is private health insurance, not insurance provided by a self-insured employer. If this is the case, the insurance

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<sup>20</sup> Carol Lee, *Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry*, 13 PACE L. REV. 189, 209 (1993).

<sup>21</sup> Orthmann, *supra* note 4, at 132. The American Society of Human Genetics (“ASHG”) Ad Hoc Committee on Insurance Issues in Genetic Testing states that “insurance companies do make decisions based on genetic information and preexisting conditions, even if they do not require genetic testing of insurance applicants,” and that this could “affect the willingness of individuals to be tested and to obtain timely treatment.” *Id.* Orthmann also mentions the Task Force on Genetic Information and Insurance, appointed by the Working Group on Ethical, Legal and Social Issues (“ELSI”) (funded by the National Institutes of Health and the U.S. Department of Energy), which opines that it is “practically impossible and morally indefensible to distinguish genetic from nongenetic disease risk” and that “risk underwriting should not determine access to health care.” *Id.* The ABA has also formed a Task Force on the Law of Reproductive and Genetic Technology. See *ABA Unit to Study Genetic Technology*, N.Y. L.J., Aug. 2, 1990, at 3.

<sup>22</sup> For a discussion of the claims process as a source of genetic information, see Dee Lord, *Something in the Genes: EEOC Takes Steps to Forestall Discrimination for Predisposition to Illness*, A.B.A. J., Apr. 1996, at 86; Mark A. Rothstein, *Genetic Testing, Jobs, and Insurance; What Public Policy Issues Should Reformers Consider?*, EMPLOYMENT TESTING — L. & POL’Y REP., Feb. 1995, at 17, 19-22 [hereinafter Rothstein, *Genetic Testing*].

carrier will be regulated under state law which may restrict what the insurance carrier can and cannot do.

What might state legislators do about the use of genetic tests by insurance companies? A state might: ban, or place a moratorium on, genetic testing for insurance purposes; permit only certain validated (highly predictive) tests to be used; recognize privacy rights of the person tested in order to keep information out of the hands of insurers; ban the use of genetic information in insurance determinations, or greatly limit the use of such information; or, alternatively, expressly permit insurers to develop and use genetic information. At the present time, insurers probably have little or no incentive to get into testing — so long as other insurers are not into it. On the other hand, there are plenty of articles announcing that the sky is falling.<sup>23</sup>

A handful of states have passed some type of genetic testing law.<sup>24</sup> The authors' home state of Kentucky has not addressed genetic testing and discrimination directly, but the legislature has adopted insurance reforms which are intended to make insurance available to persons with pre-existing conditions.<sup>25</sup> Pressure is building for the modification or repeal of much of this reform legislation now that folks have assessed the cost and determined who is going to pay the bill.<sup>26</sup> National health care would presumably "solve" much of the problem. There have also been some proposals for federal legislation on genetic information.<sup>27</sup> One suspects that the public will become more sensitive to "genetic discrimi-

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<sup>23</sup> For some of these articles, see the *Selected Bibliography, infra* at pp. 695-96.

<sup>24</sup> CAL. HEALTH & SAFETY CODE § 1374.7 (West Supp. 1996); MINN. STAT. ANN. § 72A.139 (West Supp. 1996); N.H. REV. STAT. ANN. §§ 141-H:1 to H:6 (1996); OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50 (Anderson Supp. 1995); OR. REV. STAT. § 746.135(3) (1995); VA. CODE ANN. § 38.2-508.4 (Michie Supp. 1996); WIS. STAT. ANN. § 631.89 (West 1995).

<sup>25</sup> See KY. REV. STAT. ANN. § 304.17A-110 (1996) (prohibiting denial of coverage based on pre-existing condition).

<sup>26</sup> See, e.g., Robert T. Garrett, *All Aboard Insurance "Reform" Special*, COURIER-JOURNAL (Louisville, Ky.), Mar. 2, 1997, at D1 (detailing testimony of Kentucky Insurance Commissioner George Nichols III before the Kentucky legislature). The legislature has already repealed key provisions of the 1994 insurance reforms that required "community rating" and now allows eligible insurers to employ "experiencrating." See KY. REV. STAT. ANN. § 304.18-050 (1996).

<sup>27</sup> See, e.g., The Health Security Act, S. 2357, introduced by then-Senate Majority Leader George Mitchell (D-Maine) on Aug. 4, 1994.

nation” when more is learned about the genetic contributions to more common ailments, such as cancer and heart disease, that affect greater numbers of the body politic.<sup>28</sup>

### *Problem #3*

Esau decides to reapply for a job with the local police force. While Town will not provide life and health insurance because of Esau’s genetic make-up, the salary is attractive.

When Esau’s physician, Dr. Luke, learns that Esau will be taking the job, he is concerned. When Esau and his wife had blood drawn for the CF testing, the laboratory misread the request and performed a “genetic screen” — a series of tests for the presence of several deleterious genes in addition to the CF genes. Esau learned that he has the Huntington’s disease (“HD”) gene. Dr. Luke provided thorough counseling to Esau on the implications of the test results, but Esau insisted that Dr. Luke not inform Mahalath of the results. Now, Dr. Luke not only believes that Esau’s wife should be informed of the result, but also believes that for reasons of public safety the Chief of Police should also be informed. Dr. Luke keeps trying to persuade Esau to disclose, but by the time he gets through to Esau, Esau learns that his wife is pregnant. Esau becomes suicidal.

### *Comments*

How did the Town authorities find out about the applicant’s CF carrier status? Perhaps they heard it through the “grapevine.”<sup>29</sup> In any

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<sup>28</sup> As an aside, let us note that CF has been held to be a “disability” under the ADA. Employment discrimination comes into the picture in Problem #3. However, as the discussion of that Problem indicates, section 501(c)(1) of the ADA allows insurers to continue current underwriting practices. This means that in the absence of contrary state law, insurers can exclude pre-existing conditions, limit coverage, or increase premium charges for certain conditions. *Emery v. Caravan of Dreams, Inc.*, 879 F. Supp. 640, 642-43 (N.D. Tex. 1995) (stating that plaintiff who has CF is “a person with a disability” as defined under the ADA).

<sup>29</sup> See Lord, *supra* note 22, at 86 (employers may receive information through the voluntary disclosures of an employee, an “examination required by the employer, in the course of processing insurance claims or through ‘the grapevine’”).

event, this problem provides us with an opportunity to review the possible application of the ADA.

The first thing we might ask is whether the ADA permits the employer Town to deny Esau life and health insurance based on his "genetic make-up." The legislative history of the ADA states that an employer "may not deny health insurance coverage completely to an individual based on the person's diagnosis or disability."<sup>30</sup> So long as health insurance is made available to other employees, it must be offered to Esau. But, it has been argued that the employer may be able to discriminate against certain *disabilities*,<sup>31</sup> as opposed to *individuals* with disabilities, by excluding or restricting coverage for medical services associated with a particular disability.<sup>32</sup> For example, the employer's plan could exclude from coverage any treatment for HD.<sup>33</sup> Apparently the Problem assumes that the Town is denying Esau any life and health insurance because of his (and his wife's) CF carrier status,<sup>34</sup> either because the employer believes, erroneously, that they are at risk of developing the disease, or because the employer does not want to cover a CF affected child the couple might have in the future. This may be a violation of the ADA.<sup>35</sup>

Unless the employer is self-insured (in which case the Employee Retirement Income Act ("ERISA")<sup>36</sup> preempts state law<sup>37</sup>), state law

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<sup>30</sup> SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES, THE AMERICANS WITH DISABILITIES ACT OF 1989, S. REP. NO. 101-116, at 29 (1989).

<sup>31</sup> *But see* Lord, *supra* note 22, at 86 ("The agency [EEOC] has not indicated whether an illness resulting from a genetic predisposition may be excluded from insurance coverage as a pre-existing condition.").

<sup>32</sup> *See* Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 79-80, 82 (1992) [hereinafter Rothstein, *Genetic Discrimination in Employment*]. Rothstein says that the employer's plan could exclude or restrict coverage for dialysis, so long as an otherwise qualified employee with adult polycyclic kidney disease is given the same health insurance that every other employee gets.

<sup>33</sup> *Id.* at 82. But what does "treatment for HD" mean?

<sup>34</sup> CF has been held to be a disability under the ADA. *Emery v. Caravan of Dreams, Inc.*, 879 F. Supp. 640, 642-43 (N.D. Tex. 1995) (stating that plaintiff, who has CF, is "a person with a disability" as defined under ADA section 3 (42 U.S.C. § 12102(2) (1994))).

<sup>35</sup> *See* *Anderson v. Gus Mayer Boston Store of Del.*, 924 F. Supp. 763, 773-78 (E.D. Tex. 1996) (discussing EEOC Guidelines in this context).

<sup>36</sup> Pub. L. No. 93-406, 88 Stat. 829 (1974).

<sup>37</sup> *See, e.g., FMC Corp. v. Holliday*, 498 U.S. 52, 61 (1990) (interpreting

might mandate that certain coverages be provided for certain disorders. At this point in our discussions, there is little point in dwelling on this possibility, which has already been discussed under Problem 2.

Will an unaffected carrier of a recessive disorder, or an X-linked disorder, be covered under the ADA if he is discriminated against because he and his spouse are at risk of producing a CF offspring? Discrimination includes "excluding or otherwise denying equal *jobs* or *benefits* to a qualified individual because of the known disability of an individual with whom the qualified individual *is known to have* a relationship or association."<sup>38</sup> One assumes that the words "relationship" and "association" mean existing and not future "relationships" and "associations." Esau and his wife do not have a CF child yet.

The ADA itself is silent when it comes to genetics; but at the time that the ADA was passed, Representative Henry Waxman (D-California) argued that:

an employer [cannot] discriminate against a carrier of a disease-associated gene because such individual may be at higher risk of having a child with a genetic disease, whose care would increase costs for the parent's employer. . . . If the possibility of such increased costs were allowed to justify discrimination in employment, a huge loophole would be created in the protections of the ADA.<sup>39</sup>

"Legislative history" like this tends to take on a life of its own.

Again, one concludes that the employer will have to offer Esau the insurance that it offers its other employees; but the employer may be able to exclude coverage for dependents, and may be able to exclude or cap coverage for certain treatments or services associated with CF.<sup>40</sup>

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ERISA's savings clause (ERISA § 514(a), 29 U.S.C. § 1144(a) (1994)) and deemer clause (ERISA § 514(b)(2)(B), 29 U.S.C. § 1144(b)(2)(B) (1994)) as exempting self-funded plans from state regulation).

<sup>38</sup> 42 U.S.C. § 12112(b)(4) (1994) (emphasis added); see Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 47-50 (discussing three theories related to discrimination of employees who may have affected offspring); Arpiar Saunders, Jr. & Bennett B. Mortell, *Genetic Testing — Genetic Discrimination: State and Federal Statutes Provide Possible Remedies*, N.H. B.J., Dec. 1995, at 23, 30 (discussing unaffected carriers of recessive and X-linked disorders).

<sup>39</sup> 136 CONG. REC. H4614, H4627 (1990).

<sup>40</sup> See Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 82 ("An employee for a self-insured company who had a child with . . . cystic fibrosis could suddenly lose all dependent coverage."). Again, the reader is

For the sake of discussing the ADA, let's address another question that the Problem skirts. The Problem assumes that Town is willing to hire Esau. Would Esau be covered by the ADA if Town refused to hire him because of his CF carrier status? A not altogether intuitive argument for the application of the ADA would be that Esau, in fact, suffers a current impairment because of a substantial limitation of a major life activity — procreation. This would mean that he is “a person with a disability” under the ADA.<sup>41</sup>

Others have argued that Esau also should be covered under another of the ADA's definitions of “disability” — that the employer “regards him as disabled,” even though he is not.<sup>42</sup> In 1995, the EEOC was finally lobbied into accepting this position, and the agency has incorporated this interpretation of the statute into a new *Compliance Manual*.<sup>43</sup>

The EEOC takes the position that people who are excluded from employment because of perceived future health care risks are “regarded as” disabled.<sup>44</sup> This would apply to perceived genetic predispositions. The new *Compliance Manual* provides the following example:

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directed to *Anderson*, 924 F. Supp. at 780 (Under Section 501(c) of the ADA, “it may be possible to provide certain coverage exclusions to individuals with disabilities if the risks of those disabilities so warrant and those risks are treated like other similar risks not associated with disabilities.”).

<sup>41</sup> 42 U.S.C. § 12102(2)(A) (defining disability as “a physical or mental impairment that substantially limits one or more of the major life activities of such individual”); see *Abbot v. Bragdon*, 912 F. Supp. 580, 585-86 (D. Me. 1995) (court concluded that HIV substantially limits the “major life activity” of reproduction), *aff'd*, No. 96-1643, 1997 WL 85096 (1st Cir. Mar. 5, 1997); see also Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 49 (arguing that an unaffected carrier of an X-linked disorder may be a person with a disability under the ADA since the person would have a “current impairment because of a substantial limitation of the major life activity of procreation”); Saunders & Mortell, *supra* note 38, at 28 (discussing the theory that an unaffected carrier may qualify under the definition of disability due to a substantial limitation on the ability to procreate).

<sup>42</sup> 42 U.S.C. § 12102(2)(c) (expanding the definition of disability to include an individual who is “being regarded as having such an impairment”); see Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 47-50 (discussing the theory that an unaffected carrier may qualify under the definition of disability due to a substantial limitation on the ability to procreate).

<sup>43</sup> See Lord, *supra* note 22, at 86; Orthmann, *supra* note 4, at 133.

<sup>44</sup> Saunders & Mortell, *supra* note 38, at 28.

[The charging party's] genetic profile reveals an increased susceptibility to colon cancer. [The charging party] is currently asymptomatic and may never in fact develop colon cancer. After making [ ] a conditional offer of employment, [the employer] learns about [the charging party's] increased susceptibility to colon cancer. [The employer] then withdraws the job offer because of concerns about matters such as [the charging party's] productivity, insurance costs, and attendance. [The employer] is treating the [charging party] as having an impairment that substantially limits a major life activity. Accordingly, [the charging party] is covered by the third part of the definition of "disability."<sup>45</sup>

The EEOC view may not be accepted by some courts.<sup>46</sup> But a few commentators argue that the case of *Cook v. Rhode Island Department of Mental Health, Retardation, and Hospitals*<sup>47</sup> can be cited in this context to protect persons with asymptomatic genetic conditions who might be discriminated against because of an employer's fear of future health care risks and costs.<sup>48</sup> Two commentators cite the following case history as involving violations of the ADA and New Hampshire law:

[A]n asymptomatic 53 year old . . . was diagnosed with hemochromatosis and was undergoing phlebotomy treatments at three month intervals. He was accepted into an insurance agent training program. During [an] interview he disclosed that he was being treated for hemochromatosis and when asked submitted his latest medical records. A manager of the

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<sup>45</sup> EEOC Compl. Man. (BNA) § 902.8(a) (1995).

<sup>46</sup> See Robert L. Duston, *Courts Will Scrutinize EEOC's Definition of Disability*, EMPLOYMENT TESTING — L. & POL'Y REP., July 1995, at 97, 101-02 ("Based on the trend in the courts . . . to place reasonable limits on the ADA, it appears likely that the courts will give several aspects of the EEOC's guidelines close scrutiny."); Gary Taylor, *Texas ADA Caseload Puts 5th Circuit in Major Role: Plaintiffs, EEOC Are Likely to Suffer Setbacks From Court That Continues to Define Disability Narrowly, Lawyers Say*, NAT'L L.J., Dec. 4, 1995, at B1 (The EEOC's field offices in Texas lead the nation in complaints; therefore, there is a high probability that the Fifth Circuit will be the first federal court of appeals to hear these cases; based on past decisions, "the 5th Circuit will fashion the ADA in ways favorable to employers.").

<sup>47</sup> *Cook v. Rhode Island Dep't of Mental Health, Retardation, and Hosps.*, 10 F.3d 17 (1st Cir. 1993) (holding employer liable under the Rehabilitation Act for refusing to hire a woman who, although "morbidly obese," passed a physical examination).

<sup>48</sup> Saunders & Mortell, *supra* note 38, at 28.

company told him his illness may prevent the company from offering him health insurance benefits. However, he was permitted to enter the training program. After six weeks, he was told that he would not be hired because of his diagnosis of hemochromatosis.<sup>49</sup>

Section 102(d) of the ADA makes illegal all pre-employment medical examinations and medical inquiries.<sup>50</sup> Job applicants may not be asked about their past, current, or future genetic conditions, the health histories of family members, or the genetic health conditions of their associates. But under section 102(d)(3) the employer can require examinations of conditional job offerees as long as: (1) all conditional offerees in the same job category are subject to examination, and (2) the information generated is collected and maintained in separate medical files and treated as confidential, with exceptions for managers receiving some information relevant to necessary restrictions or accommodations, and for safety personnel receiving some information pertinent to possible emergency treatment.<sup>51</sup>

The ADA also permits the employer to require a conditional offeree to sign a blanket release authorizing the offeree's health care provider to give the company all requested medical records.<sup>52</sup> Oddly enough, the EEOC interpreted the ADA to allow examinations of conditional offerees and releases of information to the company to extend to matters that are *not job related*, although the use of such information for discriminatory purposes is prohibited by the law.<sup>53</sup> This interpretation invites and facilitates prohibited discrimination.

Under current law, conditional offerees have no right to know what medical tests are being performed (e.g., the specific tests being run on a blood sample), the results of genetic and other medical tests, or why a conditional offer of employment was withdrawn. Because this information is only discoverable, if at all, after the filing of a discrimination claim, it facilitates surreptitious testing and discriminatory reliance upon non-job-related criteria in decisionmaking.<sup>54</sup>

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<sup>49</sup> *Id.* (citing Joseph S. Alper et al., *Genetic Discrimination and Screening for Hemochromatosis*, 15 J. PUB. HEALTH POL'Y 345, 350 (1994)).

<sup>50</sup> 42 U.S.C. § 12112(d)(2).

<sup>51</sup> *Id.* § 12112(d)(3).

<sup>52</sup> *Id.*

<sup>53</sup> EEOC Interim Enforcement Guide, available in Westlaw, EEOC-F-106.

<sup>54</sup> Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 58; see also Saunders & Mortell, *supra* note 38, at 30 (describing "a major loophole



The new EEOC position seems to acknowledge that some employers might act improperly on information obtained from conditional offerees. The EEOC *Compliance Manual* gives an example in which a conditional offeree's genetic profile reveals an increased risk of colon cancer, whereupon the employer withdraws the job offer. The EEOC notes that the employer has violated the ADA by the way it used this information.<sup>55</sup>

A state law, or a state ADA as interpreted by a state agency, may provide more protection than the federal ADA and prohibit non-job-related testing of conditional offerees. For example, New Hampshire's genetic testing law<sup>56</sup> does not allow genetic tests to be part of any medical entrance exam given to a conditional offeree.<sup>57</sup>

The fact that an applicant is hired does not mean he or she will suffer no adverse consequences. Section 501(c)(3) of the ADA gives a self-insured employer (covered by ERISA, so that state insurance regulation is preempted<sup>58</sup>) great leeway in classifying risks and structuring coverage.<sup>59</sup> Furthermore, actuarially-based discrimination, as opposed to

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in the ADA"). According to a recent article in the *California Lawyer*, "[m]any employers in California today have genetic testing data on their employees without [the employees'] knowledge." Vince Bielski, *Your Boss Wants More Than Your Blood: Genetic Testing Comes to the Workplace*, CAL. LAW., Nov. 1996, at 18. The article also alludes to a recent case in which employee "privacy" claims under the ADA were held time-barred. *Id.* (citing *Norman-Bloodsaw v. Lawrence Berkeley Nat'l Lab.*, No. C-95-3220 (N.D. Cal. Sept. 12, 1995)).

<sup>55</sup> See Saunders & Mortell, *supra* note 38, at 28 (noting that the EEOC classifies those denied employment because of "future health care risks" as disabled under the ADA); see also Jeff Barge, *Job Interview Can Bring ADA Liability: Revised EEOC Guidelines Help Employers Avoid Improper Disability Question*, A.B.A. J., Mar. 1996, at 34 (reviewing the EEOC's guidelines for employers that outline appropriate questioning regarding medical conditions during the interview process); Lord, *supra* note 22, at 86 (discussing the EEOC's 1995 categorization of genetic susceptibility to disease as a disability under the ADA).

<sup>56</sup> N.H. REV. STAT. ANN. § 141-H (1995).

<sup>57</sup> Saunders & Mortell, *supra* note 38, at 30 (citing N.H. REV. STAT. ANN. § 141-H:3(I)(a) (1995)).

<sup>58</sup> See *supra* note 37.

<sup>59</sup> 42 U.S.C. § 12201(c)(3) (1994) (The ADA should not be construed to prohibit "a person or organization . . . from establishing, sponsoring, observing, or administering the terms of a bona fide benefit plan that is not subject to state laws that regulate insurance.").

arbitrary or invidious discrimination, is permitted.<sup>60</sup> Up to this point, most commentators have assumed that an employer and an insurer can continue to exclude pre-existing conditions, exclude coverage for certain conditions, charge higher premiums for high risk individuals, impose low maximum caps on payments for particular treatments, and exclude dependents.<sup>61</sup> In other words, information obtained from genetic screening or non-job-related medical tests might be used to modify the employer's self-funded benefits plan, even though the information is not used to deny employment or withdraw an offer of employment.<sup>62</sup> Suggested solutions to this problem include making private group health insurance "available," or going to a regime of "universal" national health insurance.

Now let's look at Dr. Luke's dilemma. The lab performed tests that were not ordered. Is that actionable negligence? There was no consent to be "screened." Dr. Luke got the word from the lab that Esau has the HD gene. Can Dr. Luke tell Mahalath? Should Dr. Luke tell her? Can or should he tell the Chief of Police?

Let's think about this from Esau's perspective. He never asked for the test or the information. While some people may be relieved to know that they do not have the HD gene, others will be losers.

"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, executioner."<sup>63</sup>

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<sup>60</sup> Again, the reader is directed to *Anderson v. Gus Mayer Boston Store of Del.*, 924 F. Supp. 763, 779-80 (E.D. Tex. 1996). In that case, the employer switched to a new group health insurer that denied any and all coverage to individuals with AIDS. This meant that Anderson, an employee afflicted with AIDS, was denied all health insurance, while health insurance was provided to other employees.

<sup>61</sup> See *infra* Problems 4 & 7.

<sup>62</sup> Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 81-83 (explaining that using genetic screening this way is analogous to currently legal methods of limiting health care costs); see also Rothstein, *Genetic Testing*, *supra* note 22, at 19-20 (discussing employer incentives to use genetic testing to screen for heavy users of health care).

<sup>63</sup> Becker, *supra* note 15, at 281 (quoting Conneally P. Wexler & J. Gusella, *A DNA Polymorphism for Huntington's Disease Marks the Future*, 42 ARCHIVES OF NEUROLOGY 20, 22 (1985)); see also Orthmann, *supra* note 4, at 131:

Suicide is, in fact, a risk associated with knowledge.<sup>64</sup> Can a physician ever justify non-disclosure for the patient's benefit? Can a physician justify disclosure to a spouse so that the spouse can help in suicide prevention? Strangely enough, there is also some evidence that winners can be adversely affected too. In some Huntington's disease families, persons who have found out that they do not have the Huntington's mutation have suffered "significant psychological upset."<sup>65</sup>

The next issue is whether Dr. Luke should disclose Edau's condition to Mahalath.<sup>66</sup> A health care provider can be sued on a variety of theories for violating confidentiality — for disclosing information to third parties without the patient's consent.<sup>67</sup> These cases usually involve

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A positive test for Huntington's disease . . . predicts that the test subject will ultimately die of the disease, even if that person has no symptoms at the time of the testing. In the case of breast cancer, however, carriers of the BRCA1 gene have an 85 percent chance of contracting cancer in their lifetime, a risk greater than in the general population but not an inevitability. . . . Because a positive test for Huntington's disease is essentially a death sentence, individuals may understandably choose not to know whether they carry the gene. With the breast cancer gene, by contrast, the test indicates only a predisposition for the disease, individuals can take preventative measures, and chances of a cure are relatively good.

*Id.* Still, many carriers of the BRCA1 gene "do not want to know." See *Many Don't Want to Hear Cancer Gene Test Results*, HERALD-LEADER (Lexington, Ky.), June 26, 1996, at A3 (explaining a study that showed less than half of the people with a family history of breast or ovarian cancer wanted to know if they carried a gene linked to disease).

<sup>64</sup> Becker, *supra* note 15, at 282 (noting Huntington's disease victims commit suicide at a higher rate than the population as a whole and those testing positive for this gene will require "psychological support").

<sup>65</sup> Thomson, *supra* note 16, at 61-62 (using, for an example, a man in his thirties who, thinking he has the disease, has lived his life "for today" only to suddenly discover a long life ahead of him for which he has not planned).

<sup>66</sup> The arguments for and against disclosure are discussed by Andrews, *supra* note 15, at 177-82, and Becker, *supra* note 15, at 295-98. For a somewhat dated videotape that presents disclosure issues in the context of HD, see *MANAGING OUR MEDICAL MIRACLES: TRUTH OR CONSEQUENCES* (Columbia University) (on file with University of Kentucky College of Law Library).

<sup>67</sup> For a comprehensive article on the physician-patient privilege, see Steve Smith, *Medical and Psychotherapy Privileges and Confidentiality: On Giving with One Hand and Removing with the Other*, 75 KY. L.J. 473 (1986-87) (discussing exceptions that limit apparently strong protections afforded medical

disclosures to employers.<sup>68</sup> However, in one case, *MacDonald v. Klinger*,<sup>69</sup> the court ruled that a psychiatrist could be liable to a patient for disclosing "intimate facts" to the patient's wife.<sup>70</sup> This case has been cited as having some possible application to the disclosure of genetic marker information to a spouse. In our hypothetical, Esau's wife is not at risk of contracting any disease, as she would be in the case of HIV or some other communicable disease, but she has a claim to the information because of the financial and child-bearing implications. So too would a child have a need and right to know that a parent tested positive for the marker.<sup>71</sup> In the case of Huntington's disease, the case for disclosure to siblings may not be as persuasive,<sup>72</sup> but most would agree that, at some point at least, Dr. Luke should disclose to Esau's wife, if Esau will not. In any event, Dr. Luke did not have any time to disclose to Esau's wife.<sup>73</sup>

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treatment confidentiality).

<sup>68</sup> See, e.g., *Horne v. Patton*, 287 So. 2d 824, 825 (Ala. 1973) (finding doctor in breach of implied contract of confidentiality because he disclosed a patient's medical information to the patient's employer).

<sup>69</sup> *MacDonald v. Klinger*, 446 N.Y.S.2d 801 (N.Y. App. Div. 1982).

<sup>70</sup> *Id.* at 805 (finding that, compared to the standard for the release of general medical information to a spouse, a more stringent standard applies regarding release of psychiatric information).

<sup>71</sup> See *Pate v. Threlkel*, 640 So. 2d 278 (Fla. 1995) (holding that lack of privity did not bar a suit by a patient's child against a physician for failure to warn patient regarding genetically transferable nature of patient's condition (medullary thyroid carcinoma); and holding that if, on remand, the court found a duty to warn, the duty would be discharged by a warning to the patient rather than to the children). *But see Chizmar v. Mackie*, 896 P.2d 196, 207-08 (Alaska 1995) (In an AIDS disclosure case, the court found *MacDonald's* recognition of a cause of action for breach of confidentiality to be persuasive. However, the court created an exception to *MacDonald*: "[W]hen a physician diagnoses a patient with a fatal, sexually transmitted disease such as AIDS, the physician's disclosure of this diagnosis to the patient's spouse is privileged as a matter of law."); *Andrews, supra* note 15, at 178-79 (opining that since genetic defects do not present the same dangers as infectious diseases or violent behavior, there are less compelling reasons to violate the duty of confidentiality regarding genetic information).

<sup>72</sup> See *Andrews, supra* note 15, at 180-83 (pointing out that some relatives may not want to know they might have a serious, incurable disease at an unknown point in the future); *Becker, supra* note 15, at 298 (stating a line should be drawn at parent-child and spousal relationships for disclosure and not extended to siblings).

<sup>73</sup> For an interesting discussion of the difficulties of bringing "wrongful birth" and "wrongful life" claims in the context of genetic disease, see *Becker*,

Is there a duty to tell the Chief in order to protect the public? In some circumstances non-disclosure may result in liability if the harm that could have been prevented is serious enough.<sup>74</sup> The President's Commission 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 information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.<sup>75</sup>

The authors' reaction is that for now, disclosure to Town should not be made. The risks do not seem imminent. On the other hand, a real and substantial risk to third persons may develop at some point. Personality changes, depression, and schizophrenic-like symptoms may appear before physical symptoms appear.<sup>76</sup>

Assuming that he is on the job, is Esau protected from discharge if the Chief finds out? If he tells the Chief, can he be fired? One commentator, Cheryl L. Becker, reports that an employer will terminate an employee who is known to have Huntington's disease.<sup>77</sup> She argues that

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*supra* note 15, at 784-88.

<sup>74</sup> For a good discussion, see Alexander Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 618, 636 (1979) (discussing liability for economic injuries caused to the parent of a child born with an undisclosed genetic disorder). See also *Current Opinions of the AMA, Principles of Medical Ethics*, reprinted in CODES OF PROFESSIONAL RESPONSIBILITY 106 (Reno Gorlin ed., 3d ed. 1994) (requiring physicians conducting genetic testing to provide information adequate for parents to make informed decisions). For an extended discussion of disclosure law, with hypotheticals, see Suter, *supra* note 18, at 1854 (analyzing genetic testing and non-consenting disclosure among family members).

<sup>75</sup> THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 44 (1983).

<sup>76</sup> See Becker, *supra* note 15, at 277-78 (discussing clinical manifestations of Huntington's disease).

<sup>77</sup> *Id.* at 300 (noting that broad legal latitude is traditionally given private employers in discharging employees).

this is unfair when symptoms have not manifested and may not manifest for some time, but she acknowledges that once symptoms begin to appear, "the 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."<sup>78</sup> In our scenario, the person afflicted with the disorder is packing a gun.

Professor Rothstein argues that an individual who carries an unexpressed late-onset genetic disease like Huntington's should be treated as a disabled person under the ADA (and under section 504 of the Rehabilitation Act<sup>79</sup>), either as one who is impaired or as one who is regarded as being impaired.<sup>80</sup> He points out that an asymptomatic HIV-positive individual would be covered. In any event, once the disease is expressed there will be coverage under the ADA, and we must then turn to section 103(b) of the ADA, which allows for exclusion of an individual who poses a "direct threat" to himself or others in the workplace.<sup>81</sup> But Rothstein argues that "[a]n employer should not be able to exclude an individual on the ground that his or her genotype indicates that he or she will become disabled at some point in the future."<sup>82</sup>

#### GENETIC DISCRIMINATION — INSURANCE

##### *Problem #4*

A six year old boy is referred for a neurologic evaluation because of a seizure. The examining physician notes that the boy has multiple cafe-au-lait spots, two small subcutaneous neurofibromas, axillary freckling, mild scoliosis, and Lisch nodules. A diagnosis of neurofibromatosis is made. The family is referred for genetic counselling and learns that the boy's father has multiple cafe-au-lait spots and one possible neurofibroma. The father has always been in good health, and has always thought that the brown spots were "just birth marks." He, too, has neurofibroma-

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<sup>78</sup> *Id.* at 301.

<sup>79</sup> Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (1973) (codified as amended at 29 U.S.C. § 794 (1988 & Supp. III 1991)).

<sup>80</sup> Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 43-45 (citing the legislative history of the ADA and other disability law precedents).

<sup>81</sup> 42 U.S.C. § 12113(a) (establishing as a defense to a charge of discrimination that disqualification was "job-related and consistent with business necessity").

<sup>82</sup> Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 73.

tosis. The family's private health insurer subsequently drops the family because of a "pre-existing condition."

### Comments

Until recently, insurers were not thought to be charitable institutions. Historically, we have allowed them to conduct some degree of health-related screening through medical questionnaires and some lab testing so that they might classify risks — only "invidious" discrimination was considered improper.<sup>83</sup> The movement to regulate the use of genetic information began when some states began to forbid denial of insurance to persons carrying the sickle cell trait or the Tay-Sachs trait.<sup>84</sup> Then, a few states decided to forbid denials to persons infected with the HIV virus, or to persons having AIDS.<sup>85</sup>

In 1992, Wisconsin banned the use of genetic testing in insurance, and there have been similar developments in a few other states.<sup>86</sup> A case can be made that insurers are not hurt by such bans, since all are similarly affected. The competitive status quo is not threatened. Until recently, some thought that the problem would be mooted with the enactment of National Health Insurance or Mandated Employer Funded

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<sup>83</sup> The writing of articles on "discrimination" in insurance, particularly "genetic discrimination," is becoming a growth industry. Some of the best surveys are listed in the *Selected Bibliography, infra* pp. 695-96.

<sup>84</sup> See, e.g., ALA. CODE § 27-5-13 (1982) (covering sickle cell anemia); MD. CODE ANN., INSURANCE § 223(a)(3) (Supp. 1996) (covering sickle cell anemia, Tay-Sachs, and other genetic disorders).

<sup>85</sup> See KY. REV. STAT. ANN. § 304.12-013(5) (Michie 1996). Kentucky requires that the insurer "shall not exclude coverage for [HIV] . . . . [The] insurance contract shall not be canceled or nonrenewed solely because [of an HIV diagnosis] . . . . Sexual orientation shall not be used in the underwriting process . . . ." *Id.* Other states have chosen to regulate the insurer's use of HIV information and to protect the applicant's confidentiality. See, e.g., ARIZ. REV. STAT. ANN. § 20-448.01 (West Supp. 1996); CAL. INS. CODE §§ 799-799.09 (West 1993 & Supp. 1996).

<sup>86</sup> See *supra* note 24. For recent federal legislation on genetic information, portability, and pre-existing conditions, see Health Insurance and Portability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of 29 U.S.C., 42 U.S.C., 26 U.S.C., and 18 U.S.C.). This law provides that "genetic information shall not be treated as a [preexisting] condition . . . in the absence of a diagnosis of the condition related to such information." *Id.* (29 U.S.C. § 1181(b)(1)(B) (1996)).

Health Insurance, and elimination of the ERISA exemption for self-insurers.<sup>87</sup>

### *Problem #5*

A woman who is affected with adult onset polycystic kidney disease becomes pregnant. She decides that she wants to know whether her unborn baby has received the gene for this dominantly-inherited disorder, and pursues amniocentesis. The woman's HMO considers the request to pay for this amniocentesis and states, "We will pay for the prenatal diagnostic procedure ONLY if you agree to terminate the pregnancy in the event that it shows your fetus to have the gene for adult onset polycystic kidney disease. Furthermore, if you choose to have a baby with this gene, we will not provide him/her with medical insurance of any kind."

### *Comments*

Commentators claim that there have been cases in which insurers have made such demands!<sup>88</sup> A well-placed tip — to local abortion protestors — might get the insurer's attention.

### *Problem #6*

A fifty-five year old man is diagnosed with Huntington's disease. The diagnosis finds its way into a medical information database. The man's five adult children lose their insurance because of their fifty percent risk of also being affected.

### *Comments*

We may expect people to pay cash for testing in order to avoid the risk that insurers or the Medical Information Bureau<sup>89</sup> will learn of a genetic condition. Others may decide not to have genetic testing. Clearly, a case can be made for anonymous genetic counseling and testing.<sup>90</sup>

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<sup>87</sup> See *supra* note 37.

<sup>88</sup> Thomson, *supra* note 16, at 62 (reporting that in a case involving a fetus affected by the CF gene, the company was persuaded to back down, and, as a result, the parents had the child and kept their health insurance).

<sup>89</sup> See *supra* note 19.

<sup>90</sup> See, e.g., Maxwell Mehlman et al., *The Need for Anonymous Genetic*



*Problem #7*

A woman has a brother with cystic fibrosis ("CF"). She wants to know whether or not there is a test that can determine her carrier status. The local clinic in her small town tells her that they only rarely perform the test, but that it can be arranged. The woman does not pursue the test. Later that year, she marries a man who subsequently gets a job at a local factory. The factory uses the small town's clinic as its health care provider. A few days after the man's employment, the factory's insurance company calls the woman to find out if she is the lady who previously consulted the clinic about CF testing. She says that she did because her brother has CF. The company says that before it can provide her husband and his family with health insurance, their carrier status must be resolved. They must be tested, or insurance will not be provided.

*Comments*

A person who has CF is a person with a "disability" under the ADA,<sup>91</sup> since he or she is "substantially impaired in the major life activity of breathing."<sup>92</sup> However, in the Problem, neither the woman nor her husband has the disease. Assuming that they can meet one of the definitions of "disability"<sup>93</sup> they may have a case against the employer for discrimination, since the employer appears to be denying the couple any and all insurance, while providing it to other employees.<sup>94</sup> One assumes that this woman could sue the clinic for breach of confidence.<sup>95</sup>

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*Counseling and Testing*, 58 AM. J. HUM. GENETICS 393, 393-94 (1996) (advocating assignment of numeric codes to all genetic tests to prevent tests from being obtained by employers or insurance companies).

<sup>91</sup> ADA § 3 (42 U.S.C. § 12102(2)(a) (1994)).

<sup>92</sup> See, e.g., *Emery v. Caravan of Dreams*, 879 F. Supp. 640, 643 (N.D. Tex. 1995) (rejecting claim by person with cystic fibrosis that the owner of a music venue violated the ADA by allowing smoking in a facility).

<sup>93</sup> ADA § 3 (42 U.S.C. § 12102(a) (1994)).

<sup>94</sup> See *Anderson v. Gus Mayer Boston Store of Del.*, 924 F. Supp. 763, 779-80 (E.D. Tex. 1996) (completely denying health coverage is a per se violation of the ADA by employer, but coverage may be limited under certain circumstances).

<sup>95</sup> See, e.g., *Horne v. Patton*, 287 So. 2d 824 (Ala. 1973) (holding that a doctor has implied contract of confidentiality with a patient). In *Anderson*, 924 F. Supp. at 763, an HIV infected patient began seeing a private doctor for the

## GENETIC DISCRIMINATION — EMPLOYMENT

*Problem #8*

A young man graduates from the police academy and is offered a position in a small midwestern town. The town's police department soon learns that his family has a history of Huntington's disease ("HD"). The town states that the job offer is now contingent upon his being tested for the presence of the HD gene. If he refuses to be tested, he will not be hired.

*Comments*

We will assume the young man is presently asymptomatic, so that we are dealing with a case of unexpressed late-onset genetic disease. Some have argued that the young man is already a person with a disability. This argument actually has some support. See, for example, *Abbott v. Bragdon*,<sup>96</sup> which held that a person with asymptomatic HIV was covered by the ADA because the condition substantially limited one of her major life activities — reproduction.<sup>97</sup> Commentators argue that this HIV situation is analogous to the HD scenario, since there is no cure for HD and since people with the disease are counseled not to have children because any child would have a fifty percent chance of inheriting HD.<sup>98</sup> Of course, the Problem also presents a case in which the individual is "regarded as" impaired under the ADA<sup>99</sup> and the EEOC *Compliance Manual*,<sup>100</sup> so the argument that he is already impaired may not be as important as it used to be.

Can an employer make an unconditional offer, and then take it back and condition it on testing? Assuming that the young man can be required to take the test as a conditional offeree, is the use of the test permitted as

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condition, paying out of his own pocket so that he would not alert his company's health insurer. Later, after he had been diagnosed as having AIDS, his private doctor mistakenly sent a bill to the group carrier. The issue of confidentiality was not discussed in the case.

<sup>96</sup> *Abbott v. Bragdon*, 912 F. Supp. 580 (D. Me. 1995), *aff'd*, No. 96-1643, 1997 WL 85096 (1st Cir. Mar. 5, 1997).

<sup>97</sup> *Id.* at 585-87 (holding that refusing to treat a patient infected with HIV violates ADA despite legitimate concerns about virus transmission).

<sup>98</sup> See Saunders & Mortell, *supra* note 38, at 28.

<sup>99</sup> ADA § 3 (42 U.S.C. § 12102(2)(c) (1994)).

<sup>100</sup> EEOC Compl. Man., *supra* note 45, § 902.8(a).

being “job-related?” Professor Rothstein argues that this scenario should be covered by the ADA.<sup>101</sup> The EEOC *Compliance Manual* agrees.<sup>102</sup>

### *Problem #9*

Jane applies for a job with XYZ Company which makes her an offer of employment conditioned on an employment entrance examination which, among other things, involves drawing blood. Jane is not told why her blood is being drawn, except that it is “protocol” and that no one is allowed to reveal what tests are being done on the blood. Jane really needs this job and does not argue. DNA testing performed on Jane’s blood indicates that she is a carrier of the gene for Duchenne’s muscular dystrophy. Jane is not informed of the results. Rather, she merely receives a letter in the mail indicating that the job offer has been withdrawn.

### *Comments*

This is a classic case presenting an unaffected carrier of an X-linked disorder. Rothstein argues that this type of discrimination will occur because of the EEOC’s position on the testing of conditional offer-ees.<sup>103</sup> How many tested persons will figure out what is going on? An inference of health-based discrimination does not necessarily arise, and there may be other justifications advanced by the employer. Some may be legitimate and some may be pretextual — smoke screens.

### *Problem #10*

A small, isolated town in Eastern Kentucky — Borough — with a population of about one thousand depends, almost entirely on local coal mines for employment. It is common knowledge that an inordinate number of people from Borough have died at an early age from lung disease. The disorder they have is called alpha-1-antitrypsin deficiency.

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<sup>101</sup> See Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 54-61 (noting that although genetic testing may not be used to deny employment under the ADA, the mere fact that non-job-related genetic testing is allowed threatens privacy and dignity of individuals contrary to intent of ADA).

<sup>102</sup> These same issues were discussed in the Comments to Problem 3, see *supra* notes 29-82 and accompanying text.

<sup>103</sup> See Rothstein, *Genetic Discrimination in Employment*, *supra* note 32, at 55-56.

Affected individuals are highly susceptible to lung damage from pollution, tobacco smoke, coal dust, etc. Local coal companies have posted the following requirement for employment: "Any person from Borough must have genetic testing for alpha-1-antitrypsin deficiency. If affected, employment will not be offered." A group of people from Borough want to file a suit claiming discrimination.

### *Comments*

Here we have a case of screening conducted out of concern for future occupational illness, or rather the costs of future occupational illness. This exact scenario is not addressed in the ADA or EEOC regulations. Professor Rothstein argues that individuals with a genetic predisposition should be covered by the ADA, since they are "regarded as disabled" by the employer.<sup>104</sup> The EEOC recently agreed with this analysis.<sup>105</sup> Presumably, the next question under the ADA is whether an individual can be excluded by an employer for medical reasons because of a "direct threat" to that individual.<sup>106</sup> Can an employer justify an exclusion on that basis? The harm is not imminent, and screening based on concern about an illness in the distant future may be hard to support. How much difference does the condition make? What are the absolute and the relative risks? For example, may an employer exclude an applicant for employment because his risk of suffering a lung impairment is eighty-five percent if other miners have an eighty percent chance of suffering the same impairment?<sup>107</sup> What if everyone were to use protective equipment? Does available or obtainable protective equipment work? Would it not make more sense to require the employer to focus on making the workplace safe for everyone?<sup>108</sup>

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<sup>104</sup> *Id.* at 46, 73.

<sup>105</sup> EEOC Compl. Man., *supra* note 45, § 902.8(a).

<sup>106</sup> See ADA § 103(b) (42 U.S.C. § 12113(a) (as expanded by 29 C.F.R. § 1630.2(r) (1991))) ("An employer may require, as a qualification standard, that an individual not pose a direct threat to the health or safety of himself/herself or others.").

<sup>107</sup> MARK ROTHSTEIN, MEDICAL SCREENING OF WORKERS 125 (1984).

<sup>108</sup> See Orthmann, *supra* note 4, at 131 ("[E]mployers might use screening as an alternative to preventing worker exposure to carcinogens."); Gail Appelson, *Genes and Jobs: Tests Raise Legal and Ethical Questions*, A.B.A. J., Sept. 1982, at 1061, 1063 (Union officials complain that "[i]t's part of the whole effort to blame the victim," and "companies are violating workers' privacy by exchanging test results with other companies and 'blackballing' applicants. 'It will create

A similar case is discussed by Professor Elsas.<sup>109</sup> That case involved a cotton ginning plant that wanted to establish a screening test for alpha-1-antitrypsin. The geneticists hired to investigate told the employer to “forget it” because the testing would be coercive and would benefit no one but the employer.<sup>110</sup> The lung disease, bagassosis, the company said that it was worried about was probably caused by mold. The company was told to clean up the mills, paying particular attention to moldy compost that was being spread through the air conditioning.<sup>111</sup>

On another note, researchers at the University of Kentucky’s Markey Cancer Center have announced their interest in screening and studying small “homogeneous groups” in Eastern Kentucky, with a view to following BRCA1 mutations associated with breast and ovarian cancers. However, the tests are expensive, around \$1600, and researchers are not certain how to predict risks from the results.<sup>112</sup>

### *Problem #11*

In the year 2010, as a result of the Human Genome project (“HGP”), testing for practically all genetic disorders and traits is possible. In 1999, Congress passed a law stating that all employers are required to provide insurance to all employees, and the government will provide National Health Care Insurance for the rest of the population. As a result, all newborns are screened and a genetic risk profile (“GRP”) is determined based on the genetic risk factors identified. Each newborn is assigned a number reflecting his or her genetic risk. A high number is undesirable and reflects a higher risk than a lower number.

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an army of untouchables.’”); *see also* Duston, *supra* note 46, at 101-02 (discussing how courts will evaluate the EEOC’s interpretation of “disability” under the ADA).

<sup>109</sup> Elsas, *supra* note 14, at 849.

<sup>110</sup> *Id.* (noting responsibility of physician extends to employees as well as to employer).

<sup>111</sup> *Id.*

<sup>112</sup> *See Eastern Kentucky May Be Genetic Test Site*, COURIER-JOURNAL (Louisville, Ky.), Oct. 1, 1995, at A15 (noting Eastern Kentucky may provide a good location to study how the “BRCA1” genetic mutation can be common within distinct population with a similar background); *see also Proceedings of the Workshop on Inherited Breast Cancer in Jewish Women: Ethical, Legal, and Social Implications*, Apr. 26, 1996, at the Case Western Reserve University Law and Medicine Center.

In the year 2036, Bob and Tom apply for the same job. They are both equally qualified for the job, but Bob's GRP is 15.57 and Tom's is 73.32. Bob is offered the job.

The same year, William and Robert run for President. Early polling suggests that it will be a close race. One month before the election, William's campaign manager releases William's certified GRP. It is 7.38. Robert refuses to release his GRP. William goes on to win by a landslide.

### *Comments*

Mass screening would be extremely expensive, especially if it were combined with counseling.<sup>113</sup> On the other hand, the military is considering the development of a "genetic dog tag" which will be expensive, and questions have been raised about how long the information will be kept by the government and who will have access to it.<sup>114</sup> There have been several calls for federal "privacy" legislation.<sup>115</sup>

## GENETIC DISCRIMINATION — MISCELLANEOUS

### *Problem #12*

It is 2010. Jacob and Rachel are married and have congenital deafness. They want a child who is also deaf, and will abort any fetus who is genetically determined to have hearing.<sup>116</sup> Prenatal diagnosis is

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<sup>113</sup> See Hanson, *supra* note 13, at 45 (stating that mass screening for genetic defects would explode as a component of health care spending with limited associated benefits).

<sup>114</sup> *Id.* at 47-48. If the justification of the program is the need to identify the bodies of servicepersons, then critics have rightly suggested that servicepersons be given the right to de-register when they leave the service. The problem of compulsory participation has come to a head according to headlines out of Honolulu: *Marines Face Jail for Not Giving DNA*, HERALD-LEADER (Lexington, Ky.), Apr. 16, 1996, at A3. The Marines are being court-martialed for failing to give blood samples to the DNA registry. The purpose of these samples is to aid in the identification of remains. It appears that the Marines will be supported by medical ethicists, critics of the insurance industry, and the ACLU. *Id.*

<sup>115</sup> See Rorie Sherman, *Employer Use of Genetic Tests to be Restricted?*, NAT'L L.J., Nov. 25, 1991, at 15 (discussing the Human Genome Privacy Act introduced by Rep. John Conyers, Jr. (D-Michigan)); Orthmann, *supra* note 4, at 133 (alluding to model federal legislation entitled the Genetic Privacy Act that was drafted at the Boston University School of Public Health).

<sup>116</sup> Some deaf couples have stated that they would feel threatened by having

available, and the HGP has made it possible to test for this type of deafness. A pregnancy occurs, and prenatal testing indicates a fetus with normal hearing. The couple states that they will continue the pregnancy only if a recently-developed surgical procedure is performed in utero causing the fetus to lose his hearing. If the surgery is not performed, Rachel will terminate the pregnancy.

### *Comments*

This is as fraught with ethical implications as abortion for sex selection, but it is a good note to end on! *Testing is available in the U.S. for sex selection.*<sup>117</sup> It is a Brave New World after all.

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a hearing child. For analysis of the use of genetic testing to produce a child with a disability, see JOHN ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 171 (1994) (referring to the use of genetic tests to select for genetic defects as "intentional diminishment").

<sup>117</sup> See Wertz, *supra* note 5, at 1430. Wertz states that "[m]edical professionals in the United States appear increasingly willing to perform prenatal diagnosis for those making such [sex selection] requests," and that her "1993-94 survey of over 2600 geneticists in thirty-seven nations shows a clear trend toward greater willingness to perform prenatal diagnosis for sex selection . . ." *Id.* at 1430-31. She also notes that "due to inadequate care afforded to female children and to women, an estimated sixty million to one hundred million women are 'missing' from the world's population, including twenty-million in China and twenty-three million in India." *Id.* at 1432.

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### Miscellaneous

The Pennsylvania Bar Association recently created an Interdisciplinary Committee to address these issues. See Joseph Butera, *Association Interdisciplinary Committee Tackles Genetic Testing*, PA. L.J., Sept. 27, 1993, at 3.